Developing and Evaluating a Stigma Scale for People with COPD

by

Seoyoon Woo

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
(Nursing)
in the University of Michigan
2019

Doctoral Committee:

Professor Janet L. Larson, Chair
Assistant Professor Allison Earl
Associate Professor Denise M. Saint Arnault
Clinical Associate Professor Laura M. Struble
Research Assistant Professor Philip T. Veliz

Seoyoon Woo

sywoo@umich.edu

ORCID iD: 0000-0002-5623-9366

Dedication

To my Lord Jesus Christ who is a lamp on my feet and a light for my path

and

To my husband, parents, sister, and my friends for their unwavering love and support

Acknowledgement

There are many people that I must thank for their time, encouragement, and support. My sincere and deep gratitude must go to Dr. Janet Larson. Thank you for being my advisor, committee chair, and mentor, and providing substantive guidance and encouragement at every step of this journey. It would not be possible without your passion and faith in my ability to finish this work.

I would like to thank Dr. Denise Saint Arnault, for being my mentor and one of my committee members and providing all my hands-on experience that became a good steppingstone for my work. Thank you for her warm and thoughtful guidance and encouragement. I would also like to thank my other committee members, Dr. Laura Struble, Dr. Allison Earl, and Dr. Philip Veliz for their professional support and warmhearted encouragement.

I would like to thank Dr. Ellen Lavoie Smith for her enthusiastic support and encouragement throughout my graduate study. As a program director, she did the best to provide an environment where students can concentrate on their studies and building professional careers. I would also thank Dr. Milisa Manojlovich, Dr. Julia Seng, and Dr. MinKyoung Song, for providing opportunities to join their projects and work with them. I would like to thank Dr. Heejung Jang, Dr. Young-Hee Yom, Joowha Yoo, Dr. April Bigelow, and Dr. Tsui-Sui Kao, who wholeheartedly encouraged me to get started my graduate school.

I would like to express special thanks to Dr. Catherine Meldrum and Dr. Ronald Dechert for their sincere help with the data collection from the beginning to the end, and their warmhearted interest and support. I would like to thank all of the participants who contributed to

my study. I would also like to thank Chris Feak for her heartfelt encouragement and help with writing my dissertation paper in the classroom and in her office.

Thank you to my friends and colleagues at the University of Michigan School of Nursing: Kari Mendelsohn-Victor, Marlene Otto, and She'Lon Tucker for making a comfort and friendly workplace; Bethany Osborne and Christopher Connelly for their help with administrative tasks; and Celia Bridges, Carol Vos, Seunghee Choi, Miyeon Jung, Corinne Lee, Kayoung Lee, Innah Park, Ying Sheng, Yang Li, Julie Slack, Elizabeth Eisenhauer, and other doctoral students, for giving their heart when I got frustrated and for smiling together every time we could.

I would like to thank my parents for their unconditional love and support and constant prayer. I could not be where I am today without them. Thank you to my sister for listening to my concerns, making me smile, and being my best friend. Lastly, I would like to thank my husband, Chunho Park, for his firm love, encouragement, and patience, as well as being a strong supporter.

Table of contents

Dedication ii

Acknowledgement iii

List of tables vii

List of figures ix

List of appendices x

Abstract xi

Chapter 1: Introduction 1

Chapter 2: Stigma in COPD and Lung cancer: A Systematic Review 14

- Abstract 14
- Introduction 16
- Background 16
- Methods 21
- Results 24
- Discussion 33
- Conclusion 36
- References 38

Chapter 3: Cognitive Interviewing of the COPD-related Stigma Scale 113

- Abstract 113

Introduction 115
Background 115
Methods 119
Results 122
Discussion 126
Conclusion 129
References 130
Chapter 4: Psychometric Evaluation of the COPD-related Stigma Scale 142
Abstract 142
Introduction 144
Background 145
Methods 149
Results 155
Discussion 160
Conclusion 164
References 166
Chapter 5: Conclusion 189
Appendices 193

List of tables

Table 2-1-a. Summary of the qualitative studies in COPD-related stigma..... 54

Table 2-1-b. Summary of the quantitative studies in COPD-related stigma…….64

Table 2-1-c. Summary of the mixed-method studies in COPD-related stigma…….67

Table 2-2-a. Summary of the qualitative studies in Lung cancer-related stigma 70

Table 2-2-b. Summary of the quantitative studies in Lung cancer-related stigma……85

Table 2-2-c. Summary of the mixed-method studies in Lung cancer-related stigma……..107

Table 2-3. Measures of COPD-related and lung cancer-related stigma 111

Table 3-1. Sample of cognitive interviewing probes..... 135

Table 3-2. Demographic Characteristics of Subjects..... 136

Table 3-3. Overview of problematic items indicated by participants during cognitive interviewing 137

Table 4-1. Demographic and Clinical Characteristics of Subjects 175

Table 4-2. Comparison of Eigenvalues from Factor Analysis and Criterion values from Parallel Analysis..... 177

Table 4-3. Factor Loadings from Rotated Factor-Loading Pattern Matrix..... 178

Table 4-4. The 28-item version COPD-related Stigma Scale Reliability..... 180

Table 4-5. Correlations of 28-item COPD-related Stigma Scale between Subscales and with Other Measures 181

Table 4-6. Group comparisons of 28-item COPD-related Stigma Scale scores 182

Table 4-7. Multivariate Regression Analysis..... 186

List of figures

Figure 2-1. A conceptual model of the effects of stigma processes on health..... 52

Figure 2-2. PRISMA 2009 Flow Diagram..... 53

Figure 3-1. Refinement Process for the COPD-related Stigma Scale 139

Figure 3-2. Percentage of neutral answers for each item..... 140

Figure 3-3. Relative frequency of each reason for selecting the neutral option 141

List of appendices

Appendix A. Shaw et al. (2009) quality assessment checklist for quantitative studies 194

Appendix B. Shaw et al. (2009) quality assessment checklist for qualitative studies 198

Appendix C. The 52-item COPD-related Stigma Scale 201

Appendix D. COPD-related Stigma Scale 204

Appendix E. Stigma Scale for Chronic Illness 8 items (SSCI-8) 208

Appendix F. Charlson Comorbidity Index (CCI) 209

Appendix G. Hospital Anxiety and Depression Scale (HADS) 211

Appendix H. PROMIS Physical Function (Short Form-10a) 213

Appendix I. Descriptive Statistics of the 51-item COPD-related Stigma Scale 215

Abstract

Chronic obstructive pulmonary disease (COPD) is a prevalent respiratory disease and the third leading cause of death worldwide. Tobacco smoking is not only a major contributor to the prevalence of and high mortality in COPD, but a history of smoking predisposes people with COPD to being stigmatized. Stigma, like in anxiety and depression, can adversely affect psychological functioning and essential functions for disease management. Guided by "the conceptual model representing the effects of stigma processes on health," this three-paper dissertation includes a) a systematic review of stigma in people with COPD compared to lung cancer-related stigma, b) a qualitative study to evaluate and refine a 52-item preliminary COPD stigma scale using cognitive interviewing, and c) a quantitative study to examine the validity and reliability of the refined COPD stigma scale.

In a systematic review, people with COPD or lung cancer are similar in their perceptions of stigma: "they did it to themselves." Studies have shown that lung cancer-related stigma is associated with patient outcomes including increased psychological distress, poor quality of life, low help-seeking, poor medication adherence, and low social support. A small number of qualitative studies have described the phenomenon of stigma in people with COPD, and less is known about COPD-related stigma in part because there are no existing measures of COPD-related stigma.

In a qualitative study, nineteen people with COPD participated in semi-structured cognitive interviews to assess comprehension of the 52-item preliminary COPD stigma scale.

Most questionnaire items were understood and interpreted as intended. Of 52 total items, one item was dropped because it was identified as so offensive that many subjects were reluctant to answer. Eleven items were revised to improve the flow of responses to the questionnaire. Regarding response options, subjects selected the mid-point (i.e., neutral) response for various reasons. The most frequent reason for choosing the mid-point response was "both equal parts of agree and disagree," followed by "not applicable." This qualitative study provided the foundation required for further revision and evaluation of the stigma questionnaire using psychometric methods.

In the quantitative study, we identified the underlying structure and assessed the psychometric properties of the revised version of the COPD-related Stigma Scale. People with COPD (n = 148) participated in the mailed questionnaire, including the 51-item COPD-related Stigma Scale. The exploratory factor analysis indicated that the four-factor model with 28 items provided a good fit to the data with high internal consistency ($\alpha = 0.96$). The COPD-related Stigma Scale estimated by 28 items was significantly correlated with other measures—chronic illness-related stigma, psychological distress, and physical function—establishing the construct validity of the scale. This finding provided the foundation required for the further evaluation of confirming the underlying structure of the COPD-related Stigma Scale.

In conclusion, the findings in the studies above support that COPD-related stigma may adversely affect psychological and physical health. Researchers may consider further investigating the potential harmful effects of stigma on COPD management as well as developing strategies to reduce the negative influence of COPD-related stigma in this population.

Chapter 1

Introduction

Background

As the population ages, so do the number of people living with chronic health problems. This raises concerns about this population and the stigma associated with chronic health problems, which can negatively affect the quality of one's life (Earnshaw & Quinn, 2012; Gullick & Stainton, 2008; Joachim & Acorn, 2000a; Morrell, 2002). People with chronic conditions often experience functional decline, financial difficulties, burdening of family members and social isolation (Charmaz, 1983; Schulman-Green et al., 2012). They can also experience the loss of their previous positive self-image and controllability over their lives (Charmaz, 1983). All of these experiences have the potential for stigmatization. In addition, people with chronic conditions experience feelings of being stigmatized by and discriminated against in their social relationships, work opportunities, and healthcare settings, because chronic conditions may be regarded as being abnormal compared to others (Joachim & Acorn, 2000b). Multiple studies have shown that perceiving stigma and discrimination are associated with psychological distress and poor quality of life (Earnshaw & Quinn, 2012; Earnshaw, Quinn, & Park, 2012; Jacoby, 2002; Jacoby, Snape, & Baker, 2005; Quinn & Earnshaw, 2011; Schmitt, Branscombe, Postmes, & Garcia, 2014; Sehlo & Bahlas, 2013; van der Beek, Bos, Middel, & Wynia, 2013).

Stigma is a social factor that distinguishes a person with undesirable attributes from others and encroaches upon a person's quality of life. In ancient times, stigma referred to the

mark of being morally disgraced; thus, those who had the mark were regarded as subhuman (Goffman, 1963). Although the concept of being disgraced has shifted with time, the stigmatized person still has many disadvantages. The person is vulnerable to a range of discrimination that threatens his/her personal and social identity (Goffman, 1963; Link & Phelan, 2001; Major & O'brien, 2005). These negative impacts of stigma on quality of life have been widely studied, and include such areas as mental illness, HIV/AIDS, and tuberculosis (TB).

Mental health issues have deep-rooted stereotypic connotations in many cultures. It is often perceived as dangerous, untreatable, and disruptive to social interactions (Hayward & Bright, 1997; Ng, 1997; Ottati, Bodenhausen, & Newman, 2005). For that reason, people who suffer from mental illness are discriminated against in various life choices, such as education, occupation, place of domicile status, and healthcare access (Corrigan & Watson, 2002; Link & Phelan, 2001; Pettit, 2008; Rusch, Angermeyer, & Corrigan, 2005). In this context, important life opportunities and social status are devalued and self-esteem is lowered (Major & O'brien, 2005).

HIV/AIDS is another highly stigmatized health problem. Although HIV/AIDS-related stigma has a relatively short history, it affects countries all over the world. This can arise from perceptions linked to socially and morally deviant behaviors, the pernicious disease course, and its high degree of contagiousness (Alonzo & Reynolds, 1995; Parker & Aggleton, 2003). These opinions play a role in limiting people living with HIV/AIDS in every aspect of daily life. They are forced to isolate themselves from their home, community, workplaces, and public spaces (Ogden & Nyblade, 2005). They are gradually denied the rights to lead their own lives, and lose roles and power as a member of the family and community, which contributes to their

stigmatized identity (Earnshaw, Smith, Chaudoir, Amico, & Copenhaver, 2013; Ogden & Nyblade, 2005).

TB is another highly stigmatized health problem, albeit less studied. TB-related stigma is primarily caused by vague perceptions of TB transmission, from dirty air, casual contacts with household family members, occurring after other pulmonary infections, or as a precursor to cancer (Courtwright & Turner, 2010; Kelly, 1999; Kurspahić-Mujčić, Hasanović, & Sivić, 2013). The close associations with HIV and low social and economic status also contributes to TB-related stigma (Bond & Nyblade, 2006; Courtwright & Turner, 2010). In prevalent HIV areas, people with TB are also thought to have HIV because of a belief that TB is a sign of HIV (Bond & Nyblade, 2006; Courtwright & Turner, 2010). Thus, people with TB are physically, emotionally, and socially isolated from their families and communities, which lead them to conceal the diagnosis and be reluctant to seek help (Bond & Nyblade, 2006; Courtwright & Turner, 2010; Kelly, 1999; Macq, Solis, & Martinez, 2006).

Stigmatization, like other social phenomena, is a complex process. To understand this process, a number of theorists and researchers have attempted to develop conceptual frameworks. Link and Phelan (2001) define a stigma as "the co-occurrence of interrelated components of labeling, stereotyping, separation, status loss, and discrimination in a power situation" (p. 377). Prior to framing the concept, they revisited existing stigma concepts and identified several crucial points, such as variations of definitions, the existence of blind spots due to the researchers' lack of personal experience in the area, and how to holistically view stigma by not limiting it to one level. To allow for the enhanced conceptualization, Link and Phelan (2001) emphasized the importance of a comprehensive approach by considering human differences on labeling, the individual ways of linking labels to stereotypic characteristics, the rationale for

labels, the ensuing disadvantages to quality of life (e.g., employment, housing status, health care, etc.), and the role of social, economic, and political power in stigmatization.

Deacon (2006) attempted to illuminate the key issues of stigma by reviewing and discussing literature reviews on HIV/AIDS-related stigma. She defines stigma as "the process of othering, blaming and shaming (p. 418)." In defining the concept, she maintains an existing stance on stigma as a social process, but asserts that researchers should have a clear sense of the relationships between stigma, disadvantage, and discrimination. According to her explanation, discrimination is a part of the negative consequences of stigma; stigma is a disadvantage that occurs in existing social inequalities. The clarification of the these relationships will help to gain a better understanding of the complex mechanism of stigma as well as improving strategies for research and interventions (Deacon, 2006).

M. G. Weiss, Ramakrishna, and Somma (2006) and Scambler (2006, 2009) emphasized that health-related stigma is manifested in different individuals, and in particular, social and cultural contexts. M. G. Weiss et al. (2006) posit that "the discriminatory social judgments (p. 280)" on certain health problems play an important role in health-related stigma. Although these views are groundless from a medical and epidemiological point of view, they adversely and persistently affect health.

In addition, other discriminatory social judgments regarding race, ethnicity, gender, etc. adversely affect health in concert with health-related stigma. Thus, M. G. Weiss et al. (2006) suggest that studies of health-related stigma should be conducted by considering different social and cultural components associated with the stigmatized health problems. Scambler (2006) states that health-related stigmatization is anchored in social structures. Considering there are no settled social structures, research on health-related stigma needs to be formulated and

implemented with attention paid to the causal powers of social structure as well as its components, including social class, status, roles, culture, and social institutions. He also stresses the inextricable connection between health-related stigmatization and social structures. Although there are similarities in effects and outcomes of health-related stigmatization, different social structures and cultural norms are involved in its manifestations (Scambler, 2009). Thus, studies of health-related stigma and associated interventions should be culture- and health-problem-specific (Scambler, 2006, 2009).

Major, Dovidio, and Link (2018) attempted to integrate the possible consequences of health-related stigma by reviewing literature from different disciplines. They focused on two sets of stigma's impact on health: individual-level psychosocial stress and social/community-level exclusion. These negative influences may lead to health disparities between those who are stigmatized and those who are not. For example, those who are stigmatized may be more likely to have inadequate access to healthcare resources and increasing exposure to environmental threats. To better understand the linkage between stigma status and its impact on health, Major et al. (2018) proposed a conceptual model that presents pathways from stigmatization to health outcomes. Their model has six domains: 1) socially conferred marks, 2) moderating factors, 3) stigma processes, 4) individual-level responses, 5) social/community-level exclusion, and 6) health. This conceptual model guided this dissertation.

According to Major et al. (2018)'s conceptual model, the domain of socially conferred marks are sources of negative attitudes or stereotypes within a society. These marks can stem from socioeconomic status, cultural beliefs, or personal attributes and act as a distinguisher between stigmatized and non-stigmatized individuals. Being poor, mentally ill, disabled, or obese are examples of marks.

The domain of moderating factors refers to elements that intervene in the path between the domain of socially conferred marks and the domain of stigma processes and alter the characteristics and strength of stigmatization. These elements include seven dimensions (i.e., concealability, course, disruptiveness, aesthetic qualities, origin or controllability, peril, and collectivity) as well as individual and environmental characteristics.

The domain of stigma processes, developed from the domain of socially conferred marks, consists of four types of stigmas: enacted stigma (occurring at the interpersonal and structural level), felt stigma, internalized stigma, and anticipated stigma. Enacted stigma at the interpersonal level is described as bias-based negative attitudes toward stigmatized groups and discrimination against those groups. Enacted stigma at the structural level can occur through the influence of cultural norms, governmental policies, or institutional practices and adversely affects stigmatized individuals' quality of life. Felt stigma is described as how stigmatized individuals perceive their socially devalued status. Felt stigma can occur in either the presence or absence of enacted stigma. Internalized stigma refers to stigmatized individuals' adoption of negative attitudes and discrimination, which results from repeated exposure to enacted stigma, felt stigma, and/or cultural beliefs. Anticipated stigma is described as the stigmatized individual's expectation of being confronted with negative attitudes and discrimination due to their stigmatized marks. In response to these processes, stigmatized individuals can experience individual-level affective, cognitive, behavioral, and physiological reactions as well as community-level exclusions. The last domain of health is described as health-related consequences of the stigma processes.

Pathways from stigmatization to health outcomes can be bidirectional or multi-directional among the six domains. Due to this complexity, many studies on health-related stigma have

used qualitative methods. Although health-related stigma studies using qualitative methods enable a better understanding of the personal, social, and/or cultural differences, these studies limit the examination of measurable change. Thus, researchers are required to conduct both qualitative and quantitative studies on health-related stigma and associated interventions (Bos, Pryor, Reeder, & Stutterheim, 2013; Pryor & Reeder, 2011).

Research on chronic obstructive pulmonary disease (COPD) has taken note of psychological distress because of the close association with physical health outcomes (e.g., exacerbation and hospitalization) as well as quality of life (Panagioti, Scott, Blakemore, & Coventry, 2014; Quint, Baghai-Ravary, Donaldson, & Wedzicha, 2008). Depression and anxiety are the two major symptoms of psychological distress. These symptoms are prevalent and significantly associated with the poor health status of people with COPD (Frei et al., 2014; Panagioti et al., 2014). Several studies have reported that stigma attached to COPD contributes to psychological distress and decreased quality of life (A. A. Kaptein et al., 2009; Quint et al., 2008). Exploratory studies have provided support for the existence of COPD-related stigma and its negative impact on people with the condition (Berger, Kapella, & Larson, 2011; Halding, Heggdal, & Wahl, 2011; Lindqvist & Hallberg, 2010). However, little is known about how COPD-related stigma is defined and how a change of COPD-related stigma is measured.

This dissertation consists of three studies. The overall purpose of this dissertation was to explore how stigma is manifested in people with COPD and to develop a reliable and valid COPD-related stigma scale. The goal of the first study was to first describe the existing literature on stigma in people with COPD and lung cancer and summarize findings using the conceptual model proposed by Major et al. (2018). Secondly the study identifies existing measures of COPD-related and lung cancer-related stigma. The goal of the second study was to

verify the relevance of items on the 52-item preliminary COPD-related stigma scale, evaluate the scale's response option, and refine the scale. The goal of the third study was to 1) assess the structure of the 51-item refined COPD-related Stigma Scale, 2) evaluate the psychometric properties, including criterion-related validity and internal consistency reliability, and 3) examine the construct validity of the instrument with regard to COPD-related stigma and the psychological and physical well-being of people with COPD.

References

Alonzo, A. A., & Reynolds, N. R. (1995). Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory. *Social Science & Medicine, 41*(3), 303-315.

Berger, B. E., Kapella, M. C., & Larson, J. L. (2011). The experience of stigma in chronic obstructive pulmonary disease. *Western journal of nursing research, 33*(7), 916-932.

Bond, V., & Nyblade, L. (2006). The importance of addressing the unfolding TB-HIV stigma in high HIV prevalence settings. *Journal of Community & Applied Social Psychology, 16*(6), 452-461.

Bos, A. E., Pryor, J. B., Reeder, G. D., & Stutterheim, S. E. (2013). Stigma: Advances in theory and research. *Basic and applied social psychology, 35*(1), 1-9.

Charmaz, K. (1983). Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health & Illness, 5*(2), 168-195.

Corrigan, P. W., & Watson, A. C. (2002). Understanding the impact of stigma on people with mental illness. *World psychiatry, 1*(1), 16.

Courtwright, A., & Turner, A. N. (2010). Tuberculosis and stigmatization: pathways and interventions. *Public health reports, 125*(4_suppl), 34-42.

Deacon, H. (2006). Towards a sustainable theory of health-related stigma: lessons from the HIV/AIDS literature. *Journal of Community & Applied Social Psychology, 16*(6), 418-425. doi:10.1002/casp.900

Earnshaw, V. A., & Quinn, D. M. (2012). The impact of stigma in healthcare on people living with chronic illnesses. *Journal of Health Psychology, 17*(2), 157-168.

Earnshaw, V. A., Quinn, D. M., & Park, C. L. (2012). Anticipated stigma and quality of life among people living with chronic illnesses. *Chronic Illness, 8*(2), 79-88.

Earnshaw, V. A., Smith, L. R., Chaudoir, S. R., Amico, K. R., & Copenhaver, M. M. (2013). HIV stigma mechanisms and well-being among PLWH: a test of the HIV stigma framework. *AIDS and Behavior, 17*(5), 1785-1795.

Frei, A., Muggensturm, P., Putcha, N., Siebeling, L., Zoller, M., Boyd, C. M., . . . Puhan, M. A. (2014). Five comorbidities reflected the health status in patients with chronic obstructive pulmonary disease: the newly developed COMCOLD index. *Journal of clinical epidemiology, 67*(8), 904-911.

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*: Simon and Schuster.

Gullick, J., & Stainton, M. C. (2008). Living with chronic obstructive pulmonary disease: developing conscious body management in a shrinking life-world. *Journal of advanced nursing, 64*(6), 605-614.

Halding, A. G., Heggdal, K., & Wahl, A. (2011). Experiences of self-blame and stigmatisation for self-infliction among individuals living with COPD. *Scandinavian journal of caring sciences, 25*(1), 100-107.

Hayward, P., & Bright, J. A. (1997). Stigma and mental illness: A review and critique. *Journal of Mental Health*.

Jacoby, A. (2002). Stigma, epilepsy, and quality of life. *Epilepsy & Behavior, 3*(6), 10-20.

Jacoby, A., Snape, D., & Baker, G. A. (2005). Epilepsy and social identity: the stigma of a chronic neurological disorder. *The Lancet Neurology, 4*(3), 171-178.

Joachim, G. L., & Acorn, S. (2000a). Living with chronic illness: The interface of stigma and normalization. *Canadian Journal of Nursing Research Archive, 32*(3).

Joachim, G. L., & Acorn, S. (2000b). Stigma of visible and invisible chronic conditions. *Journal of advanced nursing, 32*(1), 243-248.

Kaptein, A. A., Scharloo, M., Fischer, M. J., Snoei, L., Hughes, B. M., Weinman, J., . . . Rabe, K. F. (2009). 50 years of psychological research on patients with COPD–road to ruin or highway to heaven? *Respir Med, 103*(1), 3-11.

Kelly, P. (1999). Isolation and stigma: the experience of patients with active tuberculosis. *J Community Health Nurs, 16*(4), 233-241. doi:10.1207/s15327655jchn1604_3

Kurspahić-Mujčić, A., Hasanović, A., & Sivić, S. (2013). Tuberculosis related stigma and delay in seeking care after the onset of symptoms associated with tuberculosis. *Medicinski Glasnik, 10*(2).

Lindqvist, G., & Hallberg, L. R. (2010). 'Feelings of guilt due to Self-inflicted Disease'a grounded theory of suffering from Chronic Obstructive Pulmonary Disease (COPD). *Journal of Health Psychology, 15*(3), 456-466.

Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual review of Sociology, 27*(1), 363-385.

Macq, J., Solis, A., & Martinez, G. (2006). Assessing the stigma of tuberculosis. *Psychology, health & medicine, 11*(3), 346-352.

Major, B., Dovidio, J. F., & Link, B. G. (2018). *The Oxford Handbook of Stigma, Discrimination, and Health*: Oxford University Press.

Major, B., & O'brien, L. T. (2005). The social psychology of stigma. *Annu. Rev. Psychol., 56*, 393-421.

Morrell, M. J. (2002). Stigma and epilepsy. *Epilepsy & Behavior, 3*(6), 21-25.

Ng, C. H. (1997). The stigma of mental illness in Asian cultures. *Aust N Z J Psychiatry, 31*(3), 382-390. doi:10.3109/00048679709073848

Ogden, J., & Nyblade, L. (2005). Common at its core: HIV-related stigma across contexts.

Ottati, V., Bodenhausen, G. V., & Newman, L. S. (2005). Social psychological models of mental illness stigma. *On the stigma of mental illness: Practical strategies for research and social change*, 99-128.

Panagioti, M., Scott, C., Blakemore, A., & Coventry, P. A. (2014). Overview of the prevalence, impact, and management of depression and anxiety in chronic obstructive pulmonary disease. *International journal of chronic obstructive pulmonary disease, 9*, 1289.

Parker, R., & Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social Science & Medicine, 57*(1), 13-24.

Pettit, M. L. (2008). Disease and Stigma: A Review of Literature. *Health Educator, 40*(2), 70-76.

Pryor, J. B., & Reeder, G. D. (2011). HIV-related stigma. *HIV/AIDS in the Post-HAART Era: manifestations, treatment, and Epidemiology*, 790-806.

Quinn, D. M., & Earnshaw, V. A. (2011). Understanding concealable stigmatized identities: The role of identity in psychological, physical, and behavioral outcomes. *Social Issues and Policy Review, 5*(1), 160-190.

Quint, J. K., Baghai-Ravary, R., Donaldson, G. C., & Wedzicha, J. (2008). Relationship between depression and exacerbations in COPD. *European Respiratory Journal, 32*(1), 53-60.

Rusch, N., Angermeyer, M. C., & Corrigan, P. W. (2005). Mental illness stigma: concepts, consequences, and initiatives to reduce stigma. *Eur Psychiatry, 20*(8), 529-539. doi:10.1016/j.eurpsy.2005.04.004

Scambler, G. (2006). Sociology, social structure and health-related stigma. *Psychology, health & medicine, 11*(3), 288-295.

Scambler, G. (2009). Health-related stigma. *Sociology of Health & Illness, 31*(3), 441-455.

Schmitt, M. T., Branscombe, N. R., Postmes, T., & Garcia, A. (2014). The consequences of perceived discrimination for psychological well-being: A meta-analytic review. *Psychological Bulletin, 140*(4), 921.

Schulman-Green, D., Jaser, S., Martin, F., Alonzo, A., Grey, M., McCorkle, R., . . . Whittemore, R. (2012). Processes of Self-Management in Chronic Illness. *Journal of Nursing Scholarship, 44*(2), 136-144. doi:10.1111/j.1547-5069.2012.01444.x

Sehlo, M. G., & Bahlas, S. M. (2013). Perceived illness stigma is associated with depression in female patients with systemic lupus erythematosus. *Journal of psychosomatic research, 74*(3), 248-251.

van der Beek, K. M., Bos, I., Middel, B., & Wynia, K. (2013). Experienced stigmatization reduced quality of life of patients with a neuromuscular disease: a cross-sectional study. *Clinical rehabilitation, 27*(11), 1029-1038.

Weiss, M. G., Ramakrishna, J., & Somma, D. (2006). Health-related stigma: rethinking concepts and interventions. *Psychology, health & medicine, 11*(3), 277-287.

Chapter 2

Stigma in COPD and Lung cancer: A Systematic Review

Abstract

Objectives: People with chronic obstructive pulmonary disease (COPD) or lung cancer are stigmatized by their history of smoking, but little is known about the similarities and dissimilarities in stigma associated with each condition. A comparison of the two could be useful in advancing the science. This systematic review aimed: 1) to compare existing literature on stigma in people with COPD or lung cancer and 2) to identify existing measures of COPD-related and lung cancer-related stigma.

Methods: We conducted a systematic search of CINAHL/PsycINFO/PubMed/Scopus databases for articles related to stigma in COPD or lung cancer through July 2018. We performed a quality assessment and synthesized findings according to concepts in the models of health-related stigma in people with COPD or lung cancer (Berger et al., 2011; Cataldo, Slaughter, Jahan, Pongquan, & Hwang, 2011).

Results: A total of 61 studies met criteria for review: 19 addressed stigma in people with COPD (3 quantitative, 13 qualitative, and 3 mixed-method) and 42 addressed stigma in people with lung cancer (24 quantitative, 15 qualitative, and 3 mixed-method). We identified no well-established measures of COPD-related stigma; most of the COPD research was qualitative and/or employed unvalidated questions about stigma. The most commonly used measure for lung cancer-related stigma was the Cataldo Lung Cancer Stigma Scale; it was used in 10 studies.

People with COPD linked stigma to smoking, the diagnosis itself, symptoms of COPD (e.g., cough and shortness of breath) and stigma triggers such as the use of inhalers and supplemental oxygen. People with lung cancer linked stigma to their smoking behavior, their poor prognosis, and the type of death. Previous- and current-smokers reported higher levels of stigma than people who never smoked.

Conclusions: People with COPD or lung cancer are similar in their perceptions of stigma, "they did it to themselves". Studies have shown that lung cancer-related stigma is associated with patient outcomes including increased psychological distress, poor quality of life, low help-seeking, poor medication adherence, and low social support. Less is known about COPD-related stigma in part because there are no reliable and valid measures of COPD-related stigma. It may be useful to develop a reliable and valid stigma scale specifically designed for people with COPD, thereby improving the clarity of conceptualizing COPD-related stigma, as well as providing future research directions to address this issue.

Introduction

Studies have indicated that stigma is associated with many chronic health conditions (Earnshaw & Quinn, 2012; Earnshaw, Quinn, Kalichman, & Park, 2013; Van Brakel, 2006), which can be seen in a negative light when these conditions are associated with physical or mental deformities, contagious features, and/or maladaptive behaviors, like substance abuse (Link, Struening, Rahav, Phelan, & Nuttbrock, 1997). Accordingly, people who suffer from stigmatized chronic health conditions such as leprosy, HIV/AIDS, mental illness, epilepsy, disability, and tuberculosis (Van Brakel, 2006) are also perceived as devalued or discreditable. As a result, these stigmatized individuals are more likely to be subject to delays in diagnosis (Van Brakel, 2006) and are less likely to access and obtain medical care for their symptoms (Neal, McGoldrick, & Schear, 2015). Chronic obstructive pulmonary disease (COPD) and lung cancer have been identified as stigmatized chronic conditions (Berger et al., 2011; Chambers et al., 2012; Halding et al., 2011) in relation to a causal link to smoking. Smoking is a significant risk factor for these two conditions, but not all COPD or lung cancer are caused by smoking. This systematic review will help researchers and clinicians have more comprehensive understanding the process of stigmatization in people with COPD or lung cancer as well as identify a knowledge gap regarding how best to approach the impact of stigma on these populations.

Background

Chronic obstructive pulmonary disease (COPD) and lung cancer are prevalent respiratory diseases (Adeloye et al., 2015; Torre et al., 2015) and the leading causes of death worldwide. In 2015, approximately 3.17 million deaths were attributed to COPD (World Health Organization

[WHO], 2017), and, in 2018, an estimated 1.76 million deaths were due to lung cancer (World Health Organization [WHO], 2018). Tobacco smoking has been shown to be a major factor associated with the prevalence of— and high mortality in —both COPD and lung cancer. In fact, in the U.S., 75% of COPD and nearly 90% of lung cancers are caused by tobacco smoking (U.S. Department of Health and Human Services [USDHHS], 2014, 2016), and 80% of COPD-related deaths and more than 87% of lung cancer-related deaths are attributed to history of smoking (U.S. Department of Health and Human Services [USDHHS], 2014, 2017). In addition, the effects of secondhand smoke cannot be ignored: among never-smokers, secondhand smoke exposure has been identified as a risk factor in developing COPD and lung cancer (Brennan et al., 2004; He et al., 2012; U.S. Department of Health and Human Services [USDHHS], 2006). This causal link between smoking and both diseases is the basis for stigmatizing people with COPD or lung cancer.

Smoking-related stigma has, ironically, arisen from strategies to raise social awareness about the harmful effects of smoking (Evans-Polce, Castaldelli-Maia, Schomerus, & Evans-Lacko, 2015). The 1964 Surgeon General's report played a pioneering role in tobacco control, educating the general public about the negative consequences of smoking, and contributing to declines in overall smoking rates (Cummings & Proctor, 2014). This report also provided the basis for actions such as policies on smoke-free environments, as well as smoking-cessation campaigns, programs, and interventions (U.S. Department of Health and Human Services [USDHHS], 2014). Although these efforts reduced smoking-related disease and death, they also played a profound role in stigmatizing both smoking and smokers (Bell, Salmon, Bowers, Bell, & McCullough, 2010; Kim & Shanahan, 2003).

As a result of tobacco control actions and policies, smokers have increasingly encountered smoking-related discrimination in their daily lives. In order to create a smoke-free environment, smoking has been restricted in public spaces and allowed only in isolated areas. Consequently, people who continue to smoke are more likely to be regarded as a public enemy and experience being shunned by non-smokers (Bell et al., 2010; Hammond, Fong, Zanna, Thrasher, & Borland, 2006; Kim & Shanahan, 2003). Smokers are also forced to bear a financial burden due to increasing taxes on tobacco products, which can be especially stressful for low-income smokers (Farrelly, Nonnemaker, & Watson, 2012). Additionally, smokers can be rejected by their healthcare providers because of their smoking status (Bell et al., 2010; Lehto, 2014), and, in fact, studies have shown that healthcare providers have unfavorable attitudes towards people with lung diseases who smoked (Bass et al., 2018; Chapple, Ziebland, & McPherson, 2004a) that may affect help-seeking behavior.

Because of the crucial role of tobacco smoking in developing COPD and lung cancer, the stigma attached to smoking has transferred to COPD and lung cancer themselves, and thus is naturally extended to people who are suffering from either of the diseases (Yanbaeva, Dentener, Creutzberg, Wesseling, & Wouters, 2007). Given that smoking behavior is controllable, COPD and lung cancer are in turn perceived as preventable diseases, and therefore the people who contract them are frequently viewed as being responsible for their own condition. Whether or not an individual is responsible for his or her stigmatizing condition can affect how others think about and behave towards that individual (Jones et al., 1984), and others' reactions to the condition could be intensified by the perceived controllability of its causes (Weiner, Perry, & Magnusson, 1988).

There is a growing number of empirical research on stigma associated with COPD and lung cancer, and studies have shown that people with COPD or lung cancer experience disease-related stigma — due in part to the pervasive perception that their disease is self-inflicted — and because of this are likely to face 'negative affective responses and behavioral judgements' (Weiner et al., 1988). Chambers et al. (2012) performed a systematic review of 15 studies and reported a negative aspect of stigma experiences in people with lung cancer; a recent systematic review built on that prior study also included four non-communicable respiratory diseases, i.e., lung cancer, COPD, asthma, and mesothelioma (Shiho Rose, Paul, Boyes, Kelly, & Roach, 2017). Of the twenty-five studies reviewed, 20 of them reported stigma experiences in relation to lung cancer and four reported stigma experiences associated with COPD. This review reported that people with COPD or lung cancer are more vulnerable to being stigmatized than those with other respiratory diseases because of the strong association with tobacco smoking (Shiho Rose et al., 2017).

Studies have also identified the adverse impact of stigma-related experience on psychological health and health behaviors in people with COPD or lung cancer. In both disease groups, stigma experiences were associated with an increased prevalence of depression and decreased treatment adherence and quality of life (Chambers et al., 2012; Shiho Rose et al., 2017). In those with lung cancer, stigma experiences were associated with increased anxiety, as well as a longer period between the time when subjects started to display physical symptoms or suspected something was wrong, and when they eventually sought medical help (Shiho Rose et al., 2017). In another study that examined people with lung cancer, higher levels of lung cancer-related stigma were significantly associated with higher levels of depression ($r = 0.40$, $p < 0.001$) and lowered quality of life ($r = -0.52$, $p < 0.001$) (Maguire et al., 2017). In a systematic review

that examined the relationship between medication adherence and health-related quality of life in people with COPD, perceived stigma associated with the use of inhalers was indicated as one of the possible factors that led to subjects failing to adhere to their medication regimens and thus experiencing a negative impact on their health-related quality of life (Ágh et al., 2015).

Although some stigma research on COPD and lung cancer has been conducted, much more research is needed to understand COPD-related and lung cancer-related stigma and ways to reduce these stigmas. Compared to research on lung cancer-related stigma, research on COPD-related stigma is still relatively new and therefore requires theoretical development and empirical investigation. To the end, a comparison between the two stigmas would be useful to help researchers deepen their conceptual understanding of the stigmas themselves, as well as to codify their similarities and differences beyond their shared roots (i.e., smoking). This comparison may help guide future research in resolving unanswered issues and challenges, such as the underlying logic of stigma processes, social structural involvement, and developing valid stigma measures (Bos et al., 2013; Dovidio, Pearson, & Orr, 2008; Hatzenbuehler, 2016). Valid stigma measures would play an important role in unpacking these issues and challenges. Therefore, the purpose of this study is 1) to summarize existing literature that addresses key factors in the conceptual model described below and 2) to identify existing measures used to examine COPD-related and lung cancer-related stigma.

Conceptual Framework

This study was guided by a conceptual model that represents the effects of stigma processes on health (Major et al., 2018) (see Figure 2-1). According to this model, stigma is triggered by a 'socially-conferred mark' or 'stigmatized mark' that separates the stigmatized

group from the non-stigmatized group via social norms, and 'stigma processes' refer to individual, social, and/or structural processes that elicit distressing responses from the socially-conferred mark. The effect of the socially-conferred mark is influenced by a variety of 'moderating factors' (e.g., dimensions of the mark, individual and environmental characteristics); these moderating factors play a role in determining the character, intensity, pervasiveness, and consequences of stigmatization (Major et al., 2018). For example, the perception of smoking as a voluntary, controllable behavior has led people to perceive both COPD and lung cancer as being 'self-inflicted'; this increases the severity of the stigma processes. Stigma processes refer to individual, social, and/or structural processes that elicit distressing responses from the socially-conferred mark.

For the purposes of this model, 'stigma processes' consist of four stigmas: enacted stigma, felt stigma (also called 'perceived stigma'), self-stigma (also called 'internalized stigma'), and anticipated stigma; these stigmas are interrelated. Exposure to these stigma processes creates 'cognitive, affective, behavioral, and physiological responses' on an individual, social, and community level, all of which gradually cause deteriorating 'health' outcomes. This conceptual model can be used to understand the stigma experiences in people with COPD or lung cancer, as well as to facilitate a comparison between the two stigmas.

Methods

Search strategy and eligibility criteria

Four electronic databases—CINAHL, PsycINFO, PubMed, and Scopus—were searched from 1993 through July 2018. After consultation with a health sciences librarian, the following combination of search terms was used to capture the target populations: 'chronic obstructive

pulmonary disease' OR 'COPD' OR 'lung cancer' OR 'lung neoplasms.' Stigma search terms included 'social stigma' OR 'shame' OR 'stigma.'

Studies were included if they 1) were original studies, including either quantitative or qualitative designs; 2) described any findings related to stigma among COPD and lung cancer populations; 3) were published in English; 4) included people with COPD, irrespective of oxygen therapy; and 5) included people with any stage of lung cancer. Studies that were not original studies, such as reviews, systematic reviews, meta-analyses or meta-syntheses were excluded. Case studies, case reports, comments, letters, editorials, biographies, handbooks, study protocols, and treatment guidelines were also excluded. Further, after reviewing all full-text studies that met the inclusion criteria, the decision was made to exclude studies with only non-patient subjects, such as healthcare providers and the general population.

Search outcome

The search of the four electronic databases yielded 544 studies, including 270 duplicates. After removing duplicates and screening titles and abstracts, 154 studies were selected for full-text review. Of these 154 studies, 93 were excluded for the following reasons: non-patient subjects, non-human subjects, and lack of focus on COPD-related or lung cancer-related stigma; then, 61 remained for this review (see Figure 2-2: PRISMA flow diagram 2009).

A data extraction form was created for this review. Three researchers reviewed the included studies and extracted the following data (see Tables 2-1 and 2-2): year and location of publication, sample characteristics, type of study design, stigma measures, and results relevant to the stigma model. The features of stigma measures used in quantitative and mixed-method studies are presented in Table 2-3.

Quality assessment

The methodological quality of all included studies was assessed using the Shaw et al. (2009) checklists (see Appendices A and B) adapted from the Downs and Black (1998) checklist and the Kmet, Lee, and Cook (2004) standard quality assessment criteria for evaluating original studies from a variety of fields. The checklist for quantitative studies comprises 18 items with regard to 1) study aims, 2) study design and sample characteristics, 3) data analysis and results, and 4) conclusions. Since some of the items are only applicable to randomized controlled trials, an N/A (i.e., not applicable) option is provided for other study designs (Kmet et al., 2004; Shaw et al., 2009). The checklist for qualitative studies comprises 15 items with respect to six qualities: 1) study aims and context, 2) sampling, 3) data collection, 4) data analysis, 5) reflexivity, and 6) conclusions. Each checklist item was graded according to the appropriateness and adequate description as good (2), fair (1), or poor (0). A score was calculated for each study by summing the scores of all applicable items, then dividing by the total possible sum scores. The total possible scores would be [(18 – number of "N/A") * 2] for quantitative studies and [(15 – number of "N/A") * 2] for qualitative studies (Kmet et al., 2004). The scores were displayed as a percentage.

Data synthesis

Included studies in the present review (n = 61) were grouped based on research design and sample characteristics into six categories (i.e., Tables 2-1-a, 2-1-b, 2-1-c, 2-2-a, 2-2-b, and 2-2-c). Table 2-1-a includes studies that use a qualitative design in people with COPD (n = 13); Table 2-1-b includes studies that use a quantitative design in people with COPD (n = 3); Table 2-

1-c includes studies that use a mixed-method design in people with COPD (n = 3). Table 2-2-a includes studies that use a qualitative design in people with lung cancer (n = 15); Table 2-2-b includes studies that use a quantitative design in people with lung cancer (n = 24); Table 2-2-c includes studies that use a mixed-method design in people with lung cancer (n = 3). A conceptual model representing the effects of the stigma processes on health (Major et al., 2018) was used as a framework for synthesizing the results of the included studies (see Figure 2-1).

Results

Overview of included studies

A total of 61 studies were included in this review. Of those, most studies (n = 42) examined stigma associated with lung cancer, and the others (n = 19) examined stigma associated with COPD. Of the qualitative studies (n = 28), 13 explored stigma associated with COPD and 15 explored stigma associated with lung cancer. Of the quantitative studies (n = 27), three examined stigma associated with COPD and 24 examined stigma associated with lung cancer. Of the mixed-method studies (n = 6), three examined stigma associated with COPD and three examined stigma associated with lung cancer. Findings were categorized into six groups according to major domains of the conceptual model that represents the effects of stigma processes on health (Major et al., 2018): socially-conferred mark, moderating factors, stigma processes, individual-level responses, social/community-level exclusion, and health effects (see Figure 2-1).

Quality assessment of included studies

The quality of the studies ranged from 83% to 100% for quantitative studies and from 70% to 100% for qualitative studies. In assessing the quality of quantitative studies (n = 27), the majority of them employed cross-sectional designs and four studies employed longitudinal designs. Studies employed cross-sectional designs were not assessed on checklist items relevant only to randomized controlled trials or cohort study design. For qualitative studies the most frequently unreported item was taking account of deviant or negative cases in the analysis (n = 24, 72.7%) followed by providing a rationale for termination of data collection (n = 16, 48.5%).

Domain A: Socially-conferred mark

In the vast majority of qualitative and quantitative studies, smoking-related stigma was identified as the primary source of both COPD-related stigma and lung cancer-related stigma (Arne, Emtner, Janson, & Wilde-Larsson, 2007; Berger et al., 2011; Berterö, Vanhanen, & Appelin, 2008; Bragadottir, Halldorsdottir, Ingadottir, & Jonsdottir, 2018; Brennan et al., 2004; Brown-Johnson et al., 2015; Brown & Cataldo, 2013; Carter-Harris, Hermann, Schreiber, Weaver, & Rawl, 2014; Cataldo & Brodsky, 2013; Cataldo, Jahan, & Pongquan, 2012; Cataldo et al., 2011; Chambers et al., 2015a; Chambers et al., 2015b; Chapple et al., 2004a; Criswell, Owen, Thornton, & Stanton, 2016; Dirkse et al., 2014; Earnest, 2002; Else-Quest, LoConte, Schiller, & Hyde, 2009; Ernst, Mehnert, Dietz, Hornemann, & Esser, 2017; Esser et al., 2017; Gonzalez & Jacobsen, 2012; Gysels & Higginson, 2008; Halding et al., 2011; Hamann et al., 2014; Harrison et al., 2015; Harrison, Robertson, Goldstein, & Brooks, 2017; Jonsdottir & Jonsdottir, 2007; Lebel et al., 2013a; Lebel et al., 2013b; Lehto, 2014; Lindgren, Storli, & Wiklund-Gustin, 2014; Liu et al., 2016; LoConte, Else-Quest, Eickhoff, Hyde, & Schiller, 2008; O'Neill, 2002; Occhipinti et al., 2018; Pujol, Mérel, & Roth, 2017; Rohan, Boehm, Allen, &

Poehlman, 2016; S. Rose et al., 2018; Scott, Crane, Lafontaine, Seale, & Currow, 2015; Shen et al., 2015; Shen, Hamann, Thomas, & Ostroff, 2016; Simmons et al., 2009; Tod, Craven, & Allmark, 2008; Webb & McDonnell, 2018; J. Weiss et al., 2017; Williamson et al., 2018). Studies showed that the smoking-related stigma played a huge role in perceptions of both COPD and lung cancer as self-inflicted diseases among those with COPD or lung cancer as well as the general public.

In studies of people with COPD, in addition to the smoking-related stigma, two other sources of the stigma were identified, i.e., physical symptoms and associated behaviors, and the use of therapeutic devices. These two sources of the stigma incurred unpleasant responses due to either visible signs or an underlying assumption about smoking, or both. Physical symptoms and associated behaviors, as one source, included breathlessness, uncontrollable cough and phlegm, slow-paced walking and frequent stops while walking (Berger et al., 2011; Gysels & Higginson, 2008; Harrison et al., 2015; Harrison et al., 2017; Hartman, ten Hacken, Boezen, & de Greef, 2013; A. Kaptein et al., 1993; Malpass, Kessler, Sharp, & Shaw, 2015; O'Neill, 2002; Svedsater et al., 2017). The use of therapeutic devices such as supplemental oxygen and inhaler were identified as another source of COPD-related stigma (Berger et al., 2011; Earnest, 2002; Goldbart, Yohannes, Woolrych, & Caton, 2013; Gupta et al., 2011; Harrison et al., 2017; Hartman et al., 2013; Malpass et al., 2015; Neri et al., 2006; Partridge, Dal Negro, & Olivieri, 2011; Svedsater et al., 2017).

In studies of people with lung cancer, smoking-related stigma was the major source of lung cancer-related stigma, but cancer-related stigma also played a role in stigmatization: specifically, a lung cancer diagnosis is depicted as a horrible death or an incurable disease with a poor prognosis; this notion affected how people with lung cancer perceive their condition and

help-seeking behavior (Berterö et al., 2008; Chapple et al., 2004a; Liu et al., 2016; Pujol et al., 2017; Rohan et al., 2016; Scott et al., 2015; Tod et al., 2008; Webb & McDonnell, 2018). Combined with smoking-related stigma, people with lung cancer were less likely to seek needed healthcare. In some culture, people still believe the myth that lung cancer was also regarded as contagious (Liu et al., 2016), or it was considered to be a dirty disease because of the smoking behavior (Occhipinti et al., 2018; Rohan et al., 2016).

Domain B: Moderating factors

Few studies specifically explored the moderating factors that influence characteristics of COPD-related or lung cancer-related stigma and its impact on health. A study of COPD-related stigma (Berger et al., 2011) found that four dimensions (i.e., concealability, disruptiveness, aesthetics, and origin/responsibility) could be understood to influence COPD-related stigma. The dimension in particular to note was origin/responsibility in relation to COPD-related stigma: many participants explicitly put the blame for their illness on their history of smoking (Berger et al., 2011). The dimension of origin/responsibility was also observed in a study of lung cancer-related stigma (LoConte et al., 2008); in this study, past or current smoking status was associated with higher levels of perceived cancer-related stigma. Almost thirty percent of respondents reported that their past or current behavior contributed to their disease (LoConte et al., 2008).

Domain C: Stigma processes

Stigma processes were explored in more detail in qualitative studies than in quantitative studies. In qualitative studies, all four stigmas (enacted stigma, felt stigma, self-stigma, and anticipated stigma) were identified, and there were many similarities and few differences

between COPD-related stigma and lung cancer-related stigma. Enacted stigma occurred at the interpersonal level found in studies of both COPD-related stigma and lung cancer-related stigma, with respondents reporting experiences of discrimination from friends, family, acquaintances, and healthcare professionals (Berger et al., 2011; Bragadottir et al., 2018; Brown & Cataldo, 2013; Chapple et al., 2004a; Gysels & Higginson, 2008; Halding et al., 2011; Hamann et al., 2014; Harrison et al., 2015; Jonsdottir & Jonsdottir, 2007; Lehto, 2014; Liu et al., 2016; O'Neill, 2002; Occhipinti et al., 2018; Rohan et al., 2016; Scott et al., 2015; Tod et al., 2008; Webb & McDonnell, 2018). Enacted stigma occurring at the structural level was observed only in studies of lung cancer-related stigma; respondents indicated that little research funding was allocated for lung cancer compared with other cancer diseases (Chambers et al., 2015b; Chapple et al., 2004a; Lehto, 2014; Rohan et al., 2016; Scott et al., 2015).

Qualitative studies of the two stigmas showed that enacted stigma was inter-correlated with the other three stigma processes (i.e., felt stigma, self-stigma, and anticipated stigmas). Thus, once individuals with COPD or lung cancer experienced negative reactions and discrimination in relation to the socially-conferred marks (i.e., enacted stigma), they were likely to experience the other three stigma processes as well (Berger et al., 2011; Bragadottir et al., 2018; Brown & Cataldo, 2013; Chapple et al., 2004a; Halding et al., 2011; Hamann et al., 2014; Harrison et al., 2015; Lehto, 2014; Liu et al., 2016; Malpass et al., 2015; Occhipinti et al., 2018; Scott et al., 2015; Tod et al., 2008).

In quantitative studies, stigma processes were selectively examined to seek associations between the selected stigma process and psychosocial/physical health effects. Of the four stigma processes, felt stigma and self-stigma were frequently examined in studies of both COPD-related and lung cancer-stigma.

Domain D: Individual-level responses

Individual-level responses (e.g., affective, cognitive, and behavioral responses) were explored in greater detail in qualitative studies than in quantitative studies. In most qualitative studies, respondents with COPD or lung cancer similarly experienced affective responses such as self-conscious emotions (e.g., shame, guilt, and/or embarrassment) and negative emotions (e.g., anxiety, fear, regret, and/or low self-worth). In quantitative studies, those affective responses were examined to demonstrate the experience of COPD-related stigma or lung cancer-related stigma. In addition, those affective responses were assessed to determine the impact of these two stigmas on health-related outcomes [e.g., medication adherence (Gupta et al., 2011; Neri et al., 2006), psychological adjustment (Else-Quest et al., 2009), symptom severity (Cataldo & Brodsky, 2013), help-seeking behavior (S. Rose et al., 2018) or quality of life (Brown-Johnson et al., 2015; Cataldo et al., 2012; Cataldo et al., 2011; Chambers et al., 2015a; Ernst et al., 2017; So, Chae, & Kim, 2017)].

In qualitative studies, respondents within the two disease groups also reported similar cognitive responses such as hiding their diagnosis (Berterö et al., 2008; Chapple, Ziebland, McPherson, & Summerton, 2004b; Hamann et al., 2014; Liu et al., 2016; Occhipinti et al., 2018; Westerman, Sprangers, Groen, van der Wal, & Hak, 2007), ruminating on other causes of their disease (Arne et al., 2007; Bragadottir et al., 2018; Brown & Cataldo, 2013; Chapple et al., 2004a; Halding et al., 2011; Lehto, 2014; Lindgren et al., 2014; Occhipinti et al., 2018; Westerman et al., 2007), trying to reframe their prior history of smoking (Harrison et al., 2015), or pretending to be independent (Berterö et al., 2008; Harrison et al., 2015) and healthy (Westerman et al., 2007). In quantitative studies, respondents with COPD or lung cancer showed

similar cognitive responses such as hiding their diagnosis (Gonzalez et al., 2015; Williamson et al., 2018) and ruminating on other causes of their diseases (Harrison et al., 2017; J. Weiss et al., 2017).

In qualitative studies, respondents within the two disease groups reported both negative and positive behavioral responses. Negative behavioral responses included tending to avoid social activities (Berger et al., 2011; Berterö et al., 2008; Gysels & Higginson, 2008; Harrison et al., 2015; Jonsdottir & Jonsdottir, 2007; Liu et al., 2016), non-adherence to medical treatments (Berger et al., 2011; Goldbart et al., 2013), and/or being less willing to seek further information and resources (Lindgren et al., 2014; Scott et al., 2015). Positive behavioral responses included respondents attempting to quit smoking (Arne et al., 2007; Bragadottir et al., 2018; Halding et al., 2011) and find a support group (Webb & McDonnell, 2018) or expressing interest in playing an advocacy role (Hamann et al., 2014). Few quantitative studies explored behavioral responses in reaction to stigma processes. Negative behavioral responses such as non-adherence with medical treatments were identified in respondents with COPD (Gupta et al., 2011; Neri et al., 2006).

Some differences in individual-level responses between COPD-related stigma and lung cancer-related stigma were identified in qualitative studies. Respondents with lung cancer reported fear of death or therapeutic nihilism, due to the public perception of the tragic death but self-inflicted disease in lung cancer (Berterö et al., 2008; Pujol et al., 2017; Tod et al., 2008) and others' incredulous reactions to their survival which made them feel unwelcomed (Rohan et al., 2016). Respondents with COPD, on the other hand, were relatively optimistic about their prognosis which allowed them to have positive attitudes toward their disease (Lindgren et al., 2014).

Domain E: Social/Community-level exclusion

A few studies explored social/community-level exclusion. As for similarities, respondents in the two diseases were affected by healthcare providers' negative reactions to their history of smoking (Berger et al., 2011; Chapple et al., 2004a; Hamann et al., 2014; Webb & McDonnell, 2018). When smoking-related stigma existed, those respondents were more likely to keep their distance from healthcare providers and/or less likely to be involved in treatment decision-making.

As for differences, respondents with COPD tended to avoid social activities so that they could control their limitations (Berger et al., 2011; Gysels & Higginson, 2008; Halding et al., 2011; Jonsdottir & Jonsdottir, 2007); while those with lung cancer tended to express a sense of grievance against a perceived inadequacy of existing social support and resources such as lack of research funding for lung cancer compared to other cancer groups (Chambers et al., 2015b; Chapple et al., 2004b; Hamann et al., 2014; Lehto, 2014; Occhipinti et al., 2018; Rohan et al., 2016; Scott et al., 2015; Webb & McDonnell, 2018).

Domain E: Potential health effects

Both COPD-related stigma and lung cancer-related stigma had similar health effects. In qualitative studies, stigma in the two diseases hindered respondents from seeking help for their diseases (Arne et al., 2007; Bragadottir et al., 2018; Chapple et al., 2004a; Halding et al., 2011; Harrison et al., 2015; Harrison et al., 2017; Jonsdottir & Jonsdottir, 2007; Scott et al., 2015; Tod et al., 2008). A quantitative study showed that lung cancer-related stigma was significantly associated with increased time from symptom onset to medical help-seeking behavior (Carter-

Harris et al., 2014); in a similar way, both COPD-related and lung cancer-related stigma were barriers to respondents engaging in disease-related health interventions (Chambers et al., 2015b; Harrison et al., 2015) and following treatment recommendations (Ernst et al., 2017; Goldbart et al., 2013; Gupta et al., 2011; Hartman et al., 2013; Neri et al., 2006; Simmons et al., 2009).

Stigma measures

Across the quantitative and mixed-method studies, a variety of scales were used to measure levels of stigma in people with COPD or lung cancer (see Table 2-3). There is no established scale to measure COPD-related stigma; as such studies tend to use a set of items that reflect COPD-related stigma. For example, some studies used items about attitudes toward the use of medication device (e.g., inhaler or supplemental oxygen) (Gupta et al., 2011; Neri et al., 2006; Partridge et al., 2011). Another study used a set of items that ask about the perceived social consequences of having respiratory diseases for the purpose of measuring the quality of life (A. Kaptein et al., 1993). Only one study measured self-conscious emotions with regard to COPD-related stigma using a set of scales, including the Brief Fear of Negative Evaluation Scale, the Shame and Guilt Scale, and the Self-Compassion Scale (Harrison et al., 2017).

In studies of lung cancer-related stigma, the Cataldo Lung Cancer Stigma Scale was the most frequently used (Brown-Johnson et al., 2015; Carter-Harris et al., 2014; Cataldo & Brodsky, 2013; Cataldo et al., 2012; Cataldo et al., 2011; Chambers et al., 2015a; Chambers et al., 2015b; S. Rose et al., 2018; Shen et al., 2016), though the Social Impact Scale was also frequently used (Ernst et al., 2017; Esser et al., 2017; Gonzalez & Jacobsen, 2012; Gonzalez et al., 2015; Schroyen et al., 2017a; Schroyen et al., 2017b). The State Shame and Guilt Scale, the Cancer Responsibility and Regret Scale, and the Discrimination and Stigma Scale were also used

in several studies, and some studies used a set of items independently developed by the investigators to measure lung cancer-related stigma (Else-Quest et al., 2009; Lebel et al., 2013a; Lebel et al., 2013b; LoConte et al., 2008; J. Weiss et al., 2017). The Cataldo Lung Cancer Stigma Scale is the only scale that was developed and psychometrically tested for measuring lung cancer-related stigma (Cataldo et al., 2011).

Discussion

With this systematic review, we identified similarities between COPD-related stigma and lung cancer-related stigma. Smoking-related stigma was involved in the development of these two stigmas, and some shared similarities were also found in domains such as stigma processes, individual-level responses, social/community-level exclusion, and potential health effects.

Similarities notwithstanding, it is of note that no research examined these two stigmas together. Specifically, COPD-related stigma was investigated individually in most instances and was only examined in conjunction with asthma in a few studies. However, lung cancer-related stigma was frequently studied and compared with stigmas in other cancer groups. Many studies pointed out that cancer-related stigma, irrespective of cancer type, is associated with poor psychological symptom adjustment (Else-Quest et al., 2009; Esser et al., 2017; Gökler-Danışman, Yalçınay-İnan, & Yiğit, 2017; Lebel et al., 2013a; Schroyen et al., 2017a; Schroyen et al., 2017b; So et al., 2017) and an increased risk of negative effects on cancer treatment and recovery (Simmons et al., 2009). Several studies demonstrated higher levels of lung cancer-related stigma than those of other cancer groups, such as those with head and neck cancer (Lebel et al., 2013a; Lebel et al., 2013b) and those with breast, prostate, or colon cancers (Ernst et al., 2017; LoConte et al., 2008).

One of the major differentiating factors between COPD and lung-cancer related stigma is a more generalized stigma relating specifically to cancer. Cancer-related stigma stems from an age-old notion that cancer is regarded as a death sentence and in certain societies that is further compounded by a myth that cancer is a form punishment in (Daher, 2012) and/or a belief that cancer is a consequence of one's behavior, such as smoking, obesity, unsafe sex, or sedentary lifestyle (Lebel & Devins, 2008). With those socio-cultural backgrounds, lung cancer has a universal image of a life-threatening disease, along with that of a self-inflicted disease due to a causal link to smoking behavior, which forms a unique characteristic of lung cancer-related stigma. Thus, certain issues between people with lung cancer and their family members—as well as healthcare providers—have been reported: for example, lung cancer-related stigma might lead to patients' therapeutic nihilism (Chambers et al., 2012) and negatively affected clinicians' referral patterns (Wassenaar et al., 2007). Given that early detection and prompt treatment can be an important factor that determines the outcomes of lung cancer treatment, lung cancer-related stigma should be resolved by a comprehensive approach including changing cultural beliefs (Rigney, Studts, & Criswell, 2017).

Although smoking is one of the sources of COPD-related stigma—as it is with lung cancer-related stigma—this review also found two unique, COPD-specific stigma sources: physical symptoms and associated behaviors, as well as the use of therapeutic devices. These sources of COPD-related stigma are similarly found in stigma research for chronic illnesses such as inflammatory bowel disease (IBD) and diabetes mellitus (Schabert, Browne, Mosely, & Speight, 2013; Taft & Keefer, 2016). People with IBD have experienced feelings of shame and embarrassment from symptoms (e.g., abdominal pain, fatigue, diarrhea, etc.) and ostomy (e.g., body image, smell, etc.), hence many of them tended to conceal their disease (Taft & Keefer,

2016); people with diabetes, either type 1 or type 2, experience stigma from daily insulin injections and/or perceptions that diabetes results from a poorly managed diet and weight (Browne, Ventura, Mosely, & Speight, 2013, 2014). COPD-related stigma should be assessed and considered in line with the individual treatment plan, as perceived stigma experiences may discourage people with chronic illnesses, including COPD, from actively engaging in medical care and adherence to treatment protocols (Disler, Gallagher, & Davidson, 2012).

This systematic review showed a remarkable difference in measures between COPD-related stigma and lung cancer-related stigma. Whereas a validated scale has been used to measure the phenomenon of lung cancer-related stigma, to our knowledge, there is no validated scale to measure the phenomenon of COPD-related stigma. Much remains to be done in developing measures for the phenomenon of COPD-related stigma.

Based on these findings, more research—such as interventional studies—is needed to lessen the adverse impact of lung cancer-related stigma on quality of care and health outcomes. Available studies of COPD-related stigma are more limited than those of lung cancer-related stigma. Qualitative studies in this review have described the presence of stigma-related perceptions and experiences in people with COPD, with strong consistency across these studies. It is, nevertheless, challenging to assess the extent of COPD-related stigma and its potential effects on health due to a dearth of scales of COPD-related stigma. These results, taken together, suggest a greater need for more research with valid measures.

Limitations

This systematic review provided an overview of stigma experiences from people with COPD and those with lung cancer, as well as a comparison between the two stigmas; the results

of this comparison are strengthened by integrating both quantitative and qualitative studies. Several limitations should be considered when interpreting the findings from this systematic review: first, although the included studies of this review were results from the systematic search, only studies published in English were taken into account, which might limit the scope of our results. Moreover, this systematic review excluded studies that invited only non-patient groups (e.g., general populations, healthcare providers, or caregivers) to explore COPD-related or lung cancer-related stigma. Thus, it might be possible that relevant findings from other sources were not captured. Second, a conceptual model representing the effects of stigma processes on health (Major et al., 2018) was employed as a framework for synthesizing the results of the included studies: this method facilitates the assessment of the present state of COPD-related stigma and lung cancer-related stigma individually and simultaneously. However, the findings may have been affected by selection bias in the process of the synthesis. Third, studies on stigma experiences may be susceptible to a social desirability response bias, which may limit the strengths of the self-reported results of included studies in this systematic review.

Conclusion

Although some stigma research on COPD and lung cancer has been conducted, much more research is needed to understand both lung cancer and COPD-related stigma and ways to reduce these stigmas. Studies in this systematic review focused on identifying the impact of the two stigmas on individuals' psychological health and quality of life. The stigma processes for both diseases evoked negative responses that may affect health behaviors and quality of life in an undesirable way. Although there are many similarities between COPD-related stigma and lung cancer-related stigma, there are important distinctions to be made between them. Smoking-

related stigma comes into play with both stigmas, so blame attached to smoking is prominent in those with COPD or lung cancer and while lung cancer-related stigma is also associated with cancer-related stigma, COPD-related stigma is shaped by the visibility of symptoms and medication devices. However, studies in this review could not explain why some people with lung cancer or COPD are stigmatized and others are not. Understanding what makes it different could be an important step in demonstrating the pathway from stigma processes to health. Since there is no valid measure of COPD-related stigma, research on the development of a valid COPD-related stigma scale is warranted.

References

Adeloye, D., Chua, S., Lee, C., Basquill, C., Papana, A., Theodoratou, E., . . . Campbell, H. (2015). Global and regional estimates of COPD prevalence: Systematic review and meta–analysis. *Journal of global health, 5*(2).

Ágh, T., Dömötör, P., Bártfai, Z., Inotai, A., Fujsz, E., & Mészáros, Á. (2015). Relationship between medication adherence and health-related quality of life in subjects with COPD: a systematic review. *Respiratory care, 60*(2), 297-303.

Arne, M., Emtner, M., Janson, S., & Wilde-Larsson, B. (2007). COPD patients' perspectives at the time of diagnosis: a qualitative study. *Primary Care Respiratory Journal, 16*(4), 215-221.

Bass, B., Lake, E., Elvy, C., Fodemesi, S., Iacoe, M., Mazik, E., . . . Lee, A. (2018). Smoking-Related Stigma Expressed by Physiotherapists toward Individuals with Lung Disease. *Physiother Can, 70*(1), 65-71. doi:10.3138/ptc.2016-98

Bell, K., Salmon, A., Bowers, M., Bell, J., & McCullough, L. (2010). Smoking, stigma and tobacco ‘denormalization’: Further reflections on the use of stigma as a public health tool. A commentary on Social Science & Medicine's Stigma, Prejudice, Discrimination and Health Special Issue (67: 3). *Social Science & Medicine, 70*(6), 795-799. doi:http://doi.org/10.1016/j.socscimed.2009.09.060

Berger, B. E., Kapella, M. C., & Larson, J. L. (2011). The experience of stigma in chronic obstructive pulmonary disease. *Western journal of nursing research, 33*(7), 916-932.

Berterö, C., Vanhanen, M., & Appelin, G. (2008). Receiving a diagnosis of inoperable lung cancer: patients’ perspectives of how it affects their life situation and quality of life. *Acta Oncologica, 47*(5), 862-869.

Bos, A. E., Pryor, J. B., Reeder, G. D., & Stutterheim, S. E. (2013). Stigma: Advances in theory and research. *Basic and applied social psychology, 35*(1), 1-9.

Bragadottir, G. H., Halldorsdottir, B. S., Ingadottir, T. S., & Jonsdottir, H. (2018). Patients and families realising their future with chronic obstructive pulmonary disease-A qualitative study. *J Clin Nurs, 27*(1/2), 57-64. doi:10.1111/jocn.13843

Brennan, P., Buffler, P. A., Reynolds, P., Wu, A. H., Wichmann, H. E., Agudo, A., . . . Greenberg, R. S. (2004). Secondhand smoke exposure in adulthood and risk of lung cancer among never smokers: a pooled analysis of two large studies. *International journal of cancer, 109*(1), 125-131.

Brown-Johnson, C. G., Cataldo, J. K., Orozco, N., Lisha, N. E., Hickman, N. J., 3rd, & Prochaska, J. J. (2015). Validity and reliability of the Internalized Stigma of Smoking Inventory: An exploration of shame, isolation, and discrimination in smokers with mental health diagnoses. *Am J Addict, 24*(5), 410-418. doi:10.1111/ajad.12215

Brown, C., & Cataldo, J. (2013). Explorations of lung cancer stigma for female long-term survivors. *Nursing inquiry, 20*(4), 352-362.

Browne, J. L., Ventura, A., Mosely, K., & Speight, J. (2013). 'I call it the blame and shame disease': a qualitative study about perceptions of social stigma surrounding type 2 diabetes. *BMJ open, 3*(11), e003384.

Browne, J. L., Ventura, A., Mosely, K., & Speight, J. (2014). 'I'm not a druggie, I'm just a diabetic': a qualitative study of stigma from the perspective of adults with type 1 diabetes. *BMJ open, 4*(7), e005625.

Carter-Harris, L., Hermann, C. P., Schreiber, J., Weaver, M. T., & Rawl, S. M. (2014). *Lung Cancer Stigma Predicts Timing of Medical Help–Seeking Behavior.* Paper presented at the Oncology Nursing Forum.

Cataldo, J. K., & Brodsky, J. L. (2013). Lung cancer stigma, anxiety, depression and symptom severity. *Oncology, 85*(1), 33-40.

Cataldo, J. K., Jahan, T. M., & Pongquan, V. L. (2012). Lung cancer stigma, depression, and quality of life among ever and never smokers. *European Journal of Oncology Nursing, 16*(3), 264-269.

Cataldo, J. K., Slaughter, R., Jahan, T. M., Pongquan, V. L., & Hwang, W. J. (2011). *Measuring stigma in people with lung cancer: psychometric testing of the cataldo lung cancer stigma scale.* Paper presented at the Oncology Nursing Forum.

Chambers, S. K., Baade, P., Youl, P., Aitken, J., Occhipinti, S., Vinod, S., . . . Ball, D. (2015a). Psychological distress and quality of life in lung cancer: the role of health-related stigma, illness appraisals and social constraints. *Psycho-Oncology, 24*(11), 1569-1577.

Chambers, S. K., Dunn, J., Occhipinti, S., Hughes, S., Baade, P., Sinclair, S., . . . O'Connell, D. L. (2012). A systematic review of the impact of stigma and nihilism on lung cancer outcomes. *BMC cancer, 12*(1), 184.

Chambers, S. K., Morris, B., Clutton, S., Foley, E., Giles, L., Schofield, P., . . . Dunn, J. (2015b). Psychological wellness and health-related stigma: A pilot study of an acceptance-focused cognitive behavioural intervention for people with lung cancer. *European Journal of Cancer Care, 24*(1), 60-70.

Chapple, A., Ziebland, S., & McPherson, A. (2004a). Stigma, shame, and blame experienced by patients with lung cancer: qualitative study. *Bmj, 328*(7454), 1470.

Chapple, A., Ziebland, S., McPherson, A., & Summerton, N. (2004b). Lung cancer patients' perceptions of access to financial benefits: a qualitative study. *Br J Gen Pract, 54*(505), 589-594.

Cummings, K. M., & Proctor, R. N. (2014). The changing public image of smoking in the United States: 1964–2014. *Cancer Epidemiology and Prevention Biomarkers, 23*(1), 32-36.

Daher, M. (2012). Cultural beliefs and values in cancer patients. *Annals of oncology, 23*(suppl_3), 66-69.

Disler, R., Gallagher, R., & Davidson, P. (2012). Factors influencing self-management in chronic obstructive pulmonary disease: an integrative review. *International Journal of Nursing Studies, 49*(2), 230-242.

Dovidio, J. F., Pearson, A. R., & Orr, P. (2008). Social psychology and neuroscience: Strange bedfellows or a healthy marriage? *Group Processes & Intergroup Relations, 11*(2), 247-263.

Downs, S. H., & Black, N. (1998). The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions. *Journal of Epidemiology & Community Health, 52*(6), 377-384.

Earnest, M. A. (2002). Explaining adherence to supplemental oxygen therapy. *Journal of general internal medicine, 17*(10), 749-755.

Earnshaw, V. A., & Quinn, D. M. (2012). The impact of stigma in healthcare on people living with chronic illnesses. *Journal of Health Psychology, 17*(2), 157-168.

Earnshaw, V. A., Quinn, D. M., Kalichman, S. C., & Park, C. L. (2013). Development and psychometric evaluation of the chronic illness anticipated stigma scale. *Journal of behavioral medicine, 36*(3), 270-282.

Else-Quest, N. M., LoConte, N. K., Schiller, J. H., & Hyde, J. S. (2009). Perceived stigma, self-blame, and adjustment among lung, breast and prostate cancer patients. *Psychology and Health, 24*(8), 949-964.

Ernst, J., Mehnert, A., Dietz, A., Hornemann, B., & Esser, P. (2017). Perceived stigmatization and its impact on quality of life - results from a large register-based study including breast, colon, prostate and lung cancer patients. *BMC cancer, 17*, 741-741. doi:10.1186/s12885-017-3742-2

Esser, P., Mehnert, A., Johansen, C., Hornemann, B., Dietz, A., & Ernst, J. (2017). Body image mediates the effect of cancer-related stigmatization on depression: a new target for intervention. *Psycho-Oncology*.

Evans-Polce, R. J., Castaldelli-Maia, J. M., Schomerus, G., & Evans-Lacko, S. E. (2015). The downside of tobacco control? Smoking and self-stigma: a systematic review. *Social Science & Medicine, 145*, 26-34.

Farrelly, M. C., Nonnemaker, J. M., & Watson, K. A. (2012). The consequences of high cigarette excise taxes for low-income smokers. *PloS one, 7*(9), e43838.

Gökler-Danışman, I., Yalçınay-İnan, M., & Yiğit, İ. (2017). Experience of grief by patients with cancer in relation to perceptions of illness: The mediating roles of identity centrality, stigma-induced discrimination, and hopefulness. *Journal of psychosocial oncology, 35*(6), 776-796. doi:10.1080/07347332.2017.1340389

Goldbart, J., Yohannes, A. M., Woolrych, R., & Caton, S. (2013). 'It is not going to change his life but it has picked him up': a qualitative study of perspectives on long term oxygen therapy for people with chronic obstructive pulmonary disease. *Health and quality of life outcomes, 11*(1), 124.

Gonzalez, B. D., & Jacobsen, P. B. (2012). Depression in lung cancer patients: the role of perceived stigma. *Psycho-Oncology, 21*(3), 239-246.

Gonzalez, B. D., Jim, H. S., Cessna, J. M., Small, B. J., Sutton, S. K., & Jacobsen, P. B. (2015). Concealment of lung cancer diagnosis: prevalence and correlates. *Psycho-Oncology, 24*(12), 1774-1783.

Gupta, V. K., Bahia, J. S., Maheshwari, A., Arora, S., Gupta, V., & Nohria, S. (2011). To study the attitudes, beliefs and perceptions regarding the use of inhalers among patients of obstructive pulmonary diseases and in the general population in Punjab. *J Clin Diagn Res, 5*(3), 434-439.

Gysels, M., & Higginson, I. J. (2008). Access to services for patients with chronic obstructive pulmonary disease: the invisibility of breathlessness. *Journal of pain and symptom management, 36*(5), 451-460.

Halding, A. G., Heggdal, K., & Wahl, A. (2011). Experiences of self-blame and stigmatisation for self-infliction among individuals living with COPD. *Scandinavian journal of caring sciences, 25*(1), 100-107.

Hamann, H. A., Ostroff, J. S., Marks, E. G., Gerber, D. E., Schiller, J. H., & Lee, S. J. C. (2014). Stigma among patients with lung cancer: a patient-reported measurement model. *Psycho-Oncology, 23*(1), 81-92.

Hammond, D., Fong, G. T., Zanna, M. P., Thrasher, J. F., & Borland, R. (2006). Tobacco denormalization and industry beliefs among smokers from four countries. *American journal of preventive medicine, 31*(3), 225-232.

Harrison, S. L., Robertson, N., Apps, L., C. Steiner, M., Morgan, M. D., & Singh, S. J. (2015). "We are not worthy"–understanding why patients decline pulmonary rehabilitation following an acute exacerbation of COPD. *Disability and rehabilitation, 37*(9), 750-756.

Harrison, S. L., Robertson, N., Goldstein, R. S., & Brooks, D. (2017). Exploring self-conscious emotions in individuals with chronic obstructive pulmonary disease: A mixed-methods study. *Chronic respiratory disease, 14*(1), 22-32.

Hartman, J. E., ten Hacken, N. H., Boezen, H. M., & de Greef, M. H. (2013). Self-efficacy for physical activity and insight into its benefits are modifiable factors associated with physical activity in people with COPD: a mixed-methods study. *Journal of physiotherapy, 59*(2), 117-124.

Hatzenbuehler, M. L. (2016). Structural stigma: Research evidence and implications for psychological science. *American Psychologist, 71*(8), 742.

He, Y., Jiang, B., Li, L. S., Li, L. S., Ko, L., Wu, L., . . . Hu, F. B. (2012). Secondhand smoke exposure predicted COPD and other tobacco-related mortality in a 17-year cohort study in China. *Chest, 142*(4), 909-918.

Jones, E. E., Farina, A., Hastorf, A. H., Markus, H., Miller, D. T., & Scott, R. A. (1984). *Social stigma: The psychology of marked relationships*. New York, USA: W. H. Freeman and Company.

Jonsdottir, R., & Jonsdottir, H. (2007). The experience of women with advanced chronic obstructive pulmonary disease of repeatedly relapsing to smoking. *Scandinavian journal of caring sciences, 21*(3), 297-304.

Kaptein, A., Brand, P., Dekker, F., Kerstjens, H., Postma, D., & Sluiter, H. (1993). Quality-of-life in a long-term multicentre trial in chronic nonspecific lung disease: assessment at

baseline. The Dutch CNSLD Study Group. *European Respiratory Journal, 6*(10), 1479-1484.

Kim, S. H., & Shanahan, J. (2003). Stigmatizing smokers: public sentiment toward cigarette smoking and its relationship to smoking behaviors. *J Health Commun, 8*(4), 343-367. doi:10.1080/10810730305723

Kmet, L. M., Lee, R. C., & Cook, L. S. (2004). *Standard quality assessment criteria for evaluating primary research papers from a variety of fields* (Vol. 22): Alberta Heritage Foundation for Medical Research Edmonton.

Lebel, S., Castonguay, M., Mackness, G., Irish, J., Bezjak, A., & Devins, G. M. (2013a). The psychosocial impact of stigma in people with head and neck or lung cancer. *Psycho-Oncology, 22*(1), 140-152.

Lebel, S., & Devins, G. M. (2008). Stigma in cancer patients whose behavior may have contributed to their disease. *Future Oncology, 4*, 717+.

Lebel, S., Feldstain, A., McCallum, M., Beattie, S., Irish, J., Bezjak, A., & Devins, G. M. (2013b). Do behavioural self-blame and stigma predict positive health changes in survivors of lung or head and neck cancers? *Psychology & Health, 28*(9), 1066-1081.

Lehto, R. H. (2014). Patient views on smoking, lung cancer, and stigma: a focus group perspective. *Eur J Oncol Nurs, 18*(3), 316-322. doi:10.1016/j.ejon.2014.02.003

Lindgren, S., Storli, S. L., & Wiklund-Gustin, L. (2014). Living in negotiation: patients' experiences of being in the diagnostic process of COPD. *International journal of chronic obstructive pulmonary disease, 9*, 441.

Link, B. G., Struening, E. L., Rahav, M., Phelan, J. C., & Nuttbrock, L. (1997). On stigma and its consequences: evidence from a longitudinal study of men with dual diagnoses of mental illness and substance abuse. *Journal of health and social behavior, 38*, 177-190.

Liu, H., Yang, Q., Narsavage, G. L., Yang, C., Chen, Y., Xu, G., & Wu, X. (2016). Coping with stigma: the experiences of Chinese patients living with lung cancer. *Springerplus, 5*(1), 1790. doi:10.1186/s40064-016-3486-5

LoConte, N. K., Else-Quest, N. M., Eickhoff, J., Hyde, J., & Schiller, J. H. (2008). Assessment of guilt and shame in patients with non–small-cell lung cancer compared with patients with breast and prostate cancer. *Clinical lung cancer*, *9*(3), 171-178.

Maguire, R., Lewis, L., Mcphelim, J., Cataldo, J., Milroy, R., Woods, K., & Perham, M. (2017). OA14. 07 The Relationship between Lung Cancer Stigma and Patient Reported Outcomes. *Journal of Thoracic Oncology*, *12*(1), S300.

Major, B., Dovidio, J. F., & Link, B. G. (2018). *The Oxford Handbook of Stigma, Discrimination, and Health*: Oxford University Press.

Malpass, A., Kessler, D., Sharp, D., & Shaw, A. (2015). MBCT for patients with respiratory conditions who experience anxiety and depression: a qualitative study. *Mindfulness*, *6*(5), 1181-1191.

Neal, C., McGoldrick, D., & Schear, R. M. (2015). *The experience of stigma: Impacts and implications*. Santa Barbara, CA: Abc-Clio.

Neri, M., Melani, A. S., Miorelli, A. M., Zanchetta, D., Bertocco, E., Cinti, C., . . . Pulmonologists, E. S. G. o. t. I. A. o. H. (2006). Long-term oxygen therapy in chronic respiratory failure: a Multicenter Italian Study on Oxygen Therapy Adherence (MISOTA). *Respir Med, 100*(5), 795-806.

O'Neill, E. S. (2002). Illness representations and coping of women with chronic obstructive pulmonary disease: a pilot study. *Heart & Lung: The Journal of Acute and Critical Care, 31*(4), 295-302.

Occhipinti, S., Dunn, J., O'Connell, D. L., Garvey, G., Valery, P. C., Ball, D., . . . Chambers, S. (2018). Lung Cancer Stigma Across the Social Network: Patients' and Caregivers' Perspectives. *J Thorac Oncol*. doi:10.1016/j.jtho.2018.06.015

Partridge, M. R., Dal Negro, R. W., & Olivieri, D. (2011). Understanding patients with asthma and COPD: insights from a European study. *Prim Care Respir J, 20*(3), 315-323.

Pujol, J. L., Mérel, J. P., & Roth, C. (2017). How preconceptions about lung cancer treatment interact with medical discourse for patients who accept chemotherapy? *Psycho-Oncology, 26*(6), 793-799.

Rigney, M., Studts, J., & Criswell, A. (2017). MA 04.11 A Comprehensive Vision to Reduce Lung Cancer Stigma: Changing Cultural Perspectives on Lung Cancer. *Journal of Thoracic Oncology, 12*(11), S1814.

Rohan, E. A., Boehm, J., Allen, K. G., & Poehlman, J. (2016). In their own words: A qualitative study of the psychosocial concerns of posttreatment and long-term lung cancer survivors. *Journal of psychosocial oncology, 34*(3), 169-183.

Rose, S., Boyes, A., Kelly, B., Cox, M., Palazzi, K., & Paul, C. (2018). Help-seeking behaviour in newly diagnosed lung cancer patients: Assessing the role of perceived stigma. *Psychooncology*. doi:10.1002/pon.4779

Rose, S., Paul, C., Boyes, A., Kelly, B., & Roach, D. (2017). Stigma-related experiences in non-communicable respiratory diseases: a systematic review. *Chronic respiratory disease*, 1479972316680847.

Schabert, J., Browne, J. L., Mosely, K., & Speight, J. (2013). Social stigma in diabetes. *The Patient-Patient-Centered Outcomes Research, 6*(1), 1-10.

Schroyen, S., Marquet, M., Jerusalem, G., Dardenne, B., Van den Akker, M., Buntinx, F., . . . Missotten, P. (2017a). The link between self-perceptions of aging, cancer view and physical and mental health of older people with cancer: A cross-sectional study. *Journal of geriatric oncology, 8*(1), 64-68.

Schroyen, S., Missotten, P., Jerusalem, G., Van den Akker, M., Buntinx, F., & Adam, S. (2017b). Association between self-perception of aging, view of cancer and health of older patients in oncology: a one-year longitudinal study. *BMC cancer, 17*(1), 614.

Scott, N., Crane, M., Lafontaine, M., Seale, H., & Currow, D. (2015). Stigma as a barrier to diagnosis of lung cancer: patient and general practitioner perspectives. *Prim Health Care Res Dev, 16*(6), 618-622.

Shaw, C., McNamara, R., Abrams, K., Cannings-John, R. L., Hood, K., Longo, M., . . . Williams, K. (2009). Systematic review of respite care in the frail elderly. *Health Technology Assessment, 13*(20), 1-246.

Shen, M. J., Hamann, H. A., Thomas, A. J., & Ostroff, J. S. (2016). Association between patient-provider communication and lung cancer stigma. *Supportive Care in Cancer, 24*(5), 2093-2099.

Simmons, V. N., Litvin, E. B., Patel, R. D., Jacobsen, P. B., McCaffrey, J. C., Bepler, G., . . . Brandon, T. H. (2009). Patient–provider communication and perspectives on smoking cessation and relapse in the oncology setting. *Patient Educ Couns, 77*(3), 398-403.

So, H. S., Chae, M. J., & Kim, H. Y. (2017). Reliability and Validity of the Korean Version of the Cancer Stigma Scale. *Journal of Korean Academy of Nursing, 47*(1), 121-132.

Svedsater, H., Roberts, J., Patel, C., Macey, J., Hilton, E., & Bradshaw, L. (2017). Life Impact and Treatment Preferences of Individuals with Asthma and Chronic Obstructive Pulmonary Disease: Results from Qualitative Interviews and Focus Groups. *Advances in Therapy*, 1-16.

Taft, T. H., & Keefer, L. (2016). A systematic review of disease-related stigmatization in patients living with inflammatory bowel disease. *Clinical and experimental gastroenterology*, *9*, 49.

Tod, A. M., Craven, J., & Allmark, P. (2008). Diagnostic delay in lung cancer: a qualitative study. *Journal of advanced nursing*, *61*(3), 336-343.

Torre, L. A., Bray, F., Siegel, R. L., Ferlay, J., Lortet-Tieulent, J., & Jemal, A. (2015). Global cancer statistics, 2012. *CA: a cancer journal for clinicians*, *65*(2), 87-108.

U.S. Department of Health and Human Services [USDHHS]. (2006). *The health consequences of involuntary exposure to tobacco smoke: a report of the Surgeon General.* .

U.S. Department of Health and Human Services [USDHHS]. (2014). *The Health Consequences of Smoking—50 Years of Progress: A Report of the Surgeon General*. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Office on Smoking and Health Retrieved from https://www.cdc.gov/tobacco/data_statistics/sgr/50th-anniversary/index.htm.

U.S. Department of Health and Human Services [USDHHS]. (2016). *Chronic obstructive pulmonary disease (COPD).* Retrieved from https://www.cdc.gov/copd/index.html#2.

U.S. Department of Health and Human Services [USDHHS]. (2017). *Tips from former smokers™: Smoking and COPD*. Atlanta: U.S. Department of Health and Human

Services, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Office on Smoking and Health Retrieved from https://www.cdc.gov/tobacco/campaign/tips/diseases/copd.html.

Van Brakel, W. H. (2006). Measuring health-related stigma—a literature review. *Psychology, health & medicine, 11*(3), 307-334.

Wassenaar, T. R., Eickhoff, J. C., Jarzemsky, D. R., Smith, S. S., Larson, M. L., & Schiller, J. H. (2007). Differences in primary care clinicians' approach to non-small cell lung cancer patients compared with breast cancer. *Journal of Thoracic Oncology, 2*(8), 722-728.

Webb, L. A., & McDonnell, K. K. (2018). Not a death sentence: Perspectives of African American women living with lung cancer. *Oncology Nursing Forum, 45*(1), 46-54. doi:10.1188/18.ONF.46-54

Weiner, B., Perry, R. P., & Magnusson, J. (1988). An attributional analysis of reactions to stigmas. *Journal of Personality and Social Psychology, 55*(5), 738.

Weiss, J., Yang, H., Weiss, S., Rigney, M., Copeland, A., King, J. C., & Deal, A. M. (2017). Stigma, self-blame, and satisfaction with care among patients with lung cancer. *Journal of psychosocial oncology, 35*(2), 166-179.

Westerman, M. J., Sprangers, M. A., Groen, H. J., van der Wal, G., & Hak, T. (2007). Small-cell lung cancer patients are just ‘a little bit’tired: response shift and self-presentation in the measurement of fatigue. *Quality of Life Research, 16*(5), 853-861.

Williamson, T. J., Choi, A. K., Kim, J. C., Garon, E. B., Shapiro, J. R., Irwin, M. R., . . . Stanton, A. L. (2018). A longitudinal investigation of internalized stigma, constrained disclosure, and quality of life across 12 weeks in lung cancer patients on active oncologic treatment. *J Thorac Oncol*. doi:10.1016/j.jtho.2018.06.018

World Health Organization [WHO]. (2017). *WHO report on the global tobacco epidemic, 2017: monitoring tobacco use and prevention policies*. (9241512822).

World Health Organization [WHO]. (2018). *Cancer*. Retrieved from https://www.who.int/news-room/fact-sheets/detail/cancer.

Yanbaeva, D. G., Dentener, M. A., Creutzberg, E. C., Wesseling, G., & Wouters, E. F. (2007). Systemic effects of smoking. *Chest, 131*(5), 1557-1566.

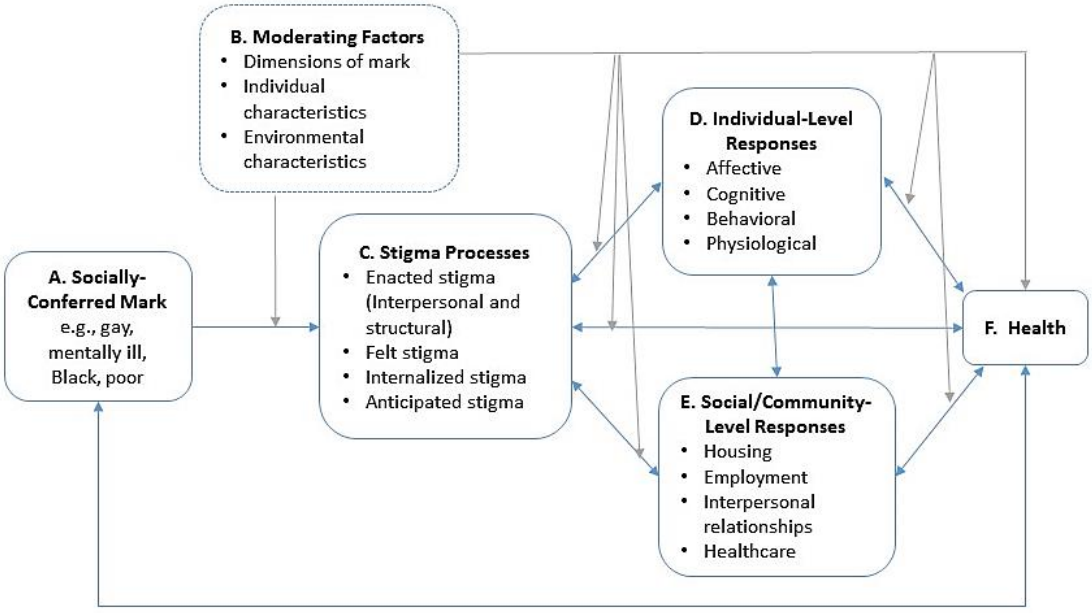

Figure 2-1. A conceptual model of the effects of stigma processes on health. Adapted from "Stigma and its implications for health: introduction and overview." by B. Major, J. F. Dovidio, B. G. Link, and S. K. Calabrese, 2018, *The Oxford handbook of stigma, discrimination, and health*, p. 9. Copyright 2018 by Oxford University Press.

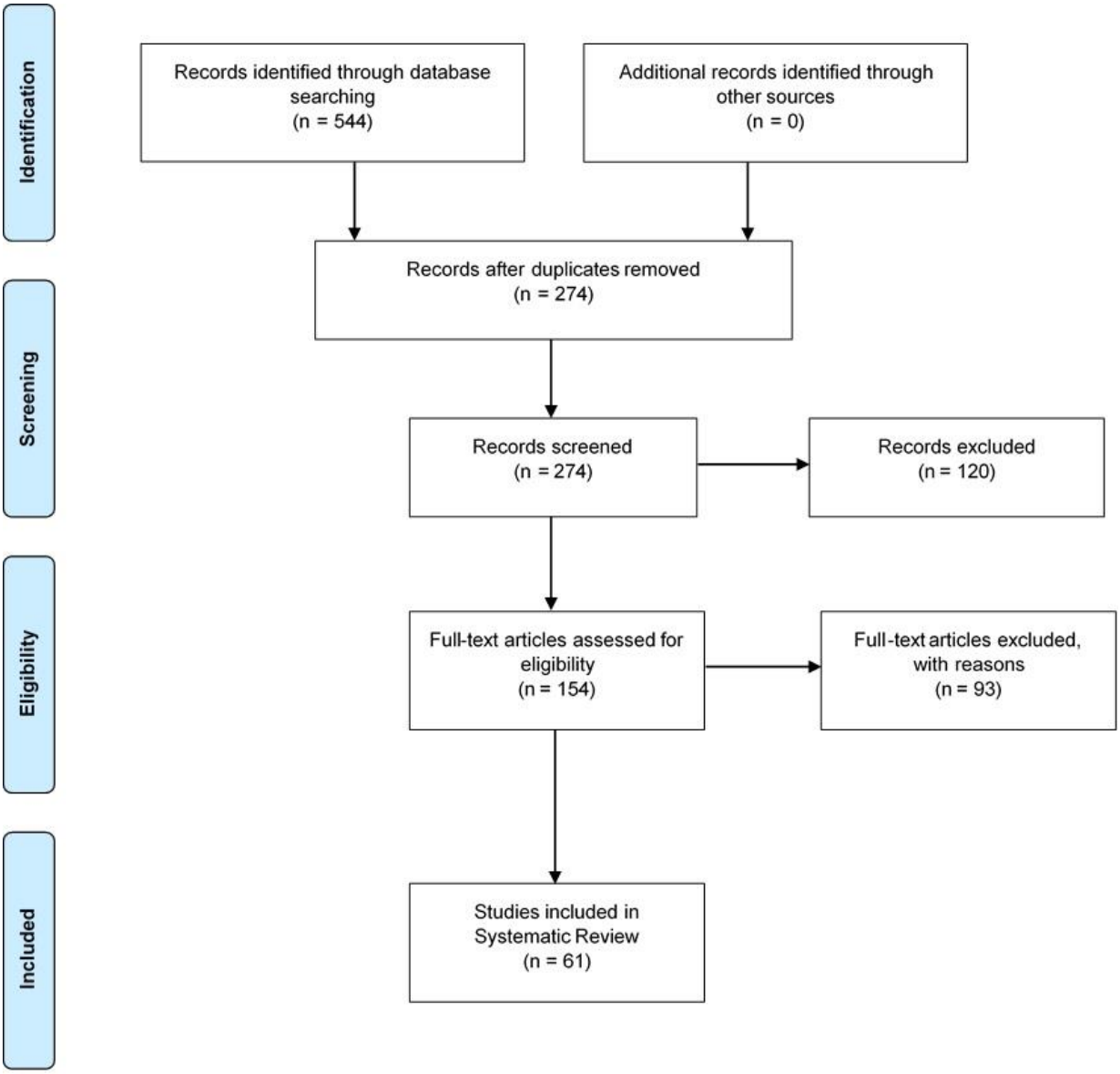

Figure 2-2. PRISMA 2009 Flow Diagram. Adapted from “Preferred reporting items for systematic reviews and meta-analysis: The PRISMA Statement,” by D. Moher, A. Liberati, J. Tetzlaff, D. G. Altman, and The PRISMA Group, 2009, PLoS Medicine, 6(7), e1000097. doi:10.1371/journal.pmed1000097

Table 2-1-a. Summary of the qualitative studies in COPD-related stigma (n = 13)

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in COPD to health*				
				A. Socially-conferred mark related to COPD	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
Earnest (2002), United States	To describe and explain the patterns of adherence to supplemental oxygen	People with COPD who use long-term supplemental oxygen (N = 27) Age (mean) = 67 yrs Smoking status: NR	Descriptive, Qualitative study of a case-series - Pulmonary function test using the ENACT AirWatch device - Brief Symptom Inventory - St. George Respiratory Questionnaire - Semi-structured interviews	COPD treatment device - supplemental oxygen Smoking-related stigma	Self-stigma - due to prior smoking history - when accepting dependence on a substance such as supplemental oxygen	Affective responses: - embarrassment - self-consciousness - fear of burdening or inconveniencing others - a sense of shame	Subjects using supplemental oxygen need to rethink their social roles and status within the family and community in a different way.	Self-stigma can be a barrier to adhere to prescribed oxygen therapy.
O'Neill (2002), United States	To explore how women recognize and respond to symptoms of COPD	Females with COPD who enrolled in pulmonary rehabilitation programs (N = 21) Age (mean) = 67 yrs Smoking status: never (n = 3); former or current (n = 18)	Descriptive, Qualitative study - Open-ended Interviews using the COPD interview guide	Smoking-related stigma combined with gender (female) COPD symptoms - Breathlessness	Enacted stigma - from the general public - from healthcare professionals with regard to smoking and/or gender (woman)	Affective responses: - embarrassment	NA	NA

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in COPD to health*				
				A. Socially-conferred mark related to COPD	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
Arne et al. (2007), Sweden	To gain an understanding of patients´ perspectives and perceptions of COPD at the time of diagnosis	People who were newly diagnosed with COPD or with suspected COPD (N = 10) Age (mean) = 63 yrs Smoking status: never (n = 0); former (n = 6); current (n = 4)	Qualitative study using grounded theory - Pulmonary function test using Spirometry - Open-ended Interviews	Smoking-related stigma	Self-stigma - due to self-inflicted disease	Affective responses: - shame Cognitive responses: - Subjects reflected on the disease in relation to smoking. Behavioral responses: - Subjects reflected on stopping smoking.	NA	Self-stigma can be a barrier to seek help.
Jonsdottir & Jonsdottir (2007), Iceland	To illuminate the experience of repeatedly relapsing to smoking	Females with COPD who had relapsed to smoking three or more times (N = 7) Age (mean) = 55 yrs Smoking status: current (n = 7)	Qualitative, Phenomenological study - Semi-structured interviews	Smoking-related stigma	Enacted stigma - from their healthcare professionals with regard to smoking Self-stigma - perceived that they brought COPD upon themselves	Affective responses: - shame - little self-worth - anger, sorrow, and guilt due to repeated relapses of smoking Cognitive responses: - being obsessive about hiding smoking and smoking	NA	Due to enacted stigma, subjects can be reluctant to seek help unless they had absolute needs.

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in COPD to health*				
				A. Socially-conferred mark related to COPD	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
						odor in order not to be blamed for smoking from others		
Gysels & Higginson (2008), United Kingdom	To explore the experience of breathlessness through patients' accounts of their interactions with services	People with moderate or severe COPD (N = 18) Age (range) = 52-78 yrs Smoking status: NR	Qualitative study using grounded theory - Semi-structured interviews	COPD symptoms - breathlessness in relation to both its effects on social relationships and smoking-related stigma	Self-stigma - related to breathlessness in public Enacted stigma - from their healthcare professionals	Affective responses: - embarrassment and anxiety when being with others Behavioral responses: - avoid social interactions	A subject experienced exclusion from his family doctor due to smoking, which makes difficult in accessing care.	NA
Berger, Kapella, & Larson (2011), United States	To describe social changes and experiences of stigma from the perspective of people with moderate to severe COPD	People with moderate or severe COPD (N = 16) Age (mean) = 70 yrs Smoking status: never (n = 0); former or current (n = 16)	Descriptive, Qualitative study - Charlson Comorbidity Index - ATS-DLD 78-A Breathlessness Scale - Functional Performance Inventory - Semi-structured interviews	Smoking-related disease Physical manifestations of COPD symptoms - breathlessness - coughing and sputum - physical limitations (e.g., slow walking) Equipment-related cues	Enacted stigma: - from family members and strangers in public - from healthcare professionals Felt stigma: - perceived themselves as different and a person who cannot be involved with others	Affective responses: - embarrassment - blame - uncertainty related to anticipated stigma Cognitive responses: - Subjects downplay stigma-related concerns as	Excluded from medical care - due to smoking Excluded from social activities - others' over-protectiveness can act as excluding the people with COPD. Potentially can be excluded from jobs:	NA

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in COPD to health*				
				A. Socially-conferred mark related to COPD	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
				that activate COPD-related stigma - inhaler and oxygen - wheelchair	Self-stigma: - a diminished sense of self-worth Anticipated stigma: yes	being unrealistic. - Subjects work on finding out alternative reasons for COPD other than smoking. Behavioral responses: - Subjects avoid socializing not to draw attention to themselves or not to cause any inconvenience. - Subjects avoid using oxygen in front of others.	- due to high health insurance costs - due to the increased possibility of being absent from work related to illness	
Halding, Heggdal, & Wahl (2011), Norway	To understand how patients with COPD experience daily life in a society with a heavy emphasis on tobacco control	People with COPD (N = 18) Age (range) = 52-81 yrs Smoking status: never (n = 2); former (n = 11); current (n = 5)	Qualitative, Descriptive, Longitudinal study - Interviews using the thematic interview guide	Perception of COPD as a smoking-related and self-inflicted disease	Enacted stigma - from their society - from their healthcare professionals Felt stigma: - Subjects felt devalued due to other's judgment on	Affective responses - felt being exiled in the world of the healthy - felt they do not receive the anticipated support in their social circles	Social support from their social circle is reduced due to having a self-inflicted disease.	Subjects, particularly current smokers, are likely to avoid seeking help.

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in COPD to health*				
				A. Socially-conferred mark related to COPD	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
					their COPD in relation to smoking-related stigma. - Subjects felt unfairly treated in terms of social support. Self-stigma: - Subjects felt they are no longer a member of a healthy society. - Subjects work on not losing their dignity. Anticipated stigma: yes	- felt self-blame and guilt Cognitive responses: - Subjects search for alternative causes of COPD. - Subjects hide COPD-related physical impairment. Behavioral responses - Subjects try to quit smoking. Physiological: - Subjects suffer painful stress.		
Goldbart et al. (2013), United Kingdom	To explore the views and experiences of COPD patients, their carers and the healthcare professionals who deliver these services, on the long-term	i) People with mild to severe COPD who have been receiving LTOT service (N = 27) Age: NR Smoking status: NR	Exploratory, Qualitative study - Semi-structured interviews - Focus groups	COPD treatment device: - oxygen	Enacted stigma: - from a club secretary - from the general public	Behavioral responses: - Subjects do not wear oxygen when going out.	NA	Stigma-related experiences can be a barrier to adhere to prescribed oxygen therapy.

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in COPD to health*				
				A. Socially-conferred mark related to COPD	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
	use of oxygen therapy (LTOT)	ii) Informal carers (N = 10) iii) Healthcare professionals (N = 10)						
Lindgren, Storli, & Wiklund-Gustin (2014), Sweden	To illuminate patients' lived experiences of going through the process of being diagnosed with COPD	People with mild to moderate COPD (N = 8) Age (range) = 60-74 yrs Smoking status: never (n = 0); former (n = 7); current (n = 1)	Qualitative, Phenomenological study - Open-ended Interviews	Perception of COPD as a self-inflicted disease The notion that people with COPD are labeled as a smoker	Felt stigma: - Subjects felt they failed in life when diagnosed with COPD, a self-inflicted disease. Self-stigma - Subjects' identity and dignity tend to be threatened when physically impaired due to COPD, a self-inflicted disease.	Affective responses: - self-judgment - guilt and shame - felt failed Cognitive responses: - Subjects struggle to find answers about their COPD. - Subjects struggle against being labeled as a COPD patient. - Subjects hide and isolate themselves from the outside world. Behavioral responses:	NA	NA

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in COPD to health*				
				A. Socially-conferred mark related to COPD	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
						- Subjects forgo further information and treatment (e.g., pulmonary rehabilitation).		
Harrison et al. (2015), United Kingdom	To explore how patients who refuse a referral to Pulmonary Rehabilitation (PR) appraise acute exacerbations of COPD, in the context of having considered and declined PR	People who recently hospitalized with an acute exacerbation COPD (N = 6) Age (mean) = 75.8 yrs Smoking status: never (n = 0); former (n = 5); current (n = 1)	Qualitative, Descriptive study - Open-ended Interviews	Perception of COPD as a self-inflicted disease COPD symptoms - coughing and sputum	Enacted stigma: - from healthcare professionals Felt stigma: - During acute exacerbation of COPD, subjects are more likely to have a guilty feeling. Self-stigma: - Subjects show decreased self-worth, e.g., using "self-limiting statements" or restraining themselves even in the context of health intervention.	Affective responses: - guilt - negative self-evaluation Cognitive responses: - Subjects try to reframe and contextualize their previous smoking behavior. - Subjects are defensive by emphasizing their independence and contributions to society. - Subjects have decreased self-worth. - Subjects diminish the impact of the	NA	Subjects can be reluctant to engage in health interventions. Subjects can be resistant to prompt help-seeking.

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in COPD to health*				
				A. Socially-conferred mark related to COPD	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
					Anticipated stigma: - To avoid others' judgment, subjects tend to isolate themselves.	disease even in the face of overwhelming symptoms. Behavioral responses: - Subjects are likely to avoid social interactions.		
Malpass et al. (2015), United Kingdom	To explore experiences of mindfulness-based Cognitive responses therapy (MBCT) in people with asthma and COPD	People with asthma and COPD taking part in an 8-week MBCT course i) Asthma (n = 6) ii) COPD (n = 6) Age: NR Smoking status: NR	Qualitative, Phenomenological study - Open-ended Interviews	COPD symptoms - breathlessness - slow paced walking and frequent stops during walking COPD treatment device and supplemental equipment: - oxygen - cane	Enacted stigma: - from the general public Felt stigma: - Subjects feel shame when people are staring at themselves.	Affective responses: - shame - embarrassment Cognitive responses: - Subjects struggle to accept their condition. Behavioral responses: - Subjects rush themselves to do the next thing to hide their limitations.	NA	NA
Svedsater et al. (2017),	To understand patients' perspectives on	Patients group i) Asthma (n = 39)	Qualitative, Descriptive study	COPD symptoms	Felt stigma:	Affective responses:	NA	NA

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in COPD to health*				
				A. Socially-conferred mark related to COPD	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
United Kingdom	asthma or COPD and identify factors that can determine treatment benefits	Age (mean) = 35.5 yrs Smoking status: never (n = 26); former (n = 8); current (n = 5) ii) COPD (n = 33) Age (mean) = 60.2 yrs Smoking status: never (n = 15); former (n = 13); current (n = 5) Clinical experts (n = 4)	- Disease severity using either the Asthma Control Test or the COPD Assessment Test - Focus groups - Semi-structured interviews	- breathlessness - uncontrollable coughing COPD treatment device: - oxygen - inhaler	- Due to visible and uncontrollable symptoms, subjects feel embarrassment.	- embarrassment Cognitive responses: - Subjects tend to suppress negative thoughts (to look like being a normal/healthy person)		
Bragadottir et al. (2018), Iceland	To gain a better understanding of having COPD from the lived experience for patients and their families	i) People with COPD (n = 22) Age (range) = 51-68 yrs Smoking status: never (n = 1); former (n = 17); current (n = 4)	Qualitative, Phenomenological study - Focus groups - Patient-Family dyad interviews	Perception of COPD as a smoking-related and self-inflicted disease	Enacted stigma - from others in public - from healthcare professionals Felt stigma: - Others' offensive words and behaviors	Affective responses: - shame - self-blame - embarrassment - anger (towards stigmatizers) and being defensive	NA	Subjects tend to avoid seeking health care.

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in COPD to health*				
				A. Socially-conferred mark related to COPD	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
		ii) Families (n = 15)			make subjects feel devalued. Self-stigma: - Some subjects think about themselves as "dirty children of Eve" (meaning personal and social exclusion). Anticipated stigma: yes (concealment of COPD)	- regret (about they did not quit smoking sooner) Cognitive responses: - Subjects search for alternative causes of COPD such as nicotine addiction. - Subjects tend to suppress negative thoughts and feelings (hence, they can avoid feeling shame and guilt). Behavioral responses: - Subjects try to quit smoking.		

Note. Pathway from Stigma in COPD or Lung cancer to health*: Findings are organized by domains in a conceptual model representing the effects of the stigma processes on health (Major et al., 2017); NA: Not available

Table 2-1-b. Summary of the quantitative studies in COPD-related stigma (n = 3)

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in COPD or Lung cancer to health*				
				A. Socially-conferred mark related to COPD	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
Kaptein et al. (1993), Netherlands	To examine the impact of chronic non-specific lung diseases (asthma and COPD) on the quality of life of the patient	People with asthma or COPD (n = 274) Age (mean) = 40 yrs Smoking status:	Quantitative, descriptive, correlational, cross-sectional study - Demographics - Lung function using a Spirometry - Quality of life using a set of six subscales comprised of valid instruments i) Anxiety, depression, and sleep disorders using the Symptom Check List ii) Optimism and Stigma using the Respiratory Illness Opinion Survey iii) Activity Daily Living - Symptoms (dyspnea, cough, wheeze, and phlegm)	COPD symptoms - dyspnea - cough	Anticipated stigma	Behavioral - Subjects are more like to be absent from work.	NA	An increased stigma level was significantly correlated with an increased risk of absence from work.
Neri et al. (2006), Italy	To evaluate the behavior and the knowledge regarding long-term oxygen therapy in a large group of	People using oxygen (N = 1504) - COPD (n = 1041) Age (mean) = 79 yrs Smoking status: never (23%);	Quantitative, descriptive, cross-sectional study - Demographic and clinical information - Oxygen utilization using a questionnaire	COPD treatment device - oxygen	Felt stigma Self-stigma	Affective - shame Behavioral - avoiding or being reluctant to use oxygen in public	NA	Of those who possess a portable oxygen device, only 40% of them used it daily primarily due to shame.

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in COPD or Lung cancer to health*				
				A. Socially-conferred mark related to COPD	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
	patients mainly using liquid oxygen	former (69%); current (8%) - Interstitial lung disease (n = 169) - Fibrosis post-TB (n = 142) - Bronchiectasis (n = 89) - Cancer (n = 50) - Kyphoscoliosis (n = 43) - Obesity (n = 62) - Obstructive sleep apnoea (n = 44) - Neuromuscular disease (n = 8)	developed by investigators					
Gupta et al. (2011), India	To study the attitudes, beliefs, and perceptions regarding the use of inhalers by obstructive pulmonary disease patients and by the general population	People with COPD (n = 1276) Age = NR Smoking status: NR General public (n = 1832)	Quantitative, descriptive, cross-sectional study - Demographics - Potential attitudes, beliefs, and perceptions using a questionnaire developed by investigators	COPD treatment device - inhaler	Self-stigma Anticipated stigma	Cognitive - hiding the inhaler use in public Behavioral - avoiding or being reluctant to use an inhaler in public	NA	i) Most subjects, those with COPD (86.8%) and the general public (84.2%), agreed that inhaler use regarded as a social stigma. ii) Most subjects, those with COPD (89.5%) and the general public (87.8%), agreed with inhibition for inhaler use in public. iii) Most subjects, those with COPD (91.6%) and

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in COPD or Lung cancer to health*				
				A. Socially-conferred mark related to COPD	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
								the general public (93.3%), preferred to keep the inhaler use a secret.

Note. Pathway from Stigma in COPD or Lung cancer to health*: Findings are organized by domains in a conceptual model representing the effects of the stigma processes on health (Major et al., 2017); NA: Not available

Table 2-1-c. Summary of the mixed-method studies in COPD-related stigma (n = 3)

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in COPD to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
Partridge, Dal Negro, & Olivieri (2011), Europe (United Kingdom, Germany, France, Italy and Spain)	To gain an insight of the needs of people with asthma and COPD and to identify opportunities for better therapeutic strategies	People with asthma (n = 1022) or COPD (n = 719) Age (mean): - asthma = 36.7 yrs - COPD = 62.4 yrs Smoking status: former or current smokers (%) - asthma = 54% - COPD = 85%	Mixed methods: Sequential exploratory design i) Qualitative phase - in-depth individual interviews (n = 120) ii) Quantitative phase - A 47-item questionnaire based on the qualitative interviews - Asthma control using the Asthma Control Questionnaire - Dyspnea using the MMRC	COPD treatment device - inhaler and oxygen	Felt stigma	Affective: - embarrassment	NA	NA
Hartman et al. (2013), Netherlands	i) To investigate perceived reasons for being physically active or sedentary among people with COPD ii) To investigate	People with mild to severe COPD (N = 115) Age (mean) = 65 yrs Smoking status: NR	Mixed methods: Concurrent embedded design i) Qualitative method - Semi-structured interviews ii) Quantitative method - Physical activity using a triaxial accelerometer	COPD treatment device - walking aid - oxygen cylinder COPD symptoms - physical limitation (e.g., slow walking and/or	Felt stigma	Affective: - shame	NA	Feeling ashamed due to physical limitations and using supplemental equipment can be a barrier to be physically active.

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in COPD to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
	whether those perceived reasons are related to the actual measured level of physical activity		- Pulmonary function using a spirometer - Dyspnea using the MMRC - Exercise capacity using a 6-min walk test	frequent stops while walking)				
Harrison et al. (2017), Canada	i) To gain an understanding of the extent to which self-conscious emotions are expressed ii) To examine any associations between self-conscious emotions and adverse health outcomes iii) To compare self-conscious emotions in people with COPD to healthy controls	People with COPD i) Qualitative phase – COPD only (n = 15) Age (mean) = 73 yrs Smoking status: never (n= 0); former (n = 13); current (n = 2) ii) Quantitative phase - COPD (n = 70) Age (mean) = 70.8 yrs Smoking status: never (0%); former (94.3%); current (5.7%) - Healthy control (n = 63) Age (mean) = 66.2 yrs	Mixed methods: Sequential exploratory design i) Qualitative phase - Semi-structured interviews ii) Quantitative phase - Self-conscious emotions (using the Brief Fear of Negative Evaluation Scale, the Shame and Guilt scale, and the self-compassion scale-short form) - COPD-specific items of self-consciousness - Health-related quality of life (using the Chronic Respiratory	Smoking-related stigma COPD symptoms - coughing COPD treatment device - walking aid - oxygen	Felt stigma Self-stigma Anticipated stigma	Affective: - self-blame - shame and guilt - regret - embarrassment Cognitive: - rumination (on causes of COPD) - suppression of negative thoughts - concealing their disability Behavioral - trying to be compliant with pulmonary rehabilitation and smoking cessation	NA	Tend to delay medical care with regard to concealing their condition All self-conscious emotions, except for guilt, were significantly associated with increased emotional responses and psychological symptoms. Compared to healthy controls, people with COPD show

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in COPD to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
		Smoking status: never (77%); former (18%); current (4.9%)	Questionnaire-Self reported) - Self-efficacy (using the Pulmonary rehabilitation adapted index of self-efficacy) - Psychological symptoms (using the HADS)			- attempting to minimize their dependence on aids		higher levels of shame and lower levels of pride as well as are less compassionate toward themselves.

Note. Pathway from Stigma in COPD or Lung cancer to health*: Findings are organized by domains in a conceptual model representing the effects of the stigma processes on health (Major et al., 2017); HADS: Hospital Anxiety and Depression Scale; MMRC: Modified Medical Research Council; NA: Not available

Table 2-2-a. Summary of the qualitative studies in Lung cancer-related stigma (n = 15)

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in COPD or Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
Chapple, Ziebland, & McPherson (2004a), United Kingdom	To gain a better understanding of stigma-related perceptions and experiences in people with lung cancer	People with lung cancer (N = 45) Age: NR Smoking status: NR	Qualitative, Descriptive study - Open-ended Interviews	Perception of lung cancer as a smoking-related and self-inflicted disease Lung cancer symptoms - gasping for air - high death rate - a horrible death	Enacted stigma - from acquaintances - family and friends Felt stigma: - Others' judgmental and negative reactions make subjects feel embarrassed. Anticipated stigma: yes (concealment of lung cancer)	Affective responses: - felt uncomfortable, particularly when acquaintance turned away - felt upset when looking at lung cancer patient's image in the TV advertisement Cognitive responses: - Subjects hide lung cancer diagnosis (i.e., concealment). - Subjects work on finding alternative causes of lung cancer such as imputing the blame on tobacco industry or national press. Behavioral responses:	Excluded from medical care - due to smoking Lung cancer is less likely to be funded by the government for screening and research compared to other cancers.	Stigma-related experiences can be a barrier to seeking help.

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in COPD or Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
						- Subjects do not want to join a support group due to fear of stigma.		
Chapple et al. (2004b), United Kingdom	To gain an understanding of the financial concerns, perceptions, and experiences of claiming the benefits of people with lung cancer	People with lung cancer (N = 45) Age: NR Smoking status: NR	Qualitative, Descriptive study - Open-ended Interviews	Cancer-related stigma	Self-stigma: - Subjects do not claim their undisputed benefits (reflecting they adopt devalued status).	Affective responses: - ashamed Cognitive responses: - Subjects do not want to be labeled as a lung cancer patient (i.e., concealment). - Subjects tend to suppress negative thoughts and feelings (to look like being a normal/healthy person).	NA	NA
Westerman et al. (2007), Netherlands	To describe lung cancer patients' response behavior when answering the question ("were you tired?"), and to search for	People newly diagnosed with small cell lung cancer (N = 23) Age (mean) = 55 yrs	Qualitative, Exploratory, Longitudinal multiple-case study - Cancer-related quality of life (using an EORTC	Cancer-related stigma	Self-stigma: - Most subjects show a discrepancy between current-self (a lung cancer patient) and desired-self (a	Cognitive responses: - Subjects tend to be positive	NA	NA

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in COPD or Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
	counter-intuitive findings	Smoking status: NR	QLQ-C30 and QLQ-CL13) was completed in combination with the Three-Step Test-Interview - Individual quality of life using the SEIQoL-DW		good/healthy person). Anticipated stigma: - Subjects try to protect themselves from stigma-related situations.	and pretend to be a good and healthy person (i.e., 'self- presentation'). - Subjects do not want to be labeled as a lung cancer patient.		
Tod, Craven, & Allmark (2008), United Kingdom	To find out factors influencing delay in reporting symptoms of lung cancer	People with lung cancer (N = 20) Age (range) = 47-81 yrs Smoking status: never (n = 3); former (n = 9); current (n = 8)	Qualitative, Exploratory study - semi-structured interviews	Cancer-related stigma - cancer is regarded as a death sentence Smoking-related stigma	Enacted stigma - from campaign, media message - from healthcare professionals Felt stigma: - Some subjects show feelings that they are unfairly treated (reflecting changes in the image of smoking).	Affective responses: - fear of death and a cancer diagnosis - blame with regard to the history of smoking	NA	Cancer-related stigma can delay reporting of symptoms, thus delay in being diagnosed.

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in COPD or Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
					Anticipated stigma: - Subjects who are either never- or ex-smokers be less likely to report their symptoms due to stigma-related experiences.			
Berterö, Vanhanen, & Appelin (2008), Sweden	To gain an insight of the impact of a diagnosis of inoperable lung cancer on the patients' life situation and quality of life	People with inoperable lung cancer (N = 23) Age (mean) = 67 yrs Smoking status: NR	Qualitative, Phenomenological study - Open-ended Interviews using a general interview guide - Quality of life using a single item	Cancer-related stigma - cancer is regarded as a death sentence Smoking-related stigma	Felt stigma: - Some subjects worry that next of kin can be stigmatized as well. Anticipated stigma: - Subjects try to hide lung cancer.	Affective responses: - fear of death - shame and guilt - blame themselves Cognitive responses: - Subjects tend to conceal their diagnosis. - Subjects do not want to be labeled as a lung cancer patient and a vulnerable person.	NA	NA

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in COPD or Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
						Behavioral responses: - Subjects limit their social activities. - Subjects try to stay independent and strong.		
Simmons et al. (2009), United States	i) to describe cancer patient-provider communication regarding tobacco use, cessation, and relapse ii) to gain an insight of patients' perspectives regarding their experiences with smoking cessation and relapse	i) People with lung (n = 10) or head/neck cancer (n = 10) Age (mean) = 61.9 yrs Smoking status: current (n = 10); relapsed (n = 10) ii) Healthcare professionals (n = 11)	Qualitative, Descriptive study - Demographic questionnaire - Smoking history - Semi-structured Interviews	Smoking-related stigma	Enacted stigma: - from their healthcare professionals Felt stigma: - Subjects, particularly those who relapsed smoking, feel devalued when discussing smoking with their healthcare providers. Anticipated stigma: yes (Subjects try to hide smoking behavior)	Affective responses: - shame and guilt - fear of being judged by their healthcare professionals Cognitive responses: - Subjects are reluctant to open their history of smoking to their healthcare professionals.	NA	Smoking-related stigma can interfere in cancer treatment or increase the risk of recurrence of cancer when patients do not share their smoking status.

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in COPD or Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
Brown & Cataldo (2013), United States	i) to gain a better understanding of lung cancer-related stigma (LCS) experiences in female long-term lung cancer survivors ii) to examine how participants discursively adhere to or reject lung cancer-related stigmatizing beliefs	Females with lung cancer (N = 8) Age: NR Smoking status: never (n = 3); former (n = 5)	Qualitative, Descriptive study - Semi-structured interviews	Smoking-related stigma	Enacted stigma: - from their healthcare professionals - from lung cancer advocacy Felt-stigma: - All subjects report unmet need or unsatisfied interactions with their healthcare providers or treatment-related care. - Subjects feel that they are differently treated (e.g., no empathy) from other cancer groups. Self-stigma: - Some subjects think people who do not have lung cancer as	Affective responses: - uncomfortable - resentful, particularly among those who were never-smokers - guilt - isolated Cognitive responses: - Subjects work on finding alternative causes of lung cancer.	NA	NA

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in COPD or Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
					normal unconsciously.			
Hamann et al. (2014), United States	To determine the main themes of lung cancer-related stigma to provide a blueprint for item development	People with lung cancer (N = 65) Age: NR Smoking status: never (n = 19); former (n = 32); current (n = 14)	Qualitative study - Semi-structured interviews - Focus groups	Smoking-related stigma	Enacted stigma - from strangers/ acquaintances - from family, friends, and colleagues - from healthcare professionals Felt stigma: - Subjects feel a discrepancy between lung cancer and other cancers in terms of societal attitudes. - Subjects experience negative appraisal and devaluation from others including family, friends, and medical teams. Self-stigma:	Affective responses: - self-blame/guilt and shame - anger - regret Cognitive responses: - Subjects try to inform others that they are not smokers. - Subjects tend to conceal their diagnosis. Behavioral responses: - Subjects are interested in playing an advocacy role.	Excluded from medical care which limits patients' involvement in treatment decisions and other medical care, particularly among smokers	NA

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in COPD or Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
					- Subjects who were recent quitters or current smokers are more engaged in self-conscious emotions such as self-blame, guilt, and regret. Anticipated stigma: - Subjects share how they pre-empt stigma reactions.			
Lehto (2014), United States	i) to gain a better understanding of lung cancer patients' experience regarding perceived stigmatization, smoking behaviors, and illness causes ii) to identify the implications of these findings	People with non-small cell lung cancer (N = 11) Age (mean) = 69.8 yrs Smoking status: NR	Qualitative, Descriptive study - Focus groups	Smoking-related stigma	Enacted stigma - from healthcare professionals - from strangers/ acquaintances Felt stigma: - Subjects feel a discrepancy between lung cancer and other cancers	Affective responses: - feel alienated - uncomfortable with regard to interacting with healthcare professionals - fear about their treatment being affected by their smoking status - guilt	Lung cancer is less likely to be funded for screening and research compared to other cancers.	Psychological health could be worsened. - A subject said that lung cancer-related stigma worsened her depression.

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in COPD or Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
	relative to the role of the nurse as a patient advocate				(e.g., breast cancer) in terms of funding and research. Anticipated stigma: - Some subjects share a fear of being treated unfairly regarding their healthcare.	- depressed - self-blame - regret - anger and frustration at others and themselves Cognitive responses: - Subjects ruminate on past choices and wished they had made different choices. - Subjects work on finding alternative causes of lung cancer.		
Scott et al. (2015), Australia	To explore the attitudes and beliefs of people with lung cancer and general practitioners (GP) in relation to stigma as a barrier to the diagnosis of lung cancer	i) People with lung cancer (n = 20) Age (mean) = NR Smoking status: never (n = 7); former (n = 13); current (n = 0)	Qualitative, Exploratory study - Semi-structured interviews	Smoking-related stigma Cancer-related stigma - cancer is regarded as a death sentence	Enacted stigma: - from their healthcare professionals and the general community - from anti-smoking messaging/ TV advertising	Affective responses: - be offensive against others' blame Behavioral responses: - Subjects are hesitant to seek medical advice	Lung cancer is less likely to be funded for screening and research compared to other cancers.	Both smoking- and cancer-related stigma can be a barrier to the diagnosis of lung cancer.

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in COPD or Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
		ii) GP (n = 10)			Felt stigma: - Current smokers tend to delay seeking help for symptoms due to smoking-related stigma. - Subjects feel devalued regarding developments of lung cancer treatment compare to other cancer groups. Anticipated stigma: yes	for their symptoms.		
Liu et al. (2016), China	To gain an insight of stigma-related experiences and coping strategies among patients with lung cancer in China	People with lung cancer (N = 17) Age (mean) = 58.3 yrs Smoking status: NR	Qualitative, Exploratory study - Semi-structured interviews	Smoking-related stigma Cancer-related stigma - cancer is regarded as a death sentence - lung cancer is viewed as a source of infection (contagious)	Enacted stigma - from their colleagues, supervisors, friends, neighbors, other patients Felt stigma: - Subjects experience being ostracized and	Affective responses: - guilt and shame - a sense of loss and self-abasement - feelings of inferiority - fear of being excluded and discriminated by others	Excluded from social relationships Excluded from job opportunities due to decreased ability to work	Shamefulness can lead to despair and suicide. Stigma-related experience can impair self-confidence and lower self-esteem.

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in COPD or Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
				Physical manifestations of lung cancer - decreased ability to work - difficulties in caring for self and family - hair loss and deteriorated general looking - poor self-image (become dependent for personal care)	discriminated from others. Self-stigma: - Some subjects devalue themselves because of having lung cancer. Anticipated stigma: yes (concealment of having lung cancer)	Cognitive responses: - Subjects tend to conceal their disease or diagnosis. - Subjects seek explanations to give to others that lung cancer is not an infectious disease. Behavioral responses: - Subjects often limit their social activities.		
Rohan et al. (2016), United States	i) to gain a better understanding of lung cancer survivors' subjective experiences regarding the psychosocial concerns of post-treatment and long-term survivorship, ii) to make recommendations to better serve	People with lung cancer (N = 21) Age (range) = 46-75 yrs Smoking status: never (n = 4); former (n = 2); current (n = 15)	Qualitative, Exploratory study - Semi-structured interviews	Smoking-related stigma Cancer-related stigma - cancer is regarded as a death sentence - lung cancer is viewed as a dirty disease	Enacted stigma: - from general community - from their healthcare professionals - family and friends Felt stigma: - Subjects perceive others' blame regarding	Affective responses: - self-blame - worthless	Lung cancer is less likely to be funded for screening and research compared to other cancers.	NA

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in COPD or Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
	this population of cancer survivors				having lung cancer. Self-stigma: - Due to others' reaction that people with lung cancer must be dying, subjects struggle with feelings of worthlessness about their survivorship.			
Pujol, Mérel, & Roth (2017), France	To gain an insight of preconceptions about lung cancer and its treatment in relation to acceptance of chemotherapy	People with lung cancer (N = 23) Age (mean) = 61.8 yrs Smoking status: NR	Qualitative study using grounded theory -Semi-structured interviews	Smoking-related stigma Cancer-related stigma - lung cancer is regarded as an incurable, poor prognosis disease	Felt stigma: - Subjects perceive social attitudes that it is a self-inflicted disease. Self-stigma - Some subjects accept having lung cancer is their fault (i.e.,	Affective responses: - guilt and shame - fear of death - worthless (regarding their remaining years as a lung cancer patient) Behavioral responses: - Active search for information about lung cancer lead subjects feel more anxious	NA	NA

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in COPD or Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
					caused by own behavior) and blame themselves.	and stigmatized, so subjects are more likely to stay uncertainty instead.		
Occhipinti et al. (2018), Australia	To gain an understanding of the subjective experience in people with lung cancer and their caregivers and how stigma signifies through their social network	i) People with lung cancer (n = 16) Age (mean) = NR Smoking status: NR ii) Caregivers (n = 12)	Qualitative, Exploratory study - Open-ended interviews	Smoking-related stigma - smoking is regarded as a dirty, disgusting habit/behavior	Enacted stigma - from anti-smoking advertisement - from family - from acquaintances Felt stigma: - Subjects and their caregivers perceive being devalued from others because of having lung cancer. Self-stigma: - Subjects regret about their smoking behavior that is regarded as a dirty and disgusting act, which leads to	Affective responses: - shame and guilt - self-blame - disgust with regard to own smoking behavior Cognitive responses: - Subjects tend to conceal their diagnosis. - Subjects try to inform others that they are non-smokers. - Subjects work on finding alternative causes of lung cancer.	Subjects perceive lack of societal supports compared to other cancers such as breast cancer or leukemia.	NA

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in COPD or Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
					feelings of shame and guilt. Anticipated stigma: yes (concealment of having lung cancer)			
Webb & McDonnell (2018), United States	To gain a better understanding of the experience of female African American lung cancer survivors, their perception of living with lung cancer, and their desire and ability to adopt positive health-related behaviors	African-American Females with lung cancer (N = 18) Age (mean) = 67 yrs Smoking status: never (n = 2); former (n = 12); current (n = 4)	Qualitative, Exploratory study - A 20-item questionnaire for demographic information, health status, and behavior information - Focus groups using a semi-structured interview guide	Cancer-related stigma - cancer is regarded as a death sentence Smoking-related stigma	Enacted stigma - from family and friends, healthcare professionals Felt stigma: - Others' reactions that people with lung cancer must be dying lead to feelings of worthlessness about subjects' survivorships and their remaining lives. Anticipated stigma: yes (concealment of having lung cancer)	Affective responses: - isolated Behavioral responses: - Subjects look for a support group.	Lack of opportunities to get a better understanding of their lung cancer diagnosis and treatment from healthcare professionals Lack of services and resources (e.g., helpful information or referrals) to improve health	NA

Note. Pathway from Stigma in COPD or Lung cancer to health*: Findings are organized by domains in a conceptual model representing the effects of the stigma processes on health (Major et al., 2017); EORTC QLQ-C30: the European Organization for Research and Treatment of Cancer Core Quality of Life Questionnaire; NA: not available; SEI-QoL-DW: the Evaluation of Individual Quality of Life-Direct Weighting; QOL: Quality of Life

Table 2-2-b. Summary of the quantitative studies in lung cancer-related stigma (n = 24)

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
LoCont et al. (2008), United States	i) to gauge the levels of guilt and shame among patients with non–small-cell lung cancer (NSCLC) compared with breast and prostate cancer ii) to examine to what extent cancer patients believe their behavior contributed to their cancer	People with stage IV NSCLC (n = 96) Age (mean) = 65.6 yrs Smoking status: never (n = 8); former (n = 77); current (n = 11) People with breast cancer (n = 30) Age (mean) = 61.8 yrs People with prostate cancer (n = 46) Age (mean) = 72.9 yrs	Quantitative, correlational, longitudinal study - Demographics - Social support - Health status - Anxiety using the Spielberger State-Trait Anxiety Inventory - Depression using the CES-D - Shame and guilt using the State Shame and Guilt Scale - Perceived cancer-related stigma using 6 items developed by investigators	Smoking-related stigma	Felt stigma	Affective: - shame and guilt - embarrassment	NA	i) The perceived cancer-related stigma level was significantly higher in people with lung cancer (score = 1.93) than other cancers (score = 1.45). ii) People who identified that their behavior contributed to their cancer showed higher levels of shame, guilt, depression, and anxiety, irrespective of cancer type. iii) A history of smoking correlated with increased levels of guilt and shame, irrespective of cancer type. iv) Among people with lung cancer, current and former smokers showed higher levels of guilt and shame as well as perceived lung cancer stigma than never smokers.

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
Else-Quest et al. (2009), United States	To examine the relationships among perceived stigma, self-blame, and psychological adjustment in people with lung, breast, or prostate cancer	People with stage IV NSCLC (n = 96) Age (mean) = 65.8 yrs Smoking status: NR People with breast cancer (n = 30) Age (mean) = 61.2 yrs People with prostate cancer (n = 46) Age (mean) = 72.9 yrs	Quantitative, correlational, cross-sectional study - Demographics - Perceived stigma using a one-item developed by investigators - Self-blame using the State Shame and Guilt Scale - Self-esteem by Rosenberg Self-Esteem Scale - Anxiety using the Spielberger State-Trait Anxiety Inventory - Anger using the Spielberger State-Trait Anger Inventory - Depressed affect using the CES-D - Causal attributions for cancer using an open-ended item	Smoking-related stigma	Felt stigma	Affective: - self-blame - low self-esteem - anxiety - anger - depression	NA	i) Compared to people with other cancers, those with lung cancer showed significantly higher agreement with a statement 'My behavior contributed to my cancer,' i.e., internal causal attributions. ii) People who reported internal causal attributions showed poorer psychological adjustment (e.g., self-esteem, anxiety, anger, and depressed affect). iii) Perceived stigma and self-blame were significantly associated with poorer psychological adjustment, irrespective of cancer type. iv) Self-blame mediated the link between perceived stigma and psychological adjustment, irrespective of cancer type.

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
Cataldo et al. (2011), United States	To develop an instrument of perceived stigma by people with lung cancer based on the HIV Stigma Scale and evaluate the psychometric properties of this instrument	People with lung cancer (n = 186) Age (mean) = 55 yrs Smoking status: never (n = 39); former or current (n = 151)	Quantitative, correlational, cross-sectional study using psychometric analysis - Cataldo Lung Cancer Stigma Scale (CLCSS) - Self-esteem using The Rosenberg Self-Esteem Scale - Depression using CES-D - Social support and social conflict using The Social Support indices from the Multi-center AIDS Cohort Coping and Change Study - Quality of life using The Quality of Life Inventory	Smoking-related stigma Cancer-related stigma	Felt stigma	Affective: - fear of rejection - low self-esteem - depression	Decreased perceived social support availability Increased perceived social conflict	In people with lung cancer, perceived stigma statistically significantly correlated with increased depression (r = 0.62), social conflict (r = 0.62), and decreased quality of life (r = - 0.62), self-esteem (r = - 0.72), and social support (r = - 0.51~ - 0.63).
Cataldo, Jahan, & Pongquan (2012), United States	i) to examine the relationship of lung cancer stigma (LCS) with depression and QOL ii) to determine whether the relationship of LCS with	People with lung cancer (n = 190) Age (mean) = 55 yrs Smoking status: never (n = 39);	Quantitative, descriptive, cross-sectional study - Smoking status - Lung cancer stigma using the CLCSS - Depression using CES-D	Smoking-related stigma	Felt stigma	Affective - depression	NA	i) Increased lung cancer stigma score significantly correlated with increased depression (r = 0.68) and decreased quality of life (r = - 0.65). ii) After controlling for age, gender, smoking

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
	depression and QOL differ between ever smokers and never smokers	former (n = 130); current (n = 21)	- Quality of life using the Quality of Life Inventory					status, and depression, lung cancer stigma has a significant and unique contribution to the explanation of the quality of life.
Gonzalez & Jacobsen (2012), United States	To determine the relationship of perceived stigma with depressive symptomatology in people with lung cancer	People with NSCLC (Stage II - IV) (n = 95) Age (mean) = 64 yrs Smoking status: never (n = 12)); former (n = 68); current (n = 15)	Quantitative, correlational, cross-sectional study - Demographic/ Clinical information - Stigma using the Social Impact Scale - Avoidant coping using the 6-item Cognitive Avoidance Subscale of the Coping Responses Inventory - Social support using the 5-item ENRICHD Social Support Instrument - Dysfunctional attitudes using the 40-item Dysfunctional Attitudes Scale - Depressive symptomatology using the CES-D - History of Depression using the	Smoking-related stigma	Felt stigma	Affective - depression	NA	Felt stigma is significantly positively associated with depression in people with lung cancer (r = 0.46).

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
			mood episode section of the Structured Clinical Interview for DSM-IV					
Cataldo & Brodsky (2013), United States	To examine the relationship of LCS with anxiety, depression and physical symptom severity	People with lung cancer (n = 144) Age (mean) = 56.7 yrs Smoking status: never (n = 30); former and current (n = 113)	Quantitative, descriptive, correlational, cross-sectional study - Lung cancer stigma using the CLCSS - Anxiety using the Spielberger State Anxiety Questionnaire - Depression using the CES-D - Symptom severity using the Lung Cancer Symptom Scale	Smoking-related stigma	Felt stigma	Affective - anxiety - depression	NA	i) Among people with lung cancer, there is a strong positive relationship between lung cancer stigma and anxiety (r = 0.41), depression (r = 0.56), and the lung cancer symptom severity (r = 0.48). ii) After controlling for age, anxiety, and depression, lung cancer stigma has a unique and significant role in explaining symptom severity.
Lebel et al. (2013a), Canada	To examine the association of stigma with (i) distress and (ii) subjective well-being in lung or head and neck cancer from the perspective of the illness	People with lung cancer (n = 107) Age (mean) = 64 yrs Smoking status: never (8.4 %); former	Quantitative, descriptive, correlational, cross-sectional study - Psychosocial impact of stigma using the Affect Balance Scale and the CES-D - Stigma using the Explanatory Model	Cancer-related stigma Smoking-related stigma	Enacted stigma Felt stigma Self-stigma	Affective - self-blame - shame	NA	i) People with lung cancer showed higher levels of self-blame than those with head and neck cancer. ii) After controlling for stressful life events, higher levels of stigma is significantly correlated with increased distress

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
	intrusiveness framework	(79.4 %); current (12.1%) People with head and neck cancer (n = 99) Age (mean) = 61.8 yrs	Interview Catalogue as a questionnaire - Illness intrusiveness using the Illness Intrusiveness Ratings Scale - Benefit finding using the Post-Traumatic Growth Inventory - Self-blame using a rating scale - Disfigurement using the Disfigurement Scale - Sociodemographic and medical variables					and decreased well-being. iii) Subjects who reported limited reliance on benefit finding reported decreasing subjective well-being with increasing stigma; whereas subjects who reported more reliance on benefit finding reported that their subjective well-being remained despite stigma increased.
Lebel et al. (2013b), Canada	i) to describe Positive Health Changes (PHCs) in survivors of lung or head and neck ii) to determine whether behavioral self-blame and stigma affect PHCs	People with lung cancer (n = 107) Age (mean) = 64 yrs Smoking status: never (8.4 %); former (79.4 %); current (12.1%) People with head and	Quantitative, descriptive, correlational, cross-sectional study - Positive health changes using a 2-item indicator - Behavioral self-blame using a rating scale - Stigma using the Explanatory Interview Catalogue as a questionnaire - Sociodemographic and medical variables	Smoking-related stigma Cancer-related stigma	Enacted stigma Felt stigma Self-stigma	Affective - self-blame Behavioral - positive health changes	NA	i) People with lung cancer showed significantly higher self-blame than people with head and neck cancer. ii) Subjects who reported self-blame were more likely to adopt more positive health changes than those who did not report self-blame.

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
		neck cancer (n = 99) Age (mean) = 61.8 yrs						
Brown Johnson, Brodsky, & Cataldo (2014), United States	i) to examine the relationship of lung cancer stigma with anxiety, depression, and QOL ii) to explore whether lung cancer stigma has a unique contribution to the explanation of QOL iii) to determine whether study variables differ by smoking status	People with lung cancer (n = 149) Age (mean) = 56.8 yrs Smoking status: never (n = 30); former and current (n = 118)	Quantitative, descriptive, correlational, cross-sectional study - Stigma using the CLCSS - Anxiety using the Spielberger State Anxiety Questionnaire - Depression using the CES-D - Quality of life using the Quality of Life Inventory	Smoking-related stigma	Felt stigma	Affective - anxiety - depression - negative self-concept	NA	i) There was a significant negative relationship between lung cancer stigma and quality of life. ii) After controlling for significant covariates, lung cancer stigma had a significant and unique role in explaining the quality of life. iii) Lung cancer stigma, depression, anxiety, and quality of life did not differ by smoking status.
Chambers et al. (2015a), Australia	To gain an insight of i) the impact of stigma on lung cancer patients' psychological distress and QOL and ii) the role of social constraints and illness appraisal as	People with lung cancer (n = 151) Age (mean) = 69 yrs Smoking status: never (n = 26);	Quantitative, descriptive, correlational, cross-sectional study - Psychological distress using the Hospital Anxiety and Depression Scale	Smoking-related stigma	Felt stigma	Affective - anxiety - depression	NA	Stigma and shame were positively associated with global distress and negatively associated with quality of life.

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
	mediators of the effect	former and current (n = 125)	- Quality of life using the Functional Assessment of Cancer Therapy-Lung - Stigma using the CLCSS - Social constraints using the Social Constraints Scale - Threat and Challenge appraisal using a stress appraisal scale					
Gonzalez et al. (2015), United States	i) to identify the prevalence and correlates of concealment of lung cancer diagnosis 2) to determine whether concealment is associated with negative affect, behavior, and self-evaluation	People with lung cancer (n = 117) Age (mean) = 64.2 yrs Smoking status: never (n = 26); former and current (n = 91)	Quantitative, descriptive, correlational, cross-sectional study - Demographic information - Clinical information - Diagnosis concealment using a brief self-report measure - Coping strategies using the Coping Responses Inventory - Extroversion using the Neuroticism-Extraversion-Openness Five-factor Inventory	Smoking-related stigma Cancer-related stigma	Felt stigma Self-stigma	Affective - anxiety - depression Cognitive - concealment (was reported by 26% of subjects)	NA	i) Those who concealed their diagnosis reported a significantly higher frequency of drinking alcohol than those who did not conceal. ii) Those who concealed their diagnosis reported significantly higher internalized shame related to lung cancer diagnosis than those who did not conceal. iii) Those who used positive reappraisal as a coping strategy were significantly more likely

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
			- Trait social anxiety and social avoidance using the Liebowitz Social Anxiety Scale - Social support using the Enhancing Recovery in Coronary Heart Disease - Anxiety and depression using the Hospital Anxiety and Depression Scale - Cancer-specific distress using the 22-item intrusion subscale of the Impact of Events Scale-Revised - Self-esteem using the Rosenberg Self-esteem Scale - Stigma using the Social Impact Scale					to conceal their diagnosis.
Shen et al. (2015), United States	i) to identify post-traumatic growth among lung cancer survivors as a potential buffer against this relationship between stigma and psychological distress	People with lung cancer (n = 141) Age (mean) = 70.7 yrs Smoking status: all	Quantitative, descriptive, correlational, cross-sectional study - Demographics - Medical characteristics - Psychological distress using the	Smoking-related stigma	Felt stigma Self-stigma	Affective - depression - anxiety - guilt - regret	NA	i) Lung cancer stigma was significantly, positively associated with psychological distress. ii) Post-traumatic growth (positive experience related to cancer) could protect against the

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
	ii) to determine whether these relationships differ by the timing of quitting smoking	former smokers	Hospital Anxiety and Depression - Stigma using the Shame and Stigma Scale (adapted version) - Post-traumatic growth using the Posttraumatic Growth Inventory - Smoking status and a history of quitting					association between stigma and psychological distress for those who quit smoking after lung cancer diagnosis.
Shen et al. (2016), United States	To examine the relationship of good patient-provider communication with levels of lung cancer stigma	People with lung cancer (n = 231) Age (mean) = 62.8 yrs Smoking status: never (n = 60); former (n = 149); current (n = 20)	Quantitative, descriptive, correlational, cross-sectional study - Demographic and clinical information - Smoking status - Patient-provider communication using the Provider Communication Subscale (6 items) of the Consumer Assessment of Health Care Providers and Systems Program - Lung cancer stigma using the CLCSS	Smoking-related stigma	Felt stigma	NR	NA	There was a significant negative relationship between good patient-provider communication and patient-reported lung cancer stigma.

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
Criswell et al. (2016), United States	i) to compare the extent of personal responsibility, regret, and medical stigma in current, former, and never smokers with lung cancer ii) to examine the impact of personal responsibility, regret, and medical stigma on psychosocial and health-related outcomes	People with lung cancer (n = 213) Age (mean) = 63.9 yrs (never smokers); 68.2 yrs (former smokers); 64.4 yrs (current smokers) Smoking status: never (n = 34); former (n = 141); current (n = 38)	Quantitative, descriptive, correlational, cross-sectional study - Demographic and medical information - Psychological adjustment using the Impact of Event Scale-Revised - Depressive symptoms using the CES-D - Distress using the Distress Thermometer - Physical functioning using the Medical Outcomes Study Short Form - Symptom bother using the Memorial Symptoms Assessment Scale-Short Form - Satisfaction with healthcare using a 10-item author-constructed scale - Supportive care needs using the Supportive Care	Smoking-related stigma	Felt stigma Self-stigma	Affective - guilt - self-blame - perceived responsibility Cognitive - regret	NA	i) Current or former smokers showed higher Personal Responsibility and Regret than never smokers. ii) Younger age was associated with higher Personal Responsibility. iii) Among never smokers, Personal Responsibility was positively associated with depressive symptoms (r = 0.49), psychological needs (r = 0.41), use of avoidance coping strategies (r = 0.37), and negatively associated with satisfaction with healthcare (r = - 0.57). iv) Among never smokers, Regret was positively associated with depressive symptoms (r = 0.67), distress (r = 0.47), symptom bother (r = 0.47), psychological needs (r = 0.50), physical and daily living

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
			Needs Survey-Short Form - Coping strategies using the COPE - The author-constructed Cancer Responsibility and Regret Scale					needs (r = 0.36), total supportive care needs (r = 0.39), and avoidance coping strategies (r = 0.36). v) Among never smokers, Medical Stigma was positively associated with depressive symptoms (r = 0.67), distress (r = 0.52), symptom bother (r = 0.46), psychological needs (r = 0.44), patient care support needs (r = 0.41), total supportive care needs (r = 0.41), and avoidance coping (r = 0.59), and negatively associated with satisfaction with healthcare (r = - 0.68).
Esser et al. (2017), Germany	i) to explore the impact of stigmatization on depressive symptomatology ii) to determine whether body image mediates this relationship between	People with lung cancer (n = 125) People with breast cancer (n = 297); prostate cancer (n = 268);	Quantitative, descriptive, correlational, cross-sectional study - Stigmatization using the Social Impact Scale - Depressive symptomatology	Smoking-related stigma	Felt stigma Self-stigma	Affective - shame	Social isolation (perceived loneliness, inferiority, and uselessness) Social rejection (perceived discrimination and	i) Stigmatization was shown to be a risk factor for depressive symptomatology among cancer patients. ii) Body image partly mediated the association between stigmatization

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
	stigmatization and depressive symptomatology	colorectal (n = 168) Age (mean) = 61 yrs Smoking status: NR	using the Patient Health Questionnaire-9 - Body image using the 20-item German Body Image Questionnaire - Physical quality of life using the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire - Visibility of the disease - Medical and sociodemographic variables				devaluation in society) Financial insecurity (consequences of discrimination in the workplace)	and psychological symptomatology.
Schroyen et al. (2017a), Belgium	To investigate the effect of these two stigmas (cancer and aging) on the health of elderly oncology patients	People with cancer over 65 years old (n = 101) - lung cancer (n = 24) - breast cancer (n = 47) - gynecological cancer (n = 25)	Quantitative, descriptive, correlational, cross-sectional study - Demographics and medical information - Cognitive level using the Mini-Mental State Examination - Self-perception of aging using the	Cancer-related stigma Stigma related to Ageism	Felt stigma Self-stigma	NA	NA	i) There was a significantly positive association between both [self-perception of aging and cancer] and global health. ii) There was a significantly positive association between self-perception of aging and physical/mental health.

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
		- hematological cancer (n = 5) Age (mean) = 73.3 yrs Smoking status: NR	Attitudes to Aging Questionnaire - Cancer view using the Social Impact Scale-Modified version - Quality of life using the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30					iii) There was a significantly positive association between cancer view and mental health.
Schroyen et al. (2017b), Belgium	To investigate the effect of these two stigmas (cancer and aging) on the health of elderly oncology patients for the 1-year follow-up	People with cancer over 65 years old (n = 101) - lung cancer (n = 24) - breast cancer (n = 47) - gynecological cancer (n = 25) - hematological cancer (n = 5) T0: n = 101	Quantitative, descriptive, correlational, longitudinal study - Demographics and medical information including updated treatment and death event - Cognitive level using the Mini-Mental State Examination (T0) - Self-perception of aging using the Attitudes to Aging Questionnaire (T0, T3, T6, T12)	Cancer-related stigma Stigma related to Ageism	Felt stigma Self-stigma	NA	NA	i) Those who died before the end of the 1-year follow-up showed more negative self-perception of aging and cancer view, poorer global and physical health than those who completed the follow-up. ii) There was a significant association between both [self-perception of aging and cancer view] and mental health outcomes over the follow-up period.

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
		T3: n = 75 T6: n = 64 T12: n = 58 Age (mean) = 73.5 yrs Smoking status: NR	- Cancer view using the Social Impact Scale-Modified version (T0, T3, T6, T12) - Quality of life using the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (T0, T3, T6, T12)					
So, Chae, & Kim (2017), Korea	To evaluate the reliability and validity of the Korean version of the Cancer Stigma Scale (KCSS)	People with cancer (n = 247) - Breast cancer (20.6%) - Colon cancer (20.2%) - Uterine cervical cancer (20.2%) - Gastric cancer (20.2%) - Lung cancer (19.0%)	Quantitative, descriptive, cross-sectional study - Cancer stigma using the Korean Cancer Stigma Scale adapted from the CLCSS - Quality of life using the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 - Psychological distress using the Psychological Symptom Inventory	Cancer-related stigma	Felt-stigma	Affective - anxiety - depression	NA	i) Increased cancer-related stigma was statistically significantly associated with decreased global and functional subscales of the quality of life. ii) There was a significantly positive association between cancer-related stigma and symptom subscale of the quality of life.

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
		Age (mean) = 57.3 yrs Smoking status: NR						
Weiss et al. (2017), United States	i) to gain an insight of the experiences of people with lung cancer ii) to determine whether attitudes differ by demographic factors	People with lung cancer (n = 174) Age (mean) = NR Smoking status: never (n = 22); former (n = 119); current (n = 33)	Quantitative, descriptive, correlational, cross-sectional study - Lung cancer-related stigma using a 63-item questionnaire designed by Zeno Group including demographic information	Smoking-related stigma	Enacted stigma - from healthcare professionals (24%) - from insurance companies (25%) - from the general public (30%) Felt stigma	Affective - self-blame - dissatisfied with health care Cognitive - causes	Public support Research on lung cancer treatment	i) Current smokers were significantly more likely to feel different by their healthcare professionals than former or never smokers. ii) Former or current smokers were significantly more likely to report self-blame than never smokers. iii) Current smokers were more likely to feel personal stigma than former smokers and never smokers; former smokers were more likely to feel personal stigma than never smokers.
Ernst et al. (2017), Germany	i) To investigate levels of stigma in four major cancer groups ii) to examine the association	People with cancer (n = 858) - breast cancer (n = 297)	Quantitative, descriptive, correlational, cross-sectional study	Smoking-related stigma	Felt stigma Self-stigma	Affective - blame - depression	Social rejection Financial insecurity	i) All dimensions of stigmatization (i.e., social rejection, financial insecurity, internalized shame, and social isolation) and quality of

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
	between stigma and QOL	- colon cancer (n = 168) - lung cancer (n = 125) - prostate cancer (n = 268) Age (mean) = 60.7 yrs Smoking status: NR	- Sociodemographic and medical data - Stigmatization using the Social Impact Scale-German version - Quality of life using the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 - Depressive symptomatology using the Patient Health Questionnaire-9-German version					life (physical, role, emotional, cognitive, and social) were significantly negatively correlated. ii) Among those with lung cancer, stigmatization was significantly negatively associated with emotional functioning. iii) Those with lung cancer reported the highest levels of isolation and internalized shame.
Gökler-Danışman, Yalçınay-İnan, & Yiğit (2017), Turkey	To gain a better understanding of the experience of grief by people with cancer in relation to perceptions of illness, with a focus on the mediating roles of identity centrality, stigma-induced discrimination, and hopefulness	People with cancer (n = 250) - Prostate cancer (3.7%) - Lymphoma (5.4%) - Lung cancer (17.0%) - Breast cancer (29.9%)	Quantitative, descriptive, correlational, cross-sectional study - Grief symptoms using the Prolonged Grief Disorder Scale-patient form - Illness perception using the Perceived Illness Scale - Identity centrality using the Importance	Cancer-related stigma	Enacted stigma Felt stigma Self-stigma	Affective - grief - loss - hopelessness Cognitive - identity centrality	NA	i) Negative experienced discrimination was significantly correlated with negative illness perceptions and more grief symptoms. ii) Negative experienced discrimination, hopefulness, and identity centrality showed a partial mediating effect on the effect of illness

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
		- Gastric cancer (4.6%) - Colon cancer (5.0%) - Ovarian cancer (6.6%) - Pancreas cancer (5.0%) - Others (22.6%) Age (mean) = 55.8 yrs Smoking status: NR	to Identity Scale (one of the subscales of the collective self-esteem scale) - Discrimination using the Discrimination and Stigma Scale - Hope using the State Hope Scale					perception on grief symptom.
Rose et al. (2018), Australia	i) to gain a better understanding of help-seeking behaviors, group identification, and perceived legitimacy of discrimination in people with lung cancer ii) to examine the potential relationship with	People with lung cancer (n = 274) Age (mean) = 67.3 yrs Smoking status: never (n = 42); former (n = 202); current (n = 28)	Quantitative, descriptive, correlational, cross-sectional study - Help-seeking from support services using the author-developed item - Help-seeking from people using the General Help-	Smoking-related stigma Cancer-related stigma	Felt stigma Self-stigma	Cognitive - group identification Behavioral - help-seeking	NA	i) There was a significant and positive association between lung cancer stigma and perceived legitimacy of discrimination. ii) There was no significant association between lung cancer stigma and both [help-seeking behaviors and group identification].

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
	perceived lung cancer stigma with help-seeking behaviors, group identification, and perceived legitimacy of discrimination		Seeking Questionnaire - Group identification using the author-developed item - Perceived legitimacy of discrimination using the author-developed items - Social support using the 12-item version of the Medical Outcomes Study-Social Support Survey - Lung cancer stigma using the CLCSS					
Steffen et al. (2018), United States	To investigate the impact of individual differences and within-person increases in hope on daily social, role, and physical functioning in lung cancer patients who undergo cancer treatment	People with lung cancer (n = 50) Age (mean) = 68.7 yrs Smoking status: never or former (n = 43); current (n = 7)	Quantitative, descriptive, correlational, cross-sectional and longitudinal study i) Level-1 predictor variables - Treatment day - Daily affect using the Positive Affect and Negative Affect Schedule-Expanded Form - Physical symptoms using the Functional	Cancer-related stigma	Self-stigma	Affective - shame - hope - anxiety - depression	Social isolation	i) At the between-person level, those who reported less hope showed poor social and role functioning in both same-day and next-day models. ii) At the within-person level, levels of hope were positively associated with daily physical, social, and role functioning only in the same-day model.

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
			Assessment of Cancer Therapy-Lung - Daily hope using the State Hope Scale - Lung cancer stigma using 5 items from the CLCSS ii) Level-1 dependent variables - Social/role functioning and Physical functioning using the European Organization for Research and Treatment of Cancer Quality of Life Core Questionnaire 30 iii) Level-2 variables - Demographics - Depression and anxiety using the Hospital Anxiety and Depression Scale					iii) At the within-person level, stigma was inversely associated with social and role functioning.
Williamson et al. (2018), United States	To examine whether lung cancer stigma and stigma-related experience of constrained disclosure affect emotional and physical/functional	People with lung cancer (n = 101) Age (mean) = 64.5 yrs Smoking status: never	Quantitative, descriptive, correlational, longitudinal study - Demographics including smoking status	Smoking-related stigma	Self-stigma Anticipated stigma	Affective - shame - self-blame - regret Cognitive - constrained disclosure (defined as	NA	i) Internalized stigma (i.e., self-stigma) and constrained disclosure were significantly and positively correlated (r = 0.20). ii) Those who were current smokers

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
	well-being across 12 weeks in people with lung cancer who undergo active oncologic treatment	(n = 37); former (n = 56); current (n = 8)	- Internalized stigma using the adapted version of the Cancer Responsibility and Regret Scale - Constrained disclosure using two adapted items from an HIV-stigma scale - Emotional and physical/functional well-being using the Functional Assessment of Cancer Therapy-Lung			avoidance or discomfort about disclosing one's lung cancer diagnosis)		reported greater levels of stigma than former or never smokers; those who were former smokers reported greater levels of stigma than never smokers. iii) There were significant and positive associations between internalized stigma and emotional and physical/functional well-being. iv) There were significant and positive associations between constrained disclosure and emotional and physical/functional well-being. v) At the 6-week follow-up, there were significant and inverse associations between internalized stigma and emotional and physical/functional well-being.

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
								vi) At the 12-week follow-up, there was a significant and inverse association between internalized stigma and emotional well-being.

Note. Pathway from Stigma in COPD or Lung cancer to health*: Findings are organized by domains in a conceptual model representing the effects of the stigma processes on health (Major et al., 2017); CES-D: the Center for Epidemiologic studies-Depression Scale; CLCSS: the Cataldo Lung cancer Stigma Scale; NA: not available; QOL: Quality of Life

Table 2-2-c. Summary of the mixed-method studies in lung cancer-related stigma (n = 3)

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
Carter-Harris et al. (2014), United States	To investigate associations between [selected sociodemographic variables, social desirability, healthcare system distrust, lung cancer stigma, smoking status,] and [the time from symptom onset to medical help-seeking behavior]	People with lung cancer (N = 93) Age (mean) = 62 yrs Smoking status: never (n = 30); former (n = 33); current (n = 30)	Mixed methods: Concurrent triangulation design i) Quantitative method - Healthcare system distrust (using the 9-item Revised Health Care System Distrust Scale) - Lung cancer stigma (using the CLCSS) - Smoking status (using the CDC's Behavioral Risk Factor Surveillance System) - Social desirability (using the 20-item Modified Marlowe-Crowne Social Desirability Scale) ii) Qualitative method - Semi-structured interviews to assess demographic information, initial symptoms, and time	Smoking-related stigma	NA	NA	NA	Lung cancer stigma was a statistically significant predictor of increased time from symptom onset to medical help-seeking behavior.

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
			from symptom onset to medical help-seeking behavior					
Dirkse et al. (2014), Canada	To investigate potential links of shame and guilt in lung cancer recovery with distress and marital adjustment	People with lung cancer (n = 8) Age (mean) = 65 yrs Their partners (n = 8)	Mixed methods: Concurrent triangulation design i) Quantitative method - Demographics - medical and smoking status - Depression (using the CES-D) - Relationship talk (using the Relationship Talk Scale) - Marital satisfaction (using the Locke-Wallace Marital Adjustment Test) - Shame and Guilt (using the State Shame and Guilt Scale) ii) Qualitative method: A series of videotaped interviews	Smoking-related stigma	Felt stigma	Affective: - shame and guilt	NA	Greater shame and guilt were associated with increased symptoms of depression. Current smokers showed greater levels of shame.

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
			- the patient-partner dyad interview for 15 minutes (once) - A patient only interview for 10 minutes (4 times)					
Chambers et al. (2015b), Australia	To examine the acceptability of an acceptance-focused cognitive-behavioral intervention with the aim of reducing stigma in people with lung cancer	People with lung cancer (N = 25) Age (mean) = 65.1 yrs Smoking status: never (n = 5); former (n = 13); current (n = 7)	Mixed methods: Sequential explanatory design i) Quantitative phase a. baseline measures - demographics - smoking behaviors - cancer-related information b. the Psychological Wellness intervention via telephone for six weeks (once per week) c. after 3 months from the intervention - in addition to baseline measures - psychological distress (using the HADS) - cancer-related distress (using the	Smoking-related stigma	Enacted stigma: - from the general public Self-stigma	Affective: - guilt and hate Cognitive: - Subjects try to suppress negative thoughts to cope with stigma-related influences. Behavioral: - To avoid having negative thoughts and feelings, subjects try to set a goal or plan a day ahead.	Lack of information resources and funding for lung cancer	Stigma can be a barrier to access interventions to reduce lung cancer-related psychological distress

Author (year), Location	Research Aim	Sample	Design and Measures	Pathway from Stigma in Lung cancer to health*				
				A. Socially-conferred mark related to Lung Cancer	C. Stigma Processes triggered by Socially-conferred mark	D. Individual-Level Responses to Stigma Processes	E. Social/ Community-Level Exclusion related to Stigma Processes	F. Potential Health Effects affected by Stigma Processes
			Impact of Events Scale) - quality of life (using the Functional Assessment of Cancer Therapy-Lung) - depression (using CES-D) - stigma about lung cancer (using the CLCSS) ii) Qualitative phase - Semi-structured interviews (n = 14)					

Note. Pathway from Stigma in COPD or Lung cancer to health*: Findings are organized by domains in a conceptual model representing the effects of the stigma processes on health (Major et al., 2017); CES-D: the Center for Epidemiologic studies-Depression Scale; CLCSS: the Cataldo Lung cancer Stigma Scale; HADS: Hospital Anxiety and Depression Scale; NA: not available; QOL: Quality of Life

Table 2-3. Measures of COPD-related and lung cancer-related stigma

Stigma-related measures	Outcome (Variables)	Items/structures	Included studies	References
Respiratory Illness Opinion Survey	Optimism and Stigma	NA	Kaptein et al. (1993)	Kinsman et al. (1976)

Cataldo Lung Cancer Stigma Scale	Perceived stigma	• 31 items
		• 4 subscales
		  ○ Stigma and shame
		  ○ Social isolation
		  ○ Discrimination
		  ○ Smoking status
			Cataldo et al. (2011; 2012; 2013)
			Brown Johnson et al. (2014)
			Carter-Harris et al. (2014)
			Chambers et al. (2015a; 2015b)
			Shen et al. (2016)
			Rose et al. (2018)
				Cataldo et al. (2011)

		• 5 items	Steffen et al. (2018): an adapted version	

Korean Cancer Stigma Scale	Perceived stigma	• 24 items
		• 6 subscales
		  ○ Social isolation
		  ○ Distancing or avoiding
		  ○ Discrimination
		  ○ Guilt
		  ○ Attribution
		  ○ Lack of medical support
			So et al. (2017)	Cataldo et al. (2011)

Social Impact Scale	Perceived stigma	• 24 items
		• Subscales
		  ○ Social rejection
		  ○ Financial insecurity
		  ○ Internalized shame
		  ○ Social isolation
			Gonzalez et al. (2012; 2015)
			Schroyen et al. (2017a; 2017b): French version
			Esser et al. (2017): German version
			Ernst et al. (2017): German version
				Fife et al. (2000)

Perceived Cancer-Related Stigma	Perceived stigma	6 items	LoConte et al. (2008)	NA
Perceived stigma	Perceived stigma	1 item	Else-Quest et al. (2009)	NA
Explanatory Model Interview Catalogue	Perceived stigma	13 items	Lebel et al. (2013a; 2013b)	Weiss (1997)

Shame and Stigma Scale	Perceived stigma and internalized stigma	• 21 items
		• 2 subscales
		  ○ Perceived stigma
		  ○ Internalized stigma
			Shen et al. (2015): an adapted version	Kissane et al. (2012)

Stigma-related measures	Outcome (Variables)	Items/structures	Included studies	References

State Shame and Guilt Scale	Generalized guilt and shame	• 10 items
		• 2 subscales
		  ○ Shame
		  ○ Guilt
			LoConte et al. (2008)
			Else-Quest et al. (2009)
			Dirkse et al. (2014)
				Marschall et al. (1994)

	Generalized guilt, shame, and pride	• 15 items
		• 3 subscales
		  ○ Shame
		  ○ Guilt
		  ○ Pride
			Harrison et al. (2017)	

Cancer Responsibility and Regret Scale	Guilt and blame	• 11 items
		• 3 subscales
		  ○ Personal responsibility
		  ○ Regret
		  ○ Medical stigma
			Criswell et al. (2016)
			Williamson et al. (2018): an adapted version
				NA

Behavioral self-blame	Behavioral self-blame	1 item	Lebel et al. (2013a; 2013b)	Christensen et al. (1999)
Attitudes toward and experiences with lung cancer	Stigma and self-blame	6 items	Weiss et al. (2017)	NA

Discrimination and Stigma Scale	Discrimination	• 37 items
		• 3 subscales
		  ○ Positive experienced discrimination
		  ○ Negative experienced discrimination
		  ○ Anticipated discrimination
			Gökler-Danışman et al. (2017)	Thornicroft et al. (2009)

Note. NA = not available

Chapter 3

Cognitive Interviewing of the COPD-related Stigma Scale

Abstract

Objectives: People with chronic obstructive pulmonary disease (COPD) are stigmatized by their history of smoking. Stigma, like anxiety and depression, can adversely affect psychological functioning and quality of life. Although a small number of qualitative studies have described the phenomenon of stigma in people with COPD, no existing measures of COPD-related stigma currently exist. This qualitative research aimed to evaluate and refine a 52-item preliminary stigma questionnaire for people with COPD, with the ultimate goal of reducing the number of items. Items were constructed using a five-point Likert scale, with higher scores indicating higher stigma level. The conceptual model of the effects of stigma processes on health guided this research (Major et al., 2018, p.9).

Methods: Nineteen people with COPD (6 men and 13 women) participated in semi-structured cognitive interviews. During the two rounds of cognitive interviews, each participant was invited to only one interview. These 90-minute interviews assessed meaning, comprehension, interpretation, and relevance of the items. All interviews were audiotaped and transcribed verbatim. Atlas.ti 8.2 qualitative software was used for interview data management.

Results: Most questionnaire items were understood and interpreted as intended. Of a total of 52 items, one item was dropped because it was identified as offensive so that many

subjects were reluctant to answer. Eleven items were revised to improve the flow of responding to the questionnaire. The rest 40 items were retained without modification. Regarding response options, subjects selected the mid-point (i.e., neutral) response for various reasons. The most frequent reason for choosing the mid-point response was "both equal parts of agree and disagree," followed by "not applicable."

Conclusions: This qualitative research provided the foundation required for further evaluation of the stigma questionnaire using psychometric methods. Although the individual experience of stigma varies, all subjects reported experiencing one or more forms of stigma. Through cognitive interviewing, we found that the COPD-related Stigma Scale was generally well received by people with COPD. Although participants did not feel highly stigmatized, their responses during cognitive interviews suggested that they had not previously thought of their experiences in terms of stigma, and the cognitive interviewing process raised their awareness of that possibility. In the next phase of this research, we would conduct a survey with 4-point Likert scale and further examine results to determine if the instrument can be shortened, ultimately with the goal of reducing subject burden for completion of the stigma questionnaire.

Introduction

Because chronic obstructive pulmonary disease (COPD) is generally considered an easily preventable, smoking-related disease (C. D. Mathers & Loncar, 2006), many people believe that those with COPD are responsible for their condition. In individuals with COPD, this stigmatization has a negative effect on psychological and social well-being, leading to sub-optimal health-seeking behaviors, such as not using oxygen properly and consistently (Earnest, 2002; Goldbart et al., 2013), not using inhalers (Gupta et al., 2011), not seeking medical advice (Arne et al., 2007), and not engaging in pulmonary rehabilitation programs (Harrison et al., 2015). Because stigma is associated with emotions such as shame and guilt, it can contribute to increased emotional burden (Odencrants, Ehnfors, & Grobe, 2007; Partridge et al., 2011) and avoidance of social interactions (Gysels & Higginson, 2008). However, little is known about COPD-related stigma. Although its measurement will facilitate better understanding of the experience of those with COPD, no instrument currently exists to assess the stigma experience in this population. Furthermore, a more refined measure of COPD-related stigma will be used in further developing a theoretical framework that can guide further development of COPD-related stigma research and intervention.

Background

COPD is one of the main diseases causally linked to tobacco smoking (USDHHS, 2014). Tobacco smoking accounts for more than 75% of cases of COPD and 80% of COPD-related deaths (USDHHS, 2014; 2017). Despite these statistics, 39% of people with COPD continue to smoke (Centers for Disease Control and Prevention, 2012). For these individuals, the health benefits of smoking cessation are considerable: it can ameliorate respiratory symptoms, slow

disease progression, and decrease the risk of developing comorbidities such as coronary heart disease and stroke (Stratelis, Mölstad, Jakobsson, & Zetterström, 2006). Therefore, smoking cessation is a key strategy for preventing and managing COPD (Ford, 2015; Vestbo et al., 2013).

As smoking control efforts in the United States have changed the public image of smoking and tobacco use, and increased public consciousness of its adverse health effects for smokers as well as nonsmokers, some smoking control advocates have taken advantage of stigma as a tool for promoting public health (Bell et al., 2010). Because smoking is now regarded as an undesirable behavior, and smoking-related disease, such as COPD, is considered self-inflicted, social awareness about smoking affects behavior in people with COPD: for example, they try to conceal their diagnosis or to find other causes for their COPD, like occupational particulates and chemicals.

COPD-related stigma has been reported in qualitative studies that examined the lived experience of people with COPD. Due to public attitudes toward smoking, those who had histories of smoking were struggling with their past (Jonsdottir & Jonsdottir, 2007; Lindgren et al., 2014). When common symptoms of COPD like dyspnea, chronic cough, and sputum production became observable by others, people with COPD experienced negative reactions, which triggered self-conscious emotions such as embarrassment, shame, and guilt, leading to withdrawal from social activities and loss of employment (Gysels & Higginson, 2008; Malpass et al., 2015; O'Neill, 2002).

Common treatments such as inhalers and/or supplemental long-term oxygen have been used to reduce symptoms and improve health status among people with COPD (Celli et al., 2004; Vestbo et al., 2013). However, adherence rates among people with COPD have only been about 50% (Bourbeau & Bartlett, 2008; Cullen, 2006), which may stem from feelings of

embarrassment about the use of inhalers and/or supplemental oxygen in public for fear of how they appear to others (Berger et al., 2011; Earnest, 2002; Goldbart et al., 2013; Gupta et al., 2011; Partridge et al., 2011).

In addition to self-consciousness about symptoms and use of treatment equipment (e.g., inhalers and/or supplemental oxygen) in public, people with COPD exhibited feelings of shame for having been diagnosed with the disease. A COPD diagnosis has been found to be emotionally distressing, which impedes people from following up with their doctors and taking control of their own life (Arne et al., 2007; Lindgren et al., 2014). Learning that COPD was a consequence of their smoking, they reported shame at having a self-inflicted disease (Arne et al., 2007). Further, some people diagnosed with COPD, regardless of the severity, minimized their past smoking history in order to diminish feelings of shame and guilt (Lindgren et al., 2014). These qualitative studies played an important role in exploring and understanding the deeply felt phenomenon of stigma among people with COPD. However, the findings from these qualitative studies are limited to describing factors that contribute to COPD-related stigma, such as which group of people are vulnerable to COPD-related stigma, what characteristics of COPD-related stigma distinguish it from other stigmas, and how COPD-related stigma interacts with both psychological distress and health-related behaviors.

To advance the science of COPD-related stigma, we need a valid measure for use in research with larger samples. Based on the findings from their study, Berger et al. (2011) initiated the development of a COPD-related stigma scale, for which they interviewed participants living with COPD to learn about how COPD affected their social relationships and how they experienced COPD-related stigma. They found that participants perceived the potential of stigma both from others and from themselves. Based on these findings, they

constructed a preliminary 60-item COPD-related stigma scale. Because the psychometrics of this scale have not yet been studied, it should be evaluated and refined before psychometric validation.

An expert group was organized to review the preliminary 60-item COPD-related stigma scale to determine whether its items reflected COPD-related stigma. The group consisted of the current research team and two other researchers (Dr. Berger and Dr. Kapella). The scale was administered to fourteen people with COPD (Bickmann & Larson, Unpublished); descriptive statistics (i.e., mean scores of the scale item) were used to gauge how well the items performed with the population of people with COPD. After individual reviews, the expert panel discussed thoroughly and decided to remove eight items which were semantically redundant with previous items.

Theoretical Framework

Cognitive interviewing assesses respondents' cognitive process while they are answering survey questions, in order to identify measurement errors that may occur (Collins, 2003). It enables researchers to determine whether a scale's response options and items are understood and interpreted as the researchers intended them, and that the items collectively are both parsimonious and comprehensive. Diagnosing potentially problematic items enables appropriate revisions that will better reflect the concepts or behaviors of interest.

To provide consistency, a semi-structured interview protocol was developed for use in the standardized cognitive interviews. The interview protocol was based on the four-stage cognitive model suggested by Tourangeau (1984), which explores four questions: (1) Do the study participants understand and interpret the questions as they are intended (comprehension)?

(2) Are study participants able to recall relevant information (retrieval)? (3) How do study participants come to the responses (judgment)? and (4) Is it easy or difficult to select and report an answer (response)? (Tourangeau, Rips, & Rasinski, 2000, pp. 1-22). By using these four questions, potential problems in the questionnaire were systematically explored.

Verbal probing techniques have the advantage of maintaining the interviewer's control of the interview, focusing on potential erroneous areas, and reducing the participants' burden of verbalizing their thought processes (Willis, 2005). Retrospective, instead of concurrent, probing techniques are appropriate for the current study because they focus on the flow of the questionnaire items and closely reflect the actual context of answering the questionnaire (Collins, 2015; Willis, 2005). Using a retrospective verbal probing cognitive interview technique, this study was able to create a safe space for study participants to express their thoughts, perceptions, and/or attitudes about the items.

Statement of purpose

The purpose of this study was to refine the preliminary COPD-related stigma scale using cognitive interviewing techniques and, specifically, to improve the accuracy of the scale items and determine whether the mid-point response option is valuable.

Methods

Study design

This study employed a cross-sectional, descriptive, qualitative study design. Cognitive interviews were conducted with 19 study participants to assure the relevance of the 52-item

COPD-related stigma scale, and to refine and evaluate the items with the aim of improving the validity of the instrument.

Participants and Setting

A convenience sample was used to select potential study participants from the University of Michigan Health System's pulmonary clinic and pulmonary rehabilitation center in Ann Arbor. Potential participants were considered if they (a) were aged 50 years or older; (b) were diagnosed with or were told by their primary care provider that they had COPD, emphysema, or chronic bronchitis; and (c) spoke English as their first language. Those who were simultaneously diagnosed with other stigmatized diseases such as severe mental illness, HIV/AIDS, lung cancer, or physical deformities were excluded from study participation. The University of Michigan Institutional Review Board reviewed and approved all study materials.

To recruit study participants, 37 potential participants were approached. Of those, 17 were either not interested or not eligible to participate: 13 (35.1 %) refused, 3 (8.1%) were not eligible, and 1 (2.7%) was eligible but could not participate due to illness. Of the 20 who were consented, 19 (51.4%) completed the interview, with one who consented but did not complete the interview. Of the 19, nine participated in the first round of interviewing and the remaining 10 participated in the second round. Upon completion of the interview, study participants received a $50 gift card.

Study procedures

Cognitive Interviews. Two rounds of semi-structured cognitive interviews were conducted (see Figure 3-1) for the 52-item COPD-related stigma scale (see Appendix C). Each

participant was interviewed only once, either in the first or second round. After the first round, the research team discussed whether the sample represented sufficient demographic variability. After the second round of the cognitive interviews, the research team discussed whether data saturation was achieved.

The interviews, which lasted approximately 1.5 hours, were conducted by the same interviewer (SW) in either the participant's home, a clinic, or a quiet and private space in a public area. After participants completed the 52-item COPD-related stigma scale, the interviewer asked semi-structured questions about each individual item using the cognitive interviewing technique, ending with questions and a request for comments about the entire scale. Examples of semi-structured questions are provided in Table 3-1. The interviews were audio recorded and transcribed verbatim.

Data Analysis. Descriptive statistics were calculated using IBM SPSS Statistics for Windows, Version 25.0. The transcripts were analyzed via ATLAS.ti 8.0 qualitative data analysis software (ATLAS.ti Scientific Software Development GmbH, Berlin, Germany). The data analysis process was guided by the steps proposed by Miller, Chepp, Willson, and Ryan (2014), which assist in synthesizing and reducing a large amount of narrative data in order to produce meaningful information about the performance of each questionnaire item. The interviewer (SW) made summaries of each interview transcript along with the interview notes (familiarization). The research team, including the interviewer, synthesized and summarized interviews by each item to understand how study participants answered questions, how they came to their answers, and any difficulties in their response process (summarization). Then the research team produced common themes by comparing summaries across study participants (comparison). Lastly, the research team synthesized and summarized the findings by explaining

how participants interpreted the items, how they mapped their responses, and whether they had any difficulties in completing the items (conclusion). Following these steps, the research team determined which items from the COPD-related Stigma Scale to retain, delete, and/or modify.

Results

Demographic Characteristics

Nineteen people with COPD (≥ 50 years old) participated in one-on-one, in-person cognitive interviews from March 2018 through October 2018. Participants' demographic characteristics are shown in Table 3-2. The mean age of participants was 65.5 years (range: 50-82), 13 (68.4%) were female, 15 (78.9%) were Caucasian or White, and 15 (78.9%) had a college degree or higher. Nine (47.4%) were married, 13 (68.4%) were living with other adults, 12 (63.2%) were retired, and only one (5.3%) was working full-time. All participants had a history of smoking: 16 (84.2%) were former smokers and 3 (15.8%) were still smoking at the time of the interview.

Cognitive Interview Results

Study participants reported they understood the instructions and response options of the 52-item COPD-related Stigma Scale. They also reported that there were no difficulties in answering items from beginning to end. Some participants said that the scale covered a wide range of stigma experiences in relation to COPD when they were asked whether there were additional items that should be considered.

After the first round of the cognitive interviews, no items were eliminated by the research team, but eight items were reformatted in response to participants' comments. A revised version

of the 52-item COPD-related Stigma Scale was used for the second round of cognitive interview, after which one item was eliminated, and three were revised.

a. Item Analysis: retained items. Of a total of 52 items, 40 items were retained without modification. The team discussed these items in terms of word/phrase choices, redundancy, and/or relevance based on participants' comments. Instead of revising at this point, those items were reserved for further evaluation with a larger sample to ensure the appropriateness of revision.

a-1. A word choice: Some participants commented that for #43 (*Having COPD is disgusting to me*), it would be appropriate to ask, "Having COPD is disappointing," "Having COPD is regrettable," or "Having COPD makes me angry/upset." However, other participants commented that there was nothing wrong with the wording of #43, although they disagreed with the statement, *Having COPD is disgusting to me*.

a-2. Redundancy: Several items were shown to be similar. For example, participants reported that #33 (*Having COPD makes me feel unclean*) and #35 (*Most people think that a person with COPD is disgusting*) seemed to explore perceptions towards COPD, albeit from different angles. As another example, they reported that #10 (*Others blame a person with COPD for having smoked*) and #11 (*Others think people with COPD are idiots for having smoked*) seemed to invoke the notion of self-inflicted disease. Participants also reported that #25 (*Telling someone I have COPD is risky*) and #37 (*I am very careful who I tell that I have COPD*) seemed to explore concealing COPD.

a-3. Relevance: Study participants indicated that a few items were probably less relevant to people with COPD or at least to themselves. For example, when participants

answered #26 (*People with COPD lose their jobs when their employers find out*), they mentioned that they had not thought about this issue because they were already retired. As another example, when participants answered #32 (*It is easier to avoid new friendships than worry about telling someone that I have COPD*), they responded that they were not quite as worried about new friendships as young people.

b. Item Analysis: deleted item. One item (i.e., #12) was dropped from the 52 items. Most participants were surprised and complained about #12 (*People think of COPD as a dirty disease*) being too offensive; hence, they were reluctant to answer. When they looked at this item, they easily connected "a dirty disease" to a transmittable disease. Shortly after reading the item, some participants tried to understand it by thinking of possible examples in relation to COPD, such as bringing up sputum while coughing or smelling bad due to smoking. Considering the actual environment (i.e., a self-administered survey), this item raised concerns about the possibility of being misinterpreted or being unanswered. During the analysis process, the research team realized that #31 (*Most people believe that a person who has COPD is dirty*) addressed a similar concept and decided to eliminate it.

c. Item Analysis: modified item. Eleven of 52 items were revised (see Table 3-3). Eight items were modified to improve the flow of responding to the questionnaire. The 8 items were: (1) #1 (*People shy away from me when they see I'm wearing oxygen*), (2) #2 (*No one seems embarrassed by my coughing*), (3) #3 (*My family doesn't like me to use my inhaler in public*), (4) #6 (*I avoid using my oxygen in public, so others won't think I'm ill*), (5) #7 (*It embarrasses me to use the inhaler in front of other people*), (6) #9 (*I'm more likely to be embarrassed by my symptoms when I'm among strangers*), (7) #18 (*I avoid using oxygen in front of other people*), and (8) #21 (*Others are put off by my coughing and sputum*). Because these items ask about

stigma experiences associated with either using an inhaler/supplemental oxygen or having COPD-related symptoms, some participants left these items blank and explained that these items were not applicable to them. At the completion of the first round of the cognitive interviews, the research team decided to apply a skip logic to these 8 items to avoid interruption while responding to the questionnaire items. For example, before going to item 1, participants answered a yes-or-no question of "Do you use supplemental oxygen for COPD?" If they answered "no," they could skip item 1 and go to the next item. The revised items were applied to the second round of the cognitive interviews and showed improvement.

Of the 11 items, three were changed to improve clarity or wording based on participants' comments and suggestions. The 3 items were: #14 (*Health care providers have been abrupt with me about smoking*), #31 (*Most people believe that a person who has COPD is dirty*), and #34 (*Since learning I have COPD, I feel set apart and isolated from the rest of the world*). When participants answered #14, they were confused about whether they should think about all past and current health care providers. To increase clarity, #14 was revised to "*Some health care providers have been abrupt with me about smoking.*" Item 31 was discussed along with #12 because these two items displeased many participants and made them hesitant to respond. The research team decided to revise #31 by using the word "unclean" instead of "dirty." Item 12 was dropped. Regarding #34, some participants commented that they partly agreed with this item because it asked two different feelings. The research team decided to change "set apart" into "singled out" to improve the clarity of #34.

d. Response Option Analysis.

None of the participants had problems with matching items and response categories. A few participants marked an X between strongly disagree and disagree, or between agree and

strongly agree, suggesting that they wanted a more nuanced response options; no one suggested having fewer options. Several participants were confused about items that required responding in the opposite direction, such as #2 (*No one seems embarrassed by my coughing*). In those cases, they corrected wrong answers they found while in the cognitive interviews.

Of the 52 items of COPD-related Stigma Scale, the mid-point option (i.e., neutral) was selected 17.41% (ranged from 0% to 47.37%) of the time in both rounds of the cognitive interviewing (see Figure 3-2). Interestingly, participants were less likely to select the mid-point option when they had to explain the reason. More specifically, 20.94% (ranged from 0% to 66.67%) of answers were the mid-point option in the first round of the cognitive interviews and 14.23% (ranged from 0% to 50%) in the second round of the cognitive interviews. Only those who participated in the second round of the cognitive interviews were required to give detailed information on why they selected the neutral option. The most frequently described reason was "both equal parts of agree and disagree" (31.40%) and followed by "not applicable" (27.91%) (see Figure 3-3). For example, a participant gave her reason for choosing neutral regarding #48 (*I have stopped socializing with some people because of their reactions to my having COPD*): "*I might avoid it if there's a few people there that I know will make me uncomfortable … so if it's more of an intimate group of 10 or 12 couples and a couple of them are nasty, I'll not go. But if it's more than that, I don't care, I can be on the other side of the room.*" She chose neutral because she partially agreed with #48.

Discussion

The present study was part of the development of a scale to measure COPD-related stigma (i.e., COPD-related Stigma Scale). To the best of our knowledge, this was the first study

employing cognitive interviewing technique to assess the validity of the COPD-related Stigma Scale based on item content and response categories. Findings from the present study support employing cognitive interviewing technique to improve the clarity and relevance of items and the accuracy of participants' responses.

Cognitive interviewing verified that most items were understood and interpreted as intended, including instructions and response categories. It also allowed us to discover potential problems with the items and response. Potential problems were related to (a) the wording and tone of the items and (b) the design of response categories. The problems were straightforward and could be readily addressed in the process of revisions after each round of cognitive interviews.

For several items that inquired whether COPD-related stigma is associated with morality, participants exhibited non-verbal cues (e.g., slightly pouting lips or knitted brow) and verbal sounds such as "hmm," "ha!" or "really!" and stated that the language of some of the items—"I was surprised" or "…unclean has a different connotation…"—did not accurately describe the experience of COPD-related stigma. Because many of the items in the COPD-related Stigma Scale were derived from Berger et al.'s (2001) HIV stigma scale, they might lack relevance to people with COPD.

By adding a question probing the meaning of neutral responses in the second round of cognitive interviews, we found that the proportion of neutral responses was reduced from 20.94% (n = 9) to 14.23% (n = 10). Of the total number of neutral responses, less than 13% were selected for reasons of true neutrality. As seen in Figure 3-3, 31.4% of participants chose the neutral option because, depending on varying possible interpretations of the items, they could either agree or disagree. They also might have used the neutral option for conveying

indifference to (10.47%) or lack of knowledge about (17.44%) an item. Some of these uses of the neutral option could be interpreted as hiding participants' true reactions to the items (Baka, Figgou, & Triga, 2012). While the neutral option might indicate that the participant did not have a strong opinion about a particular item, in some cases we observed that participants read the item again carefully and changed the original answer after thinking about why they chose the neutral option. Hence, if the neutral option were not provided, participants might either agree or disagree with the item (Weijters, Cabooter, & Schillewaert, 2010), which raises the concern that a neutral option may increase the likelihood of response bias.

Limitations

This qualitative study allowed us to evaluate the COPD-related Stigma Scale, detect the existence of potential problems, and refine the problematic items. However, we cannot entirely exclude the possibility of remaining errors (Beatty & Willis, 2007), because it may be impossible to articulate all cognitive processes. Also, verbalizing one's cognitive process might require careful training (Willis, 2005). Although study participants were well informed about the cognitive interviewing technique, they may have given incomplete explanations to probing questions.

Another limitation is the generalizability of the study findings. Participants were recruited from a single academic health system in the United States, which may not be representative of the broader population. Most participants were Caucasian/White (78.9%) and not actively engaged in employment (94.7%). Further evaluations are needed to ensure that the COPD-related Stigma Scale reflects the stigma experiences of people of other racial/ethnic groups and occupational status, as well as of non-smokers.

Conclusion

The results from this study show that all participants experienced some form of stigma due to their COPD. Through cognitive interviewing, we found that the COPD-related Stigma Scale was generally well received by people with COPD. Although responses to the COPD-related Stigma Scale indicated that participants did not feel highly stigmatized, their responses during cognitive interviews suggested that they had not previously thought of their experiences in terms of stigma, and the cognitive interviewing process raised their awareness of that possibility. Additional research with diverse and larger groups of people with COPD is needed for a thorough evaluation of the COPD-related Stigma Scale. Moreover, given the possible adverse impacts of COPD-related stigma on health, and the benefit of better understanding and assessment of COPD-related stigma, the COPD-related Stigma Scale should be psychometrically validated in future studies.

References

Arne, M., Emtner, M., Janson, S., & Wilde-Larsson, B. (2007). COPD patients' perspectives at the time of diagnosis: a qualitative study. *Primary Care Respiratory Journal*, *16*(4), 215-221.

Baka, A., Figgou, L., & Triga, V. (2012). 'Neither agree, nor disagree': a critical analysis of the middle answer category in Voting Advice Applications. *International Journal of Electronic Governance*, *5*(3-4), 244-263.

Beatty, P. C., & Willis, G. B. (2007). Research synthesis: The practice of cognitive interviewing. *Public opinion quarterly*, *71*(2), 287-311.

Bell, K., Salmon, A., Bowers, M., Bell, J., & McCullough, L. (2010). Smoking, stigma and tobacco ‘denormalization’: Further reflections on the use of stigma as a public health tool. A commentary on Social Science & Medicine's Stigma, Prejudice, Discrimination and Health Special Issue (67: 3). *Social Science & Medicine*, *70*(6), 795-799. doi:http://doi.org/10.1016/j.socscimed.2009.09.060

Berger, B. E., Ferrans, C. E., & Lashley, F. R. (2001). Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale¶. *Research in nursing & health*, *24*(6), 518-529.

Berger, B. E., Kapella, M. C., & Larson, J. L. (2011). The experience of stigma in chronic obstructive pulmonary disease. *Western journal of nursing research*, *33*(7), 916-932.

Bickmann, J., & Larson, J. L. (Unpublished). *Validation of a Chronic Obstructive Pulmonary Disease Stigma Questionnaire*. Unpublished manuscript. School of Nursing. University of Michigan.

Bourbeau, J., & Bartlett, S. (2008). Patient adherence in COPD. *Thorax, 63*(9), 831-838.

Celli, B. R., MacNee, W., Agusti, A., Anzueto, A., Berg, B., Buist, A. S., . . . Fahy, B. (2004). Standards for the diagnosis and treatment of patients with COPD: a summary of the ATS/ERS position paper. *European Respiratory Journal, 23*(6), 932-946.

Centers for Disease Control and Prevention, C. (2012). Chronic obstructive pulmonary disease among adults--United States, 2011. *MMWR. Morbidity and mortality weekly report, 61*(46), 938.

Collins, D. (2003). Pretesting survey instruments: an overview of cognitive methods. *Quality of Life Research, 12*(3), 229-238.

Collins, D. (2015). *Cognitive Interviewing Practice* Retrieved from http://methods.sagepub.com/book/cognitive-interviewing-practice doi:10.4135/9781473910102

Cullen, D. (2006). Long term oxygen therapy adherence and COPD: what we don't know. *Chronic respiratory disease, 3*(4), 217-222.

Earnest, M. A. (2002). Explaining adherence to supplemental oxygen therapy. *Journal of general internal medicine, 17*(10), 749-755.

Ford, E. S. (2015). Trends in mortality from COPD among adults in the United States. *Chest, 148*(4), 962-970. doi:10.1378/chest.14-2311

Goldbart, J., Yohannes, A. M., Woolrych, R., & Caton, S. (2013). 'It is not going to change his life but it has picked him up': a qualitative study of perspectives on long term oxygen therapy for people with chronic obstructive pulmonary disease. *Health and quality of life outcomes, 11*(1), 124.

Gupta, V. K., Bahia, J. S., Maheshwari, A., Arora, S., Gupta, V., & Nohria, S. (2011). To study the attitudes, beliefs and perceptions regarding the use of inhalers among patients of obstructive pulmonary diseases and in the general population in Punjab. *J Clin Diagn Res*, *5*(3), 434-439.

Gysels, M., & Higginson, I. J. (2008). Access to services for patients with chronic obstructive pulmonary disease: the invisibility of breathlessness. *Journal of pain and symptom management*, *36*(5), 451-460.

Harrison, S. L., Robertson, N., Apps, L., C. Steiner, M., Morgan, M. D., & Singh, S. J. (2015). "We are not worthy"–understanding why patients decline pulmonary rehabilitation following an acute exacerbation of COPD. *Disability and rehabilitation*, *37*(9), 750-756.

Jonsdottir, R., & Jonsdottir, H. (2007). The experience of women with advanced chronic obstructive pulmonary disease of repeatedly relapsing to smoking. *Scandinavian journal of caring sciences*, *21*(3), 297-304.

Lindgren, S., Storli, S. L., & Wiklund-Gustin, L. (2014). Living in negotiation: patients' experiences of being in the diagnostic process of COPD. *International journal of chronic obstructive pulmonary disease*, *9*, 441.

Malpass, A., Kessler, D., Sharp, D., & Shaw, A. (2015). MBCT for patients with respiratory conditions who experience anxiety and depression: a qualitative study. *Mindfulness*, *6*(5), 1181-1191.

Mathers, C. D., & Loncar, D. (2006). Projections of global mortality and burden of disease from 2002 to 2030. *PLoS medicine*, *3*(11), e442.

Miller, K., Chepp, V., Willson, S., & Ryan, J. M. (2014). Analysis. In K. Miller, V. Chepp, S. Willson, & J. L. Padilla (Eds.), *Cognitive Interviewing Methodology: A Sociological Approach for Survey Question Evaluation* (1 ed., pp. 35-50): John Wiley & Sons.

O'Neill, E. S. (2002). Illness representations and coping of women with chronic obstructive pulmonary disease: a pilot study. *Heart & Lung: The Journal of Acute and Critical Care, 31*(4), 295-302.

Odencrants, S., Ehnfors, M., & Grobe, S. J. (2007). Living with chronic obstructive pulmonary disease (COPD): part II. RNs' experience of nursing care for patients with COPD and impaired nutritional status. *Scandinavian journal of caring sciences, 21*(1), 56-63.

Partridge, M. R., Dal Negro, R. W., & Olivieri, D. (2011). Understanding patients with asthma and COPD: insights from a European study. *Prim Care Respir J, 20*(3), 315-323.

Stratelis, G., Mölstad, S., Jakobsson, P., & Zetterström, O. (2006). The impact of repeated spirometry and smoking cessation advice on smokers with mild COPD. *Scandinavian journal of primary health care, 24*(3), 133-139.

Tourangeau, R. (1984). Cognitive sciences and survey methods. *Cognitive aspects of survey methodology: Building a bridge between disciplines*, 73-100.

Tourangeau, R., Rips, L. J., & Rasinski, K. (2000). *The psychology of survey response*. Cambridge, UK: Cambridge University Press.

U.S. Department of Health and Human Services [USDHHS]. (2014). *The Health Consequences of Smoking—50 Years of Progress: A Report of the Surgeon General*. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Office on

Smoking and Health Retrieved from https://www.cdc.gov/tobacco/data_statistics/sgr/50th-anniversary/index.htm.

U.S. Department of Health and Human Services [USDHHS]. (2017). *Tips from former smokers™: Smoking and COPD*. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Office on Smoking and Health Retrieved from https://www.cdc.gov/tobacco/campaign/tips/diseases/copd.html.

Vestbo, J., Hurd, S. S., Agustí, A. G., Jones, P. W., Vogelmeier, C., Anzueto, A., . . . Rodriguez-Roisin, R. (2013). Global Strategy for the Diagnosis, Management, and Prevention of Chronic Obstructive Pulmonary Disease. *187*(4), 347-365. doi:10.1164/rccm.201204-0596PP

Weijters, B., Cabooter, E., & Schillewaert, N. (2010). The effect of rating scale format on response styles: The number of response categories and response category labels. *International Journal of Research in Marketing, 27*(3), 236-247.

Willis, G. (2005). *Cognitive Interviewing* Retrieved from http://methods.sagepub.com/book/cognitive-interviewing doi:10.4135/9781412983655

World Health Organization (2003). *Media centre. Chronic obstructive pulmonary disease (COPD.* Retrieved from http://www.who.int/mediacentre/factsheets/fs315/en

Table 3-1. Sample of cognitive interviewing probes

It's embarrassing not to be able to keep up with others when we're walking.	SD	D	N	A	SA
1) When you answered this question, what kinds of thoughts did you have?					
2) What does the term "keep up with others" mean to you?					
3) For those who choose a "Neutral" option, would you give a reason for that?					
4) How could we say this question better?					

Note. SD = Strongly disagree; D = Disagree; N = Neutral; A = Agree; SA = Strongly agree.

Table 3-2. Demographic Characteristics of Subjects (N = 19)

Characteristics		
Age (years)	Mean age (SD) [range]	N (%)
50 – 59		3 (15.8%)
60 – 69		11 (57.9%)
70 – 79		4 (21.2%)
> 80		1 (5.3%)
Total	65.5 (8.8) [50 – 82]	
Gender		
Female		13 (68.4%)
Male		6 (31.6%)
Race/ethnicity		
Caucasian / White		15 (78.9%)
Black / African American		1 (5.3%)
American Indian / Native American		1 (5.3%)
Other		2 (10.5%)
Education		
< 12th grade		4 (21.1%)
Some college		9 (47.4%)
College degree		4 (21.1%)
Advanced degree		2 (10.5%)
Relationship status		
Never married		1 (5.3%)
Married		9 (47.4%)
Divorced		4 (21.1%)
Widowed		4 (21.1%)
Missing		1 (5.3%)
Living arrangement		
Alone		4 (21.1%)
With other adult(s)		13 (68.4%)
With other adult(s) and dependent(s)		2 (10.5%)
Occupational status		
Homemaker		1 (5.3%)
Retired		12 (63.2%)
Disability		4 (21.1%)
Leave of absence		1 (5.3%)
Employed full-time		1 (5.3%)
Smoking status		
Current		3 (15.8%)
Former		16 (84.2%)

Table 3-3. Overview of problematic items indicated by participants during cognitive interviewing

Type of stigma	Item no.	Original item	Problems	Revised item
Perceived (Felt) stigma	1	People shy away from me when they see I'm wearing oxygen.	This item is only applicable to those who use supplemental oxygen.	A skip function was added to these items that allow participants to skip if the item does not apply to them. For example, "Do you use supplemental oxygen for COPD? If no, please go to the next item."
Self-stigma	6	I avoid using my oxygen in public, so others won't think I'm ill.		
Anticipated stigma	18	I avoid using oxygen in front of other people.		
Perceived (felt) stigma	3	My family doesn't like me to use my inhaler in public.	This item is only applicable to those who use an inhaler in public. For example, some use an inhaler only in private places such as a restroom.	
Self-stigma	7	It embarrasses me to use the inhaler in front of other people.		
Perceived (Felt) stigma	2	No one seems embarrassed by my coughing.	This item is only applicable to those who have obtrusive COPD-related symptoms.	
Anticipated stigma	9	I'm more likely to be embarrassed by my symptoms when I'm among strangers.		
Perceived (felt) stigma	21	Others are put off by my coughing and sputum.		
Self-stigma	34	Since learning I have COPD, I feel set apart and isolated from the rest of the world.	"Set apart" and "isolated" should not be used in the same item, because it is possible to feel isolated but not set apart, which makes it difficult to answer.	Since learning I have COPD, I feel singled out and isolated from the rest of the world.
Self-stigma	6	I avoid using my oxygen in public, so others won't think I'm ill.	Some participants noted that the reason ("others won't think I'm ill") may not be their case.	Retained as the same

Type of stigma	Item no.	Original item	Problems	Revised item
Self-stigma	19	I plan my activities carefully, so others won't notice I can't do as much as I used to.		Retained as the same
Enacted stigma	14	Health care providers have been abrupt with me about smoking.		Some health care providers have been abrupt with me about smoking.
Perceived (Felt) stigma	12	People think of COPD as a dirty disease.		Deleted
Perceived (Felt) stigma	31	Most people believe that a person who has COPD is dirty.		Most people believe that a person who has COPD is unclean.

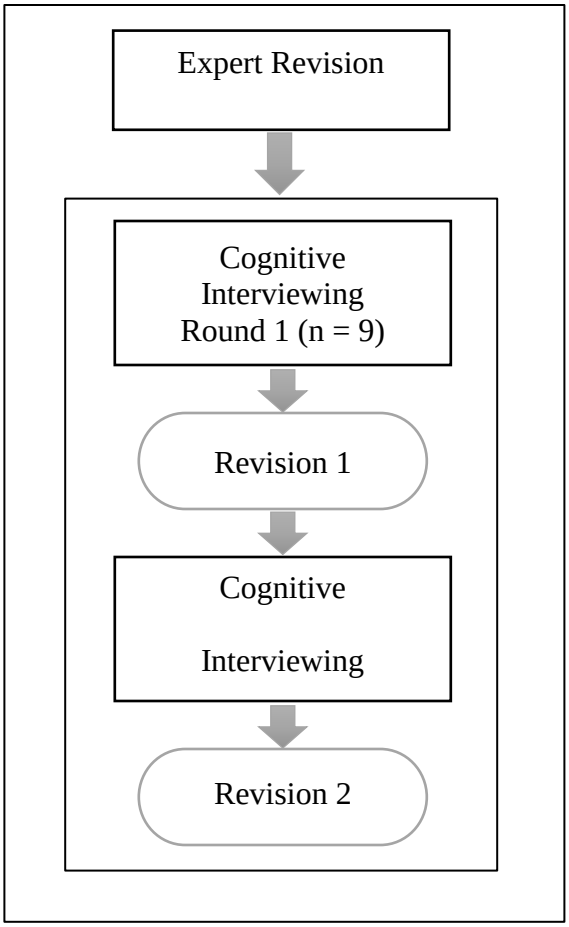

Figure 3-1. Refinement Process for the COPD-related Stigma Scale

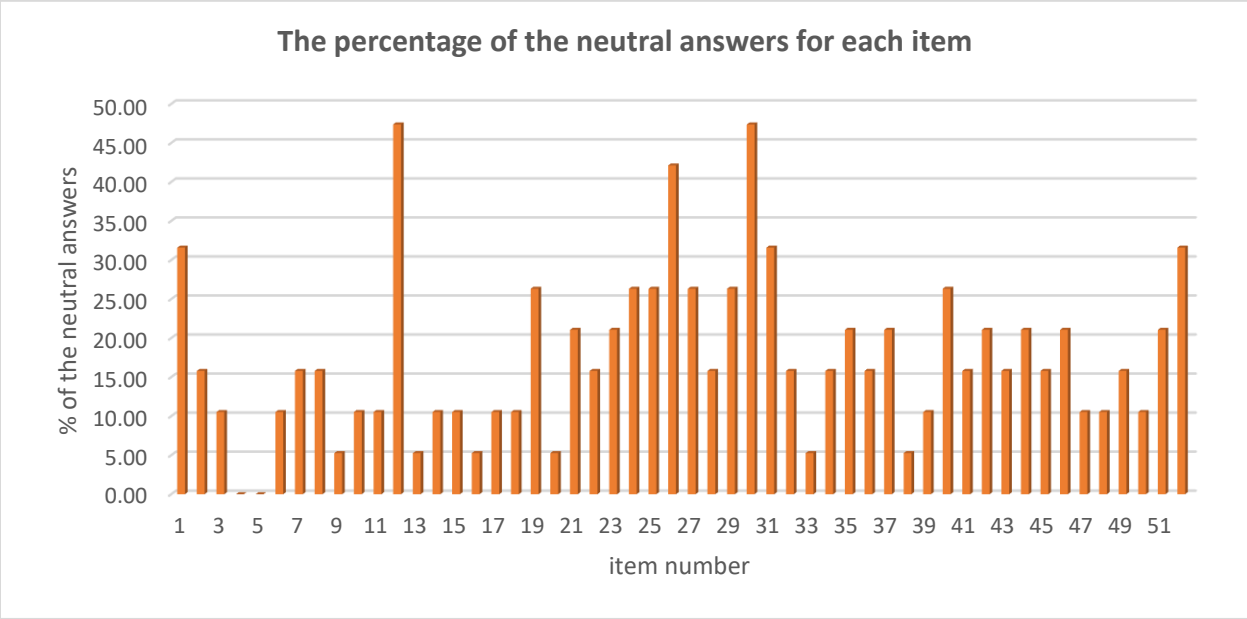

Figure 3-2. Percentage of neutral answers for each item

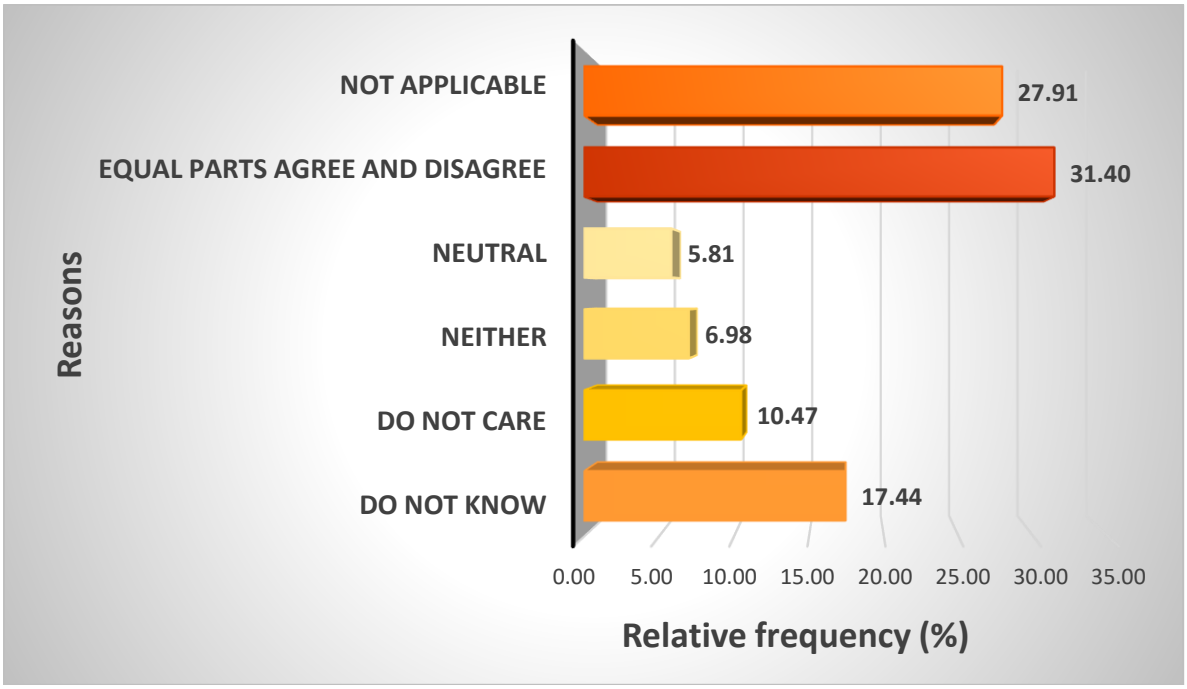

Figure 3-3. Relative frequency of each reason for selecting the neutral option

Chapter 4

Psychometric Evaluation of the COPD-related Stigma Scale

Abstract

Objectives: Stigma experiences in people with chronic obstructive pulmonary disease (COPD) have been reported in qualitative studies. COPD-related stigma contributes to psychological distress and affects help-seeking behavior. Despite the seriousness of COPD-related stigma, no well-established stigma measure exists for this population. The primary purpose was to identify the underlying constructs of the COPD-related Stigma Scale and evaluate the reliability and validity of the scale. The secondary purpose was to assess the usability of the scale to predict psychological distress.

Methods: A descriptive, cross-sectional, correlational study using a mailed survey method was conducted. Participants (N = 148; mean age = 64.1 years) completed the 51-item COPD-related Stigma Scale. Eight COPD-specific stigma items were not included in this analysis because they were only applicable to some participants and not others (e.g., those who use oxygen and inhalers), leaving 43 items for this analysis. Item-level analysis, including evaluating the ceiling and floor effects, the inter-item correlations, and the item-total correlations, was used to reduce the number of items. Cronbach's alpha coefficients were used to evaluate internal consistency reliability. Exploratory factor analysis was used to determine the

underlying structure. Convergent validity was used to evaluate whether the COPD-related Stigma Scale measures accurately and is correlated with related constructs.

Results: In the item-level analysis, 13 items were deleted, leading 30 items for factor analysis. The four-factor model with 28 items ($\alpha = 0.96$) was derived from factor analysis: social stigma ($\alpha = 0.95$), self-blame ($\alpha = 0.90$), physical limitation ($\alpha = 0.84$), and self-inflicted disease ($\alpha = 0.70$). Moderate to high correlations were found between the 28-item COPD-related Stigma Scale and the Stigma Scale for Chronic Illness 8-item ($r = 0.84$, $p < 0.0001$), the Hospital Anxiety and Depression Scale ($r = 0.53$, $p < 0.0001$), and the PROMIS Physical Function Short Form 10a ($r = -0.36$, $p < 0.0001$). However, correlation with Charlson Comorbidity Index was not significant. Mean scores of the 28-item COPD-related stigma were higher in women than men. Mean scores of physical limitation subscale were significantly higher in those who use supplemental oxygen than those who do not as well as those who use inhalers than those who do not.

Conclusions: Findings support that the 28-item COPD-related Stigma Scale is a reliable and valid scale for people with COPD. The findings from this study will assist in conceptualizing COPD-related stigma and explore relationships with other health outcome variables and the quality of life. Further research is needed to confirm this four-factor model and in a larger sample to examine the potential for including the eight items that were deleted because they were not relevant to all participants.

Introduction

Chronic obstructive pulmonary disease (COPD) is a chronic, progressively worsening lung disease that causes difficulties in breathing. COPD treatment focuses on slowing the progress of the disease by mitigating symptoms, preventing acute COPD exacerbations, and enhancing exercise tolerance (U.S. Department of Health and Human Services [USDHHS], 2016). To reduce the risk factors for adverse outcomes and promote COPD patients' health-related quality of life, a combination of treatment interventions, such as smoking cessation, pharmacological therapy, long-term oxygen therapy, nutrition, and pulmonary rehabilitation, plays a pivotal role in COPD treatment (Celli et al., 2004; McCarthy et al., 2015). Notwithstanding these treatment interventions, high rates of non-adherence to COPD treatment are a significant obstacle to better clinical outcomes and health-related quality of life (Holmgren, DiBonaventura, Karlsson, Bergstrom, & Ding, 2016; Jamal, Menon, Yousoof, & Vardhan, 2016).

The major barriers to treatment adherence include cultural factors, psychological issues, and patients' lack of understanding of the complex prescribed treatment for COPD and its importance in managing the disease (Sanduzzi et al., 2014). Additional factors such as COPD patients' self-conscious emotions of embarrassment about the use of inhalers (Jamal et al., 2016) and comorbid psychological diseases such as anxiety and depression (Franssen & Rochester, 2014; Panagioti et al., 2014; Turan, Yemez, & Itil, 2014) also contribute to poor treatment adherence. Further, an issue that cannot be overlooked is COPD-related stigma, which has the potential to influence adherence to COPD treatment. This issue has received scant attention (Earnest, 2002; Gysels & Higginson, 2008; Harrison et al., 2015); thus, little is known about the strength of the association between stigma and adherence to COPD treatment. To understand

this association more fully, the authors conducted a review of the literature on COPD-related stigma, which revealed a dearth of measures of COPD-related stigma. Because an inability to accurately measure this phenomenon may impede further understanding of factors associated with stigma, the authors refined the preliminary 51-item COPD-related Stigma Scale (see Chapter 3). In this chapter, we described the reliability and validity of the scale and evaluated the factor structure of the COPD-related Stigma Scale.

Background

In 2004, approximately 64 million people worldwide were estimated to have COPD (C. Mathers, Fat, & Boerma, 2008), and approximately 3 million died from the disease, accounting for 5.1% of total deaths. Due to the high prevalence and mortality of COPD, the World Health Organization (WHO) has deemed it a globally burdensome disease (C. Mathers et al., 2008). In the United States, an estimated 15.7 million adults had COPD in 2013 (Wheaton, Cunningham, Ford, & Croft, 2015). Although the mortality rate from COPD decreased slightly from 1999 to 2011, COPD is still the third leading cause of death worldwide (Ford, 2015; Vestbo et al., 2013).

COPD is especially burdensome because deteriorating lung function hampers economic and social activities as well as the activities of daily living. Compared to people who do not report COPD, those with COPD are less likely to be employed, more likely to experience difficulties in walking and climbing stairs, and more likely to use a medical device to manage their health condition (Wheaton et al., 2015). Respiratory symptoms of COPD, such as chronic dyspnea, cough, and sputum production, play a part in increasing the burden of this disease. People with COPD also experience symptoms such as pain, fatigue, depression, anxiety, insomnia, and/or anorexia (Solano, Gomes, & Higginson, 2006). They also have an increased

risk of comorbidities, such as pneumonia, osteoporosis, respiratory infection, myocardial infarction, angina, fractures, and glaucoma than do people without COPD (Soriano, Visick, Muellerova, Payvandi, & Hansell, 2005).

In addition, symptoms such as psychological distress and cognitive impairment may negatively affect disease management and daily functioning. For example, psychological distress—including depression and anxiety (Panagioti et al., 2014)—experienced by people with COPD is associated with low self-confidence or self-efficacy, loss of interest in daily activities, irritability, and difficulty with concentration and memory, all of which significantly reduce health-related quality of life and increase healthcare utilization (Laurin, Moullec, Bacon, & Lavoie, 2012; Panagioti et al., 2014). Cognitive dysfunction is often comorbid with COPD: mild cognitive impairment affects 25% of people with COPD (Yohannes, Chen, Moga, Leroi, & Connolly, 2016). Cognitive decline can cause difficulties in complying with prescribed treatments (Zawada, Bratek, & Krysta, 2015) and increase the risk of impaired activities of daily living and instrumental activities of daily living (Martinez, Richardson, Han, & Cigolle, 2014).

COPD-related stigma also places a substantial burden on people living with COPD because it contributes to psychological distress and affects help-seeking behavior. When people are diagnosed with COPD, they tend to regard it as a self-inflicted disease, which may make them sink into a slough of shame that interferes with help-seeking (Arne et al., 2007; Berger et al., 2011; Lindgren et al., 2014). As the disease progresses, dyspnea, cough, and sputum production worsen, and the visibility of those symptoms may trigger COPD-related stigma (Berger et al., 2011; O'Neill, 2002). When people with COPD exert effort breathing in front of others, they may feel embarrassment, blame themselves, and fear others' negative reactions (Gysels & Higginson, 2008; Jonsdottir & Jonsdottir, 2007). COPD treatments, including the use

of inhalers and supplemental oxygen, can also serve as triggers for stigma. When people with COPD use these treatments in public, they feel shame in showing illness and/or dependence on the devices (Earnest, 2002; Gupta et al., 2011; Partridge et al., 2011) because others are staring at them (Goldbart et al., 2013). As a result, people who experience COPD-related stigma are more likely to conceal their disease (Lindgren et al., 2014), avoid outside activities (Earnest, 2002; O'Neill, 2002), be isolated (Jonsdottir & Jonsdottir, 2007), be non-compliant with the treatment as prescribed (Neri et al., 2006), and experience threats to their sense of self-worth (Earnest, 2002).

Furthermore, people with COPD, who expect support from healthcare professionals, instead experience disease-related stigma and can be disappointed about the preconceived notions that COPD is a self-inflicted disease. Because they are frequently asked by their healthcare providers about smoking habits, they may feel that their condition, concerns, and needs are not considered as important as their smoking status (Gysels & Higginson, 2008; Halding et al., 2011; O'Neill, 2002). People with COPD often perceive their healthcare providers' attitudes towards smoking and/or smokers as condemnatory, which makes them feel that they have a socially unacceptable disease (Berger et al., 2011; Gysels & Higginson, 2008). These negative reactions of health professionals can cause people with COPD to feel depressed and helpless, and can limit their health-seeking behaviors (Berger et al., 2011; Gysels & Higginson, 2008).

Despite the seriousness of COPD-related stigma, no well-established stigma measure exists for this population. The author conducted a systematic literature review with the aim of comparing the existing literature on stigma in people with COPD and in people with lung cancer and of identifying existing measures of COPD-related stigma and lung cancer-related stigma.

Although the literature review revealed that both COPD and lung cancer are considered self-inflicted diseases due to patients' history of smoking, there were differences between the two conditions. For example, when it comes to stigma triggers, lung cancer-related stigma was brought about by smoking-related stigma. In contrast, COPD-related stigma was triggered not only by smoking-related stigma, but by symptoms such as cough and phlegm, and the use of inhalers/oxygen in public. The systematic literature review revealed that no well-established measure of COPD-related stigma exists.

Developing reliable and valid measures of COPD-related stigma is required not only to make sense of the phenomenon of stigma in people with COPD, but also to advance our knowledge of COPD-related stigma. Therefore, a preliminary 60-item COPD-related Stigma Scale was developed by Larson, Kapella, and Berger based on the findings from their qualitative study on stigma in people with COPD (Berger et al., 2011) and the HIV Stigma Scale developed by (Berger et al., 2001). The initial 60 items were reviewed by two experts on stigma (Dr. Berger) and COPD (Drs. Larson and Kapella). Eight items were removed to decrease redundancy and increase relevance to the target population. The 52-item preliminary COPD-related Stigma Scale was refined through cognitive interviewing methodology to improve clarity and accuracy, resulting in the 51-item COPD-related Stigma Scale (see Chapter 3).

Conceptual Framework

This study was guided by the general factor model (DeVellis, 2016). The model assumed that an observed item score is caused by a latent variable and multiple latent variables would serve as causes of variation in a set of items. We performed exploratory factor analysis (EFA) to determine how many latent variables or constructs underlie responses to the items (i.e., the

COPD-related Stigma Scale) and evaluate whether the items reliably measure the intended constructs. Then, a large number of the original items can be reduced by eliminating items that do not fit into the derived factors (DeVellis, 2016).

Statement of purpose

The primary purpose of this study was to describe the psychometric properties of the COPD-related Stigma Scale, including reliability and validity, and identify the underlying constructs of the scale. The secondary purpose of this study was to examine the usability of the newly revised version of the COPD-related Stigma Scale, whether the scale predicts psychological distress.

Methods

Study design

This study employed a descriptive, cross-sectional, correlational study using a mailed survey method.

Participants

Study participants were recruited from the University of Michigan Health System's pulmonary and medical clinics in Ann Arbor. Potential participants were included if they (a) were aged 50 years or older; (b) were diagnosed with or were told by their primary care provider that they had COPD, emphysema, or chronic bronchitis; and (c) spoke English as their first language. Those who were simultaneously diagnosed with other stigmatized diseases such as severe mental illness, HIV/AIDS, lung cancer, or physical deformities were excluded from study

participation. All study procedures and materials were approved by the University of Michigan Institutional Review Board.

Measures

COPD-related Stigma Scale. The COPD-related Stigma Scale consisted of 51 items. Some items were about stigmatization by others (e.g., "*Some people act as though it's my fault I have COPD.*"), a feeling of shame (e.g., *I blame myself for having COPD.*), social isolation (e.g., *I have lost friends by telling them I have COPD.*), discrimination (e.g., *If they learn I have COPD, I worry about people discriminating against me.*), concealing (e.g., *I work hard to keep my COPD a secret.*), and smoking (e.g., *People have told me that getting COPD is what I deserve for having smoked cigarettes.*). Each stigma item was rated on a 4-point Likert scale (1 = strongly disagree, 4 = strongly agree) (see Appendix D). A higher score is interpreted as an increased frequency of stigma experience.

Stigma Scale for Chronic Illness. The Stigma Scale for Chronic Illness 8 items (SSCI-8), a well-established and valid instrument, was used to demonstrate the convergent validity of the COPD-related Stigma Scale. The SSCI-8, a shortened version of the 24-item SSCI, was developed to assess stigma for people with chronic conditions (Molina, Choi, Cella, & Rao, 2013; Rao et al., 2009). The SSCI-8 has a 5-point Likert scale from 1 (*Never*) to 5 (*Always*) and assesses enacted stigma and internalized stigma. Five items assess enacted stigma (e.g., *Because of my illness, some people avoided me*.), two items measure internalized stigma (e.g., *I felt embarrassed about my illness*.), and one item (*Because of my illness, I felt left out of things*.) is a combined measure of both enacted and internalized stigma (Molina et al., 2013). A raw summed score (range = 8 – 40) was used for this study. A higher score is interpreted as an increased

frequency of stigma experience. The SSCI-8 showed good internal consistency reliability (Cronbach's alpha = 0.85 - 0.92) and significant correlations with the PROMIS global health scale (physical health domain: r = -0.25 ~ -0.63; mental health domain: r = -0.34 ~ -0.60) (National Institutes of Neurologic Disorders and Stroke, 2010) (see Appendix E). In this study, Cronbach's alpha was 0.91.

Comorbid Conditions. The Charlson Comorbidity Index (CCI) was developed to form a taxonomy for concomitant conditions which are significant predictors of hospital mortality (M. E. Charlson, Pompei, Ales, & MacKenzie, 1987). Each condition is assigned a different weight based on its adjusted risk of mortality. The CCI total score calculation is based on the sum of the weights of all comorbid conditions for the individual, with a higher score associated with higher mortality. The CCI has been extensively validated to examine the impact of comorbid conditions on patients (M. Charlson, Wells, Ullman, King, & Shmukler, 2014; Frenkel, Jongerius, Mandjes-van Uitert, Munster, & Rooij, 2014; Radovanovic et al., 2014; Tessier, Finch, Daskalopoulou, & Mayo, 2008) (see Appendix F). In this study, Cronbach's alpha was 0.55.

Psychological Distress. The Hospital Anxiety and Depression Scale (HADS) is a 14-item, four-point scale developed to assess two common emotional disorders, i.e., anxiety and depression, in general medical patients (Zigmond & Snaith, 1983). The HADS consists of two 7-item subscales, one each for anxiety and depression. A higher score indicates more severe emotional distress. Psychometric properties have been assessed in numerous studies of versions in different languages (Bjelland, Dahl, Haug, & Neckelmann, 2002; Mykletun, Stordal, & Dahl, 2001). Cronbach's alpha for the HADS-anxiety ranged from 0.68 to 0.93 and for the HADS-

depression from 0.67 to 0.90 (Bjelland et al., 2002) (see Appendix G). In this study, Cronbach's alpha was 0.89.

PROMIS Physical Function. PROMIS Physical Function (Short Form-10a) is a 10-item, five-point scale that evaluates patients' capability to perform various physical activities (Cella et al., 2010). This includes basic and advanced activities of daily life (Cella et al., 2015). Examples of items include "*Does your health now limit you in walking more than a mile?*" and "*Are you able to do chores such as vacuuming or yard work?*" Response scales have five options: 1 = unable to do, 2 = with much difficulty, 3 = with some difficulty, 4 = with a little difficulty, and 5 = without any difficulty. A lower score indicates poorer physical functioning (Cella et al., 2010) (see Appendix H). A PROMIS measure of physical functioning has been validated in the general population as well as in individuals with chronic conditions, including chronic obstructive pulmonary disease (Cook et al., 2016; Schalet et al., 2016). The PROMIS Physical Function Short Form (SF)-10a is correlated with the PROMIS Physical Function full item version (r = 0.96), which correlates with two well-established questionnaires measuring the same concept, i.e., the Health Assessment Questionnaire (r = -0.8) and SF-36 (r = -0.88) and demonstrates good reliability (Cella et al., 2010). In this study, Cronbach's alpha was 0.91.

Procedures

From February 2019 to July 2019, a questionnaire was mailed to 691 potential participants at their home addresses. It included demographic questions, the 51-item COPD-related Stigma Scale, the Stigma Scale for Chronic Illness (Molina et al., 2013), the Charlson Comorbidity Index (M. E. Charlson et al., 1987), the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983), and the Patient-Reported Outcome Measurement Information System

(PROMIS) Physical Function Short-form 10a (Cella et al., 2010). Participants who had not responded within eight weeks received another mail carrying the same set of questionnaires as a reminder. Participants who returned the questionnaire received a $10 gift card for their time.

Of the 691 questionnaires, 51 were returned as non-deliverable because of incorrect address and 5 were returned with a note that the addressee had died. Of the 635 remaining questionnaires, 150 were returned after the two mailings (23.62 % response rate).

Data analysis

All analyses were conducted using IBM SPSS Statistics for Windows, Version 26.0. Demographic variables and study measures were described using means and standard deviations or using proportions with 95% confidence intervals. Two participants did not answer most items on the COPD-related Stigma Scale (64.7%, 82.4%), and were therefore not included in the analyses.

Item analysis was used to reduce the number of items prior to factor analysis. Distributional characteristics of 51 items were examined, including mean, range, the frequency and percentage of each response category, and percentages of minimum and maximum responses for the floor and ceiling effects. Of the 51 items, eight items were only applicable to participants using supplemental oxygen and/or an inhaler and having COPD-related symptoms; hence, these items were not included for the subsequent analysis. In the next step inter-item correlations and item-total correlations were assessed; items were deleted if they had consistently low ($r < 0.3$) or high ($r > 0.7$) correlations with other items, removal did not negatively affect the Cronbach's alpha, and they were reviewed by a COPD content expert and judged as not crucial for the scale. The remaining items were reviewed for redundancy. Using a similar process, items were deleted

if they were considered to be redundant, removal did not have a negative effect on the Cronbach's alpha, and a COPD expert judged them as not crucial for the scale.

The dimensional structure of the COPD-related Stigma Scale was assessed using exploratory factor analysis (EFA), which was performed on 30 items of the COPD-related Stigma Scale. To evaluate factor analysis suitability, the Kaiser-Meyer-Olkin (KMO) Measure of Sampling Adequacy and Bartlett's Test of Sphericity were conducted. A KMO value greater than 0.5 (range from 0 to 1) is considered suitable for the factor analysis (Dziuban & Shirkey, 1974; Kaiser, 1974), as is a Bartlett's test of sphericity value at a significance level of $p < 0.05$.

To determine the appropriate number of factors, the eigenvalue rule (Kaiser, 1960), the scree test (Cattell, 1966), and the parallel analysis were used. Factors that contain an eigenvalue of 1.0 or greater are retained by the eigenvalue rule (Kaiser, 1960). The scree test uses a plot based on the eigenvalues of the extracted factors (DeVellis, 2016). A sharp breaking point in the plot was considered to determine the 'right' number of factors (Cattell, 1966). To reduce the limitations of each method, e.g., arbitrariness, subjectivity, and ambiguity (Hayton, Allen, & Scarpello, 2004), parallel analysis was used along with the eigenvalue rule and the scree test. To conduct parallel analysis, random data that contains corresponding eigenvalues to the research data were generated (DeVellis, 2016; Hayton et al., 2004; Williams, Onsman, & Brown, 2010). To determine the number of factors, the magnitude of eigenvalues from both the research data and the randomly generated data were compared; factors for eigenvalues of the research data that were greater than those of the random data were retained (DeVellis, 2016; Hayton et al., 2004).

To increase the interpretability, extracted factors were rotated using the varimax method, which would provide clearer factor loading patterns and help researchers interpret findings from the factor analysis (DeVellis, 2016; Osborne, 2015). As the last step, factor loadings were

evaluated. Item-to-factor loading greater than 0.40 was considered the cut-off value for this study. When an item loads on two or more factors, both the strength of the relationship between the item and the factor as well as the nature of the latent variable, i.e., the theoretical perspective, were considered together (Johnson & Rogers, 2006; Yong & Pearce, 2013).

The internal consistency reliability of the COPD-related Stigma Scale was assessed using Cronbach's alpha coefficients. The convergent validity of the COPD-related Stigma Scale was assessed by demonstrating correlations with the Stigma Scale for Chronic Illness 8 items (SSCI-8). The convergent validity was also assessed by examining relationships between the COPD-related Stigma Scale score and scores from the CCI, the HADS, and the PROMIS Physical Function Short Form.

Using independent sample t-tests, the COPD-related Stigma Scale scores were compared between groups: 1) those who were versus were not using supplemental oxygen, 2) those who were versus were not using inhalers, and 3) those who were versus were not having COPD-related symptoms. The COPD-related Stigma Scale scores were also compared among smoking status groups using a one-way analysis of variance.

Using multiple linear regression analysis, the association between COPD-related Stigma Scale scores and the other measures, including demographic variables was examined. The associations were also examined between each subscale—social stigma, self-blame, physical limitation, and self-inflicted disease—and the other measures.

Results

Demographic Characteristics

Demographic characteristics of participants (N = 148) are shown in Table 4-1. The mean age of participants was 64.1 years (range: 51-84), 73 (49.3%) were female, 134 (90.5%) were Caucasian or White, and 83 (56.1%) had a college degree or higher. Fifty-seven (38.5%) were married, 107 (72.3%) were living with other adults, dependents, or other adults and dependents, 60 (40.5%) were retired, and 24 (16.2%) were employed either part- or full-time or were self-employed. All participants had a history of smoking: 35 (23.6%) were former smokers, and 113 (76.4%) were still smoking either regularly or once in a while. A majority of participants (83.1%) were using an inhaler, and 32 (21.6%) were using supplemental oxygen for COPD.

Item Analysis and Item Reduction

There was no evidence of ceiling or floor effects; all 51 items encompassed the full range of response options (see Appendix I). Most of the inter-item correlation coefficients for items 4, 12, 13, 19, 21, and 28 were low ($r \leq 0.3$), and these items were deleted from the scale. Item 13 was restored because this item reflects attitudes towards help-seeking, an important potential effect of stigma. Further, items 8, 24, 25, 32, 33, 37, 48, and 51 were deleted from the scale because they were deemed to be redundant to other items on the scale, removing them did not affect the Cronbach' alpha, and the COPD expert did not consider them to be crucial for the scale.

Structural Validity

Once the 13 items were deleted in the item analysis, the factorability tests showed that the factor analysis was suitable with the 30-item COPD-related Stigma Scale. The KMO measure of sampling adequacy was 0.94, exceeding the recommended value of 0.5. Bartlett's test of

sphericity was significant ($\chi 2_{(378)} = 2746.685$, $p < 0.0001$), indicating that the correlation structure is adequate for factor analysis. The principal component analysis with varimax rotation was used to reduce the number of items and identify the number and meaning of factors that underlie the 30 items. We retained items with factor loadings ≥ 0.40.

Initial eigenvalues yielded a five-factor solution, which accounted for 69.27% of the total variance. Eigenvalues combined with parallel analysis (Table 4-2) and a scree plot suggested a three-factor solution, which explained 61.48% of a total variance. Given these findings, we examined possible solutions from a three-, four- and five-factor solution to maximize the explained variance and the internal consistency. We examined the influence of Cronbach's alpha value for the total 30 items and subscales as well as double loaded items across factors. As a result, two items were dropped, leaving 28 total items.

The four-factor solution was regarded as the best fit for the data, which explained a total of 66.41% of the variance for the entire set of items. The first factor, labeled *social stigma*, was comprised of 10 items that explained 49.30% of the variance with factor loadings from 0.618 to 0.857. The items loaded on the first factor were related to enacted stigma at the interpersonal level and social isolation. The second factor, labeled *self-blame*, was comprised of nine items that explained 7.69% of the variance with factor loadings from 0.530 to 0.709. These items referred to self-conscious emotions that relate to having COPD and disclosure of having COPD. The third factor, labeled *physical limitation*, was comprised of five items that explained 5.03% of the variance with factor loadings from 0.545 to 0.730. These items were related to changes in physical capabilities due to having COPD. The fourth factor, labeled *self-inflicted disease*, was comprised of four items that explained 4.39% of the variance with factor loadings from 0.510 to 0.731. These items referred to perceptions of smoking with regard to COPD. Although the

fourth factor explained less than 5 % of the variance, we selected the four-factor solution because it improved the interpretability of the factors. Factor loadings from the rotated factor-loading pattern matrix, along with mean and standard deviation scores of each item, is shown in Table 4-3.

Internal Consistency Reliability

The Cronbach's α coefficient for the 28-item version of the COPD-related Stigma Scale was 0.96 and, for the four factors—subscales of social stigma, self-blame, physical limitation, and self-inflicted disease—were 0.95, 0.90, 0.84, and 0.70, respectively (see Table 4-4). Reliability was strong for the 28-item COPD-related Stigma Scale and the social stigma, self-blame, and physical limitation subscales, but acceptable for the self-inflicted disease subscale.

Convergent Validity

Convergent validity was assessed via correlations between the 28-item version of the COPD-related Stigma Scale scores and the SSCI-8, CCI, HADS, and PROMIS Physical Function scores (see Table 4-5). The mean scores of the total 28 items COPD-related Stigma Scale and the SSCI-8 scores was highly correlated ($r = 0.84$). The mean scores of each factor (i.e., social stigma subscale, self-blame subscale, physical limitation subscale, and self-inflicted disease subscale) and the SSCI-8 scores were moderately or highly correlated ($r = 0.76$, 0.77, 0.69, and 0.64, respectively). Individuals with higher stigma scores were more likely to report psychological distress ($r = 0.53$, $p < 0.0001$) and more likely to demonstrate poorer physical functioning ($r = -0.36$, $p < 0.0001$). However, stigma scores were not significantly correlated with the severity of comorbid conditions.

Group Comparison

Group comparisons were conducted to determine if stigma varied by demographics (see Table 4-6). Mean scores for the 28-item COPD-related Stigma Scale were significantly higher in women than in men [$F(1, 146) = 9.25$, $p = 0.003$], as were those of the social stigma, self-blame, and self-inflicted disease subscales [$F(1, 146) = 7.34$, $p = 0.008$; $F(1, 146) = 7.94$, $p = 0.006$; $F(1, 146) = 11.64$, $p = 0.001$, respectively]. In addition, physical limitation subscale scores were significantly higher in those who use supplemental oxygen versus those who do not [$F(1, 146) = 13.72$, $p < 0.0001$] and in those who use inhalers versus those who do not [$F(1, 146) = 14.04$, $p < 0.0001$].

Multiple Linear Regression Analysis

Results of multiple linear regression analysis were shown in see Table 4-7. Results indicated that there was a collective significant effect between other measures and 1) the 28-item COPD-related Stigma Scale in model 1 [$F(34,121) = 2.94$, $p < 0.0001$], 2) social stigma subscale in model 2 [$F(34,121) = 1.99$, $p = 0.006$], 3) self-blame subscale in model 3 [$F(34,121) = 2.14$, $p = 0.002$], 4) physical limitation subscale in model 4 [$F(34,121) = 4.28$, $p < 0.0001$], and self-inflicted disease subscale in model 5 [$F(34,121) = 1.98$, $p = 0.006$]. After controlling of other measures, the HADS was a significant predictor in all models, and the PROMIS physical function was a significant predictor in model 4.

Discussion

Findings from this study support the reliability and validity of the 28-item COPD-related Stigma Scale. From the factor analysis, four factors were derived and entitled social stigma, self-blame, physical limitation, and self-inflicted disease. While the social stigma subscale measures social reactions to people with COPD, the other three subscales—self-blame, physical limitation, and self-inflicted disease—measure self-conscious emotions of having COPD and internalization of social reactions to them, which implies that COPD is an emotionally burdensome disease for individuals with COPD.

Given the heightened burden encountered in people with COPD, we sought to develop a concise but comprehensive stigma scale that assesses all possible aspects of stigma in people with COPD based on literature (Berger et al., 2011) as well as our previous qualitative study (see Chapter 3). However, we could not include eight items that described stigma experiences related to the visible characteristics of having COPD, including the use of supplemental oxygen/inhaler and eye-catching symptoms, in our analysis because quite a small number of participants could answer those items. These items have been reported as meaningful stigma cues that can lead to feelings of shame and embarrassment as well as being isolated from society (Earnest, 2002; Goldbart et al., 2013; Gysels & Higginson, 2008; O'Neill, 2002). Although we could not include these items to the scale, we found in our group comparison that people who use the supplement oxygen or inhaler showed higher levels of stigma in the physical limitation domain than those who do not use these treatment devices. Considering the evidence in the literature and our study, those eight items should be dealt with in the future study.

In addition, we took iterative steps to identify a shorter set of items that reflected various aspects of COPD-related stigma. While examining items, we encountered discrepancies between

numerical findings from statistical analysis and empirical evidence from a qualitative study and experts' review. For example, item 13, "*Some health care providers have been abrupt with me about smoking,*" was flagged for dropping from the scale because of the low inter-item correlation coefficients with most items. However, this item assesses potential barriers to effective health communications, and there is no item to cover similar aspect; thus, this item was retained. Findings from our cognitive interview study (see Chapter 3) supported our decision. The following are excerpts from this cognitive interview study in that regard; "*…I have had health care providers be abrupt with me and I thought, "Well, I won't be back," is the kind of thoughts I had…[ICS103]*", "*…one nurse I remember, … I was in my mother-in-law's when she was dying in the hospital, … when I came in, the nurse looked at me with total disgust and said, "I can smell cigarette smoke on you." And I said, "Yeah, you probably can."…I mean it was just terrible, the way she said it was, "You idiot, I can smell cigarette smoke on you." It was a terrible thing to say…[ICS204]*", and *"…when the doctor years ago said to me about that-- just the way he worded how my condition was. It was scary, … it's better to come across with solutions how to improve your life quality and your health, to not come across judgmental. … [ICS210].*"

Along with breathing difficulties and progression of the disease itself, COPD-related stigma can be one factor in the psychological distress that people with COPD often experience (Kunik et al., 2005; Maurer et al., 2008). As hypothesized, our study found that the HADS was a significant predictor of the total 28-item COPD-related Stigma Scale and all four subscales. This finding is in line with literature on the impact of stigma on psychological distress. Regarding the COPD-related stigma, there was a study: Harrison et al. (2017) showed that self-conscious

emotions in people with COPD are significantly associated with anxiety and depression, and health-related quality of life.

This psychological distress-stigma relationship was also found in other chronic respiratory illnesses. A study in people with lung cancer showed that perceived stigma was a significant contributor to depressive symptoms (Gonzalez & Jacobsen, 2012). In other studies, lung cancer-related stigma was strongly associated with depression and quality of life (Cataldo et al., 2012) as well as lung cancer symptom severity (Cataldo & Brodsky, 2013). In a study in people with asthma, higher levels of stigma were significantly associated with poorer psychological health and poorer asthma control (Andrews, Jones, & Mullan, 2013). Given these consistent relationships between health-related stigma and psychological distress, we should carefully consider the impact of COPD-related stigma on psychological distress.

In terms of physical function, this study found that people with COPD can experience self-conscious feelings due to their physical limitations, which is distinguishable from other chronic illness-related stigmas. This could be explained in several ways. First, limited physical functioning may cause emotional distress (Looper & Kirmayer, 2004) related to a component of seeking help to others or characteristics of COPD, i.e., a self-inflicted disease. Second, limited physical functioning can be regarded as undesirable, particularly when individuals are relatively younger than those who show similar levels of decline in physical function (Bierman & Statland, 2010). Third, how society views individuals with COPD may affect how they perceive their disease. Some qualitative studies reported that people with COPD felt embarrassment (Svedsater et al., 2017) or were aware of the potential stigma (Berger et al., 2011) with regard to decreased physical capabilities. Considering the importance of disease management in people with COPD

being physically active, it may provide helpful information when examining self-conscious emotions related to physical limitations in subsequent studies.

Although this study supported the convergent validity of the 28-item COPD-related Stigma Scale with measures of psychological distress and physical function, evaluating the associations between the 28-item COPD-related Stigma Scale and comorbid conditions did not support the convergent validity. This may suggest that the impact of comorbid conditions on levels of COPD-related stigma could be minor.

The 28-item COPD-related Stigma Scale may be more comprehensive than the general stigma scale for chronic illness (i.e., SSCI-8), and thus more appropriate for people with COPD. The SSCI-8 assesses two domains—enacted stigma and internalized stigma, whereas the 28-item COPD-related Stigma Scale assesses four stigma domains specific to COPD—social stigma, self-blame, physical limitation, and self-inflicted disease. The social stigma domain includes most items of the enacted stigma domain and shows a high correlation between the two domains ($r = 0.75$). The internalized stigma domain is encompassed by and shows moderate to high correlations with the self-blame ($r = 0.73$) and physical limitation ($r = 0.77$) domains. In addition to those shared items, the social stigma domain includes additional items assessing socializing with friends and acquaintances as well as negative images or beliefs toward people with COPD. The domains of self-blame and physical limitation encompass items that may assess perceived social identity in relation to a stigmatized condition and ensuing behavioral changes. In terms of the self-inflicted disease domain, because this domain reflects stigma experiences from healthcare providers and others, it may be conceptually important in understanding COPD-related stigma. Items in the self-inflicted disease domain not only ask about exposure to stigmatization attached to smoking, but also assess feelings of disrespect from

healthcare providers and others, which can shed light on the help-seeking behaviors of people with COPD, because several studies indicate that those who anticipate stigma by healthcare workers were less willing to seek healthcare (Chin & Armstrong, 2019; Earnshaw & Quinn, 2012). Therefore, the 28-item COPD-related Stigma Scale provides a more global view of COPD-related stigma than does the SSCI-8.

Limitations

This study has several limitations, one of which is the limited generalizability of the findings. Participants were recruited from a single academic health system in the United States, which may not be representative of the broader population, and the vast majority of participants were Caucasian/White (90.1%) and not actively employed (83.9%). Further evaluations are needed to ensure that the COPD-related Stigma Scale reflects the stigma experiences of people from diverse groups and geographically different regions. Further, we expected to compare levels of COPD-related stigma in groups: those who ever smoked vs. never smoked, those who use vs. do not use supplemental oxygen, and those who use vs. do not use inhalers. However, due to the unequal sample sizes of the groups, findings from the group comparisons should be interpreted carefully. Another limitation is that social desirability may tempt participants to provide untruthful answers. If this happens, item validity is compromised.

Conclusion

This study used quantitative methods to develop and test the 28-item COPD-related Stigma Scale for evaluating patient-reported stigma experiences in people with COPD. Findings provide support for the reliability and validity of the 28-item COPD-related Stigma Scale. This

new instrument includes four domains—social stigma, physical limitation, self-blame, and smoking—that reflect COPD-related stigma. The findings of this study can be used to understand the underlying concepts of stigma in people with COPD and its impact on their psychological and physical health. Further research is needed to evaluate the stability of the derived four-factor model across groups of individuals or over time, and to determine how the scale should best be scored.

References

Andrews, K. L., Jones, S. C., & Mullan, J. (2013). Stigma: Still an important issue for adults with asthma. *Journal of Asthma & Allergy Educators, 4*(4), 165-171.

Arne, M., Emtner, M., Janson, S., & Wilde-Larsson, B. (2007). COPD patients' perspectives at the time of diagnosis: a qualitative study. *Primary Care Respiratory Journal, 16*(4), 215-221.

Berger, B. E., Ferrans, C. E., & Lashley, F. R. (2001). Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale¶. *Research in nursing & health, 24*(6), 518-529.

Berger, B. E., Kapella, M. C., & Larson, J. L. (2011). The experience of stigma in chronic obstructive pulmonary disease. *Western journal of nursing research, 33*(7), 916-932.

Bierman, A., & Statland, D. (2010). Timing, social support, and the effects of physical limitations on psychological distress in late life. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 65*(5), 631-639.

Bjelland, I., Dahl, A. A., Haug, T. T., & Neckelmann, D. (2002). The validity of the Hospital Anxiety and Depression Scale: an updated literature review. *Journal of psychosomatic research, 52*(2), 69-77.

Cataldo, J. K., & Brodsky, J. L. (2013). Lung cancer stigma, anxiety, depression and symptom severity. *Oncology, 85*(1), 33-40.

Cataldo, J. K., Jahan, T. M., & Pongquan, V. L. (2012). Lung cancer stigma, depression, and quality of life among ever and never smokers. *European Journal of Oncology Nursing, 16*(3), 264-269.

Cattell, R. B. (1966). The scree test for the number of factors. *Multivariate behavioral research, 1*(2), 245-276.

Cella, D., Hahn, E. A., Jensen, S. E., Butt, Z., Nowinski, C. J., Rothrock, N., & Lohr, K. N. (2015). *Patient-Reported Outcomes in Performance Measurement* (Vol. 97): RTI Press.

Cella, D., Riley, W., Stone, A., Rothrock, N., Reeve, B., Yount, S., . . . Choi, S. (2010). The Patient-Reported Outcomes Measurement Information System (PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005–2008. *Journal of clinical epidemiology, 63*(11), 1179-1194.

Celli, B. R., MacNee, W., Agusti, A., Anzueto, A., Berg, B., Buist, A. S., . . . Fahy, B. (2004). Standards for the diagnosis and treatment of patients with COPD: a summary of the ATS/ERS position paper. *European Respiratory Journal, 23*(6), 932-946.

Charlson, M., Wells, M. T., Ullman, R., King, F., & Shmukler, C. (2014). The Charlson Comorbidity Index Can Be Used Prospectively to Identify Patients Who Will Incur High Future Costs. *PLOS ONE, 9*(12), e112479. doi:10.1371/journal.pone.0112479

Charlson, M. E., Pompei, P., Ales, K. L., & MacKenzie, C. R. (1987). A new method of classifying prognostic comorbidity in longitudinal studies: Development and validation. *Journal of Chronic Diseases, 40*(5), 373-383. doi:http://dx.doi.org/10.1016/0021-9681(87)90171-8

Chin, E. D., & Armstrong, D. (2019). Anticipated stigma and healthcare utilization in COPD and neurological disorders. *Applied Nursing Research, 45*, 63-68.

Cook, K. F., Jensen, S. E., Schalet, B. D., Beaumont, J. L., Amtmann, D., Czajkowski, S., . . . Cella, D. (2016). PROMIS measures of pain, fatigue, negative affect, physical function, and social function demonstrated clinical validity across a range of chronic conditions.

Journal of clinical epidemiology, 73, 89-102. doi:http://dx.doi.org/10.1016/j.jclinepi.2015.08.038

DeVellis, R. F. (2016). *Scale development: Theory and applications* (Vol. 26): Sage publications.

Dziuban, C. D., & Shirkey, E. C. (1974). When is a correlation matrix appropriate for factor analysis? Some decision rules. *Psychological Bulletin, 81*(6), 358.

Earnest, M. A. (2002). Explaining adherence to supplemental oxygen therapy. *Journal of general internal medicine, 17*(10), 749-755.

Earnshaw, V. A., & Quinn, D. M. (2012). The impact of stigma in healthcare on people living with chronic illnesses. *Journal of Health Psychology, 17*(2), 157-168.

Ford, E. S. (2015). Trends in mortality from COPD among adults in the United States. *Chest, 148*(4), 962-970. doi:10.1378/chest.14-2311

Franssen, F. M. E., & Rochester, C. L. (2014). Comorbidities in patients with COPD and pulmonary rehabilitation: do they matter? *European Respiratory Review, 23*(131), 131-141. doi:10.1183/09059180.00007613

Frenkel, W. J., Jongerius, E. J., Mandjes-van Uitert, M. J., Munster, B. C., & Rooij, S. E. (2014). Validation of the Charlson Comorbidity Index in acutely hospitalized elderly adults: a prospective cohort study. *Journal of the American Geriatrics Society, 62*(2), 342-346.

Goldbart, J., Yohannes, A. M., Woolrych, R., & Caton, S. (2013). 'It is not going to change his life but it has picked him up': a qualitative study of perspectives on long term oxygen therapy for people with chronic obstructive pulmonary disease. *Health and quality of life outcomes, 11*(1), 124.

Gonzalez, B. D., & Jacobsen, P. B. (2012). Depression in lung cancer patients: the role of perceived stigma. *Psycho-Oncology, 21*(3), 239-246.

Gupta, V. K., Bahia, J. S., Maheshwari, A., Arora, S., Gupta, V., & Nohria, S. (2011). To study the attitudes, beliefs and perceptions regarding the use of inhalers among patients of obstructive pulmonary diseases and in the general population in Punjab. *J Clin Diagn Res*, *5*(3), 434-439.

Gysels, M., & Higginson, I. J. (2008). Access to services for patients with chronic obstructive pulmonary disease: the invisibility of breathlessness. *Journal of pain and symptom management*, *36*(5), 451-460.

Halding, A. G., Heggdal, K., & Wahl, A. (2011). Experiences of self-blame and stigmatisation for self-infliction among individuals living with COPD. *Scandinavian journal of caring sciences*, *25*(1), 100-107.

Harrison, S. L., Robertson, N., Apps, L., C. Steiner, M., Morgan, M. D., & Singh, S. J. (2015). "We are not worthy"–understanding why patients decline pulmonary rehabilitation following an acute exacerbation of COPD. *Disability and rehabilitation*, *37*(9), 750-756.

Harrison, S. L., Robertson, N., Goldstein, R. S., & Brooks, D. (2017). Exploring self-conscious emotions in individuals with chronic obstructive pulmonary disease: A mixed-methods study. *Chronic respiratory disease*, *14*(1), 22-32.

Hayton, J. C., Allen, D. G., & Scarpello, V. (2004). Factor retention decisions in exploratory factor analysis: A tutorial on parallel analysis. *Organizational research methods*, *7*(2), 191-205.

Holmgren, U., DiBonaventura, M., Karlsson, N., Bergstrom, G., & Ding, B. (2016). The association between COPD treatment adherence and patient outcomes in Europe and the

US. *European Respiratory Journal, 48*(suppl 60). doi:10.1183/13993003.congress-2016.PA1142

Jamal, S., Menon, B., Yousoof, M., & Vardhan, H. (2016). Reason for non-compliance to inhaled medications among adult patients of asthma and COPD attending outpatient department in a tertiary care hospital. *European Respiratory Journal, 48*(suppl 60). doi:10.1183/13993003.congress-2016.PA852

Johnson, M. J., & Rogers, S. (2006). Development of the purposeful action medication-taking questionnaire. *Western journal of nursing research, 28*(3), 335-351.

Jonsdottir, R., & Jonsdottir, H. (2007). The experience of women with advanced chronic obstructive pulmonary disease of repeatedly relapsing to smoking. *Scandinavian journal of caring sciences, 21*(3), 297-304.

Kaiser, H. F. (1960). The application of electronic computers to factor analysis. *Educational and Psychological measurement, 20*(1), 141-151.

Kaiser, H. F. (1974). Kaiser-Meyer-Olkin measure for identity correlation matrix. *Journal of the Royal Statistical Society, 52*, 296-298.

Kunik, M. E., Roundy, K., Veazey, C., Souchek, J., Richardson, P., Wray, N. P., & Stanley, M. A. (2005). Surprisingly high prevalence of anxiety and depression in chronic breathing disorders. *Chest, 127*(4), 1205-1211.

Laurin, C., Moullec, G., Bacon, S. L., & Lavoie, K. L. (2012). Impact of anxiety and depression on chronic obstructive pulmonary disease exacerbation risk. *Am J Respir Crit Care Med, 185*(9), 918-923. doi:10.1164/rccm.201105-0939PP

Lindgren, S., Storli, S. L., & Wiklund-Gustin, L. (2014). Living in negotiation: patients' experiences of being in the diagnostic process of COPD. *International journal of chronic obstructive pulmonary disease, 9*, 441.

Looper, K. J., & Kirmayer, L. J. (2004). Perceived stigma in functional somatic syndromes and comparable medical conditions. *Journal of psychosomatic research, 57*(4), 373-378.

Martinez, C. H., Richardson, C. R., Han, M. K., & Cigolle, C. T. (2014). Chronic obstructive pulmonary disease, cognitive impairment, and development of disability: the health and retirement study. *Annals of the American Thoracic Society, 11*(9), 1362-1370.

Mathers, C., Fat, D. M., & Boerma, J. T. (2008). *The global burden of disease: 2004 update*: World Health Organization.

Maurer, J., Rebbapragada, V., Borson, S., Goldstein, R., Kunik, M. E., Yohannes, A. M., & Hanania, N. A. (2008). Anxiety and depression in COPD: current understanding, unanswered questions, and research needs. *Chest Journal, 134*(4_suppl), 43S-56S.

McCarthy, B., Casey, D., Devane, D., Murphy, K., Murphy, E., & Lacasse, Y. (2015). Pulmonary rehabilitation for chronic obstructive pulmonary disease. *The Cochrane Library*. doi:10.1002/14651858.CD003793.pub3

Molina, Y., Choi, S. W., Cella, D., & Rao, D. (2013). The Stigma Scale for Chronic Illnesses 8-Item Version (SSCI-8): Development, Validation and Use Across Neurological Conditions. *International Journal of Behavioral Medicine, 20*(3), 450-460. doi:10.1007/s12529-012-9243-4

Mykletun, A., Stordal, E., & Dahl, A. A. (2001). Hospital Anxiety and Depression (HAD) scale: factor structure, item analyses and internal consistency in a large population. *British Journal of Psychiatry, 179*(6), 540-544. doi:DOI 10.1192/bjp.179.6.540

National Institutes of Neurologic Disorders and Stroke. (2010). *Measuring Quality of Life in Neurological Disorders: Final Report of the Neuro-QOL Study*. Retrieved from http://www.healthmeasures.net/images/neuro_qol/NeuroQOL-Final_report-2013.pdf.

Neri, M., Melani, A. S., Miorelli, A. M., Zanchetta, D., Bertocco, E., Cinti, C., . . . Pulmonologists, E. S. G. o. t. I. A. o. H. (2006). Long-term oxygen therapy in chronic respiratory failure: a Multicenter Italian Study on Oxygen Therapy Adherence (MISOTA). *Respir Med, 100*(5), 795-806.

O'Neill, E. S. (2002). Illness representations and coping of women with chronic obstructive pulmonary disease: a pilot study. *Heart & Lung: The Journal of Acute and Critical Care, 31*(4), 295-302.

Osborne, J. W. (2015). What is rotating in exploratory factor analysis. *Practical assessment, research & evaluation, 20*(2), 1-7.

Panagioti, M., Scott, C., Blakemore, A., & Coventry, P. A. (2014). Overview of the prevalence, impact, and management of depression and anxiety in chronic obstructive pulmonary disease. *International journal of chronic obstructive pulmonary disease, 9*, 1289.

Partridge, M. R., Dal Negro, R. W., & Olivieri, D. (2011). Understanding patients with asthma and COPD: insights from a European study. *Prim Care Respir J, 20*(3), 315-323.

Radovanovic, D., Seifert, B., Urban, P., Eberli, F. R., Rickli, H., Bertel, O., . . . Buchholz, S. (2014). Validity of Charlson Comorbidity Index in patients hospitalised with acute coronary syndrome. Insights from the nationwide AMIS Plus registry 2002–2012. *Heart, 100*(4), 288-294. doi:10.1136/heartjnl-2013-304588

Rao, D., Choi, S. W., Victorson, D., Bode, R., Peterman, A., Heinemann, A., & Cella, D. (2009). Measuring Stigma across Neurological Conditions: The Development of the Stigma Scale for Chronic Illness (SSCI). *Quality of Life Research, 18*(5), 585-595.

Sanduzzi, A., Balbo, P., Candoli, P., Catapano, G. A., Contini, P., Mattei, A., . . . Stanziola, A. A. (2014). COPD: adherence to therapy. *Multidisciplinary Respiratory Medicine, 9*(1), 60. doi:10.1186/2049-6958-9-60

Schalet, B. D., Hays, R. D., Jensen, S. E., Beaumont, J. L., Fries, J. F., & Cella, D. (2016). Validity of PROMIS physical function measured in diverse clinical samples. *Journal of clinical epidemiology, 73*, 112-118. doi:http://dx.doi.org/10.1016/j.jclinepi.2015.08.039

Solano, J. P., Gomes, B., & Higginson, I. J. (2006). A comparison of symptom prevalence in far advanced cancer, AIDS, heart disease, chronic obstructive pulmonary disease and renal disease. *Journal of pain and symptom management, 31*(1), 58-69.

Soriano, J. B., Visick, G. T., Muellerova, H., Payvandi, N., & Hansell, A. L. (2005). Patterns of comorbidities in newly diagnosed COPD and asthma in primary care. *Chest Journal, 128*(4), 2099-2107.

Svedsater, H., Roberts, J., Patel, C., Macey, J., Hilton, E., & Bradshaw, L. (2017). Life Impact and Treatment Preferences of Individuals with Asthma and Chronic Obstructive Pulmonary Disease: Results from Qualitative Interviews and Focus Groups. *Advances in Therapy*, 1-16.

Tessier, A., Finch, L., Daskalopoulou, S. S., & Mayo, N. E. (2008). Validation of the Charlson Comorbidity Index for Predicting Functional Outcome of Stroke. *Archives of Physical Medicine and Rehabilitation, 89*(7), 1276-1283. doi:http://dx.doi.org/10.1016/j.apmr.2007.11.049

Turan, O., Yemez, B., & Itil, O. (2014). The effects of anxiety and depression symptoms on treatment adherence in COPD patients. *Prim Health Care Res Dev, 15*(3), 244-251. doi:10.1017/s1463423613000169

U.S. Department of Health and Human Services [USDHHS]. (2016). *Chronic obstructive pulmonary disease (COPD).* Retrieved from https://www.cdc.gov/copd/index.html#2.

Vestbo, J., Hurd, S. S., Agustí, A. G., Jones, P. W., Vogelmeier, C., Anzueto, A., . . . Rodriguez-Roisin, R. (2013). Global Strategy for the Diagnosis, Management, and Prevention of Chronic Obstructive Pulmonary Disease. *187*(4), 347-365. doi:10.1164/rccm.201204-0596PP

Wheaton, A. G., Cunningham, T. J., Ford, E. S., & Croft, J. B. (2015). Employment and activity limitations among adults with chronic obstructive pulmonary disease—United States, 2013. *MMWR Morb Mortal Wkly Rep, 64*(11), 289-295.

Williams, B., Onsman, A., & Brown, T. (2010). Exploratory factor analysis: A five-step guide for novices. *Australasian Journal of Paramedicine, 8*(3).

Yohannes, A., Chen, W., Moga, A., Leroi, I., & Connolly, M. (2016). Mild cognitive impairment in chronic obstructive pulmonary disease and chronic heart failure: A systematic review and meta-analysis: Eur Respiratory Soc.

Yong, A. G., & Pearce, S. (2013). A beginner's guide to factor analysis: Focusing on exploratory factor analysis. *Tutorials in Quantitative Methods for Psychology, 9*(2), 79-94.

Zawada, K., Bratek, A., & Krysta, K. (2015). Psychological distress and social factors in patients with asthma and chronic obstructive lung disease. *Psychiatria Danubina, 27*(1), 462-464.

Zigmond, A. S., & Snaith, R. P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica, 67*(6), 361-370. doi:10.1111/j.1600-0447.1983.tb09716.x

Table 4-1. Demographic and Clinical Characteristics of Subjects (N = 148)

Characteristics	Mean (SD) [range]	N (%)
Age (years)	64.06 (7.27) [51 – 84]	
Age Groups		
50 – 59		45 (30.4%)
60 – 69		66 (44.6%)
70 – 79		34 (23.0%)
> 80		3 (2.0%)
Gender		
Female		73 (49.3%)
Male		75 (50.7%)
Race/ethnicity		
Caucasian / White		134 (90.5%)
Black / African American		8 (5.4%)
Other		5 (3.5%)
American Indian / Native American and Caucasian		2 (1.4%)
Greek and Caucasian		1 (0.7%)
Sinhalese		1 (0.7%)
Western Europe		1 (0.7%)
Missing		1 (0.7%)
Education		
≤ 12th grade		65 (43.9%)
Some college		58 (39.2%)
College degree		17 (11.5%)
Advanced degree		8 (5.4%)
Relationship status		
Never married		22 (14.9%)
Married		57 (38.5%)
Partnered		6 (4.1%)
Separated		6 (4.1%)
Divorced		44 (29.7%)
Widowed		12 (8.1%)
Missing		1 (0.7%)
Living arrangement		
Alone		37 (25.0%)
No dependents		2 (1.4%)
With other adult(s)		82 (55.4%)
With dependent(s) only		8 (5.4%)
With other adult(s) and dependent(s)		17 (11.5%)

Characteristics	Mean (SD) [range]	N (%)
Missing		2 (1.4%)
Occupational status		
Homemaker		5 (3.4%)
Unemployed		6 (4.1%)
Retired		60 (40.5%)
Disability		51 (34.5%)
Leave of absence		2 (1.4%)
Employed part-time		4 (2.7%)
Employed full-time		15 (10.1%)
Self-employed		5 (3.4%)
Smoking status		
Current		113 (76.4%)
a. On a regular basis		91 (61.5%)
b. Only once in a while		22 (14.9%)
Former		35 (23.6%)
Duration of having COPD (years)	8.84 (7.87) [0 – 39][§]	
Supplemental oxygen usage		
Yes		32 (21.6%)
No		116 (78.4%)
Inhaler usage		
Yes		123 (83.1%)
No		25 (16.9%)
COPD symptoms such as cough, phlegm, or shortness of breath		
Yes		129 (87.2%)
No		19 (12.8%)
Stigma Scale for Chronic Illnesses-8 items	2.06 (0.83) [1.0 – 5.0]	
Charlson Comorbidity Index	3.48 (3.51) [0 – 20]	
Hospital Anxiety and Depression Scale (14 items)	2.02 (0.58) [1 – 3.5]	
PROMIS Physical Function-10 items	3.43 (0.79) [1.6 – 5.0]	

Note. COPDSS = COPD-related Stigma Scale; SD = Standard Deviation; PROMIS = Patient-Reported Outcomes Measurement Information System; [§]N = 130

Table 4-2. Comparison of Eigenvalues from Factor Analysis and Criterion values from Parallel Analysis

Factor number	Actual eigenvalue from factor analysis	Criterion value from parallel analysis	Decision
1	19.351	2.268544	Accept
2	2.754	2.046756	Accept
3	2.249	1.894408	Accept
4	1.762	1.813212	Reject
5	1.577	1.706183	Reject

Note. Factors from the actual data with eigenvalues greater than the corresponding values from the parallel analysis would be retained (Hayton et al., 2004).

Table 4-3. Factor Loadings from Rotated Factor-Loading Pattern Matrix (N = 112)

Item	28-item COPDSS	Factor Loading			
	Mean (SD)	1	2	3	4
35. Most people with COPD are rejected when others find out.	1.79 (0.65)	**0.857**	0.275	0.026	0.144
34. Most people think that a person with COPD is disgusting.	1.81 (0.70)	**0.773**	0.308	0.087	0.183
31. It is easier to avoid new friendships than worry about telling someone that I have COPD.	1.87 (0.72)	**0.769**	0.152	0.260	0.043
30. Most people believe that a person who has COPD is unclean.	1.87 (0.68)	**0.765**	0.146	0.217	0.056
39. Most people are uncomfortable around someone with COPD.	2.01 (0.75)	**0.715**	0.340	0.138	0.332
50. People who know I have COPD tend to ignore my good points.	1.76 (0.65)	**0.715**	0.412	0.089	0.166
29. People with COPD are treated like outcasts.	2.10 (0.74)	**0.708**	0.199	0.225	0.200
38. If they learn I have COPD, I worry about people discriminating against me.	1.95 (0.79)	**0.689**	0.327	0.222	0.264
47. I have stopped socializing with some people because of their reactions to my having COPD.	1.91 (0.77)	**0.685**	0.481	0.185	0.180
43. I have been hurt by how people reacted to learning I have COPD.	1.94 (0.77)	**0.618**	0.560	0.193	0.248
22. I feel guilty because I have COPD.	2.42 (0.88)	0.096	**0.709**	0.371	0.030
23. People's attitudes about COPD make me feel worse about myself.	2.24 (0.93)	0.269	**0.687**	0.344	0.248
42. Having COPD is disgusting to me.	2.17 (0.78)	0.439	**0.624**	0.101	0.190
44. I regret having told some people that I have COPD.	1.99 (0.74)	0.557	**0.616**	0.146	0.154
46. Some people act as though it's my fault I have COPD.	2.54 (0.92)	0.361	**0.613**	0.035	0.480
41. I worry that people may judge me when they learn I have COPD.	2.12 (0.76)	0.474	**0.596**	0.210	0.205
26. I work hard to keep my COPD a secret.	1.94 (0.76)	0.456	**0.560**	0.065	0.044
27. I feel I am not as good a person as others because I have COPD.	2.10 (0.91)	0.378	**0.549**	0.354	0.047
Reversed 40. I never feel the need to hide the fact that I have COPD.	2.17 (0.82)	0.385	**0.530**	0.201	-0.084
16. My COPD puts a burden on my friends and loved ones.	2.25 (0.92)	-0.012	0.258	**0.730**	0.068
15. Having COPD has changed my view of what I can do.	2.95 (0.91)	0.142	0.166	**0.724**	0.219
5. It's embarrassing not to be able to keep up with others when we're walking.	2.83 (0.97)	0.225	0.016	**0.700**	0.176
14. I feel flawed because I have COPD.	2.42 (1.02)	0.426	0.222	**0.610**	0.291
18. I plan my activities carefully so others won't notice I can't do as much as I used to.	2.30 (0.86)	0.399	0.379	**0.545**	0.182

Item	28-item COPDSS	Factor Loading			
	Mean (SD)	1	2	3	4
10. Others blame a person with COPD for having smoked.	3.13 (0.85)	0.145	0.229	0.229	**0.731**
11. Others think people with COPD are idiots for having smoked.	2.92 (0.92)	0.100	0.231	0.368	**0.675**
13. Some health care providers have been abrupt with me about smoking.	2.52 (0.97)	0.215	-0.186	0.263	**0.510**
45. People have told me that getting COPD is what I deserve for having smoked cigarettes.	2.33 (0.96)	0.326	0.580	-0.111	**0.557**

Note. COPDSS = COPD-related Stigma Scale; SD = Standard Deviation; F1 = social stigma subscale; F2 = self-blame subscale; F3 = physical limitation subscale; F4 = self-inflicted disease subscale

Table 4-4. The 28-item version COPD-related Stigma Scale Reliability

	Cronbach's Alpha
28-item COPD-related Stigma Scale	0.96
Social Stigma (Factor 1: 10 items)	0.95
Self-blame (Factor 2: 9 items)	0.90
Physical limitation (Factor 3: 5 items)	0.84
Self-inflicted disease (Factor 4: 4 items)	0.70

Table 4-5. Correlations of 28-item COPD-related Stigma Scale between Subscales and with Other Measures

	28-item	COPDSS					SSCI-8				PROMIS
	COPDSS	F1	F2	F3	F4	SSCI-8	SSCI-8 (E)	SSCI-8 (I)	CCI	HADS	PF
28-item COPDSS	1.00					0.84**	0.78**	0.79**	0.07	0.53**	-0.36**
F1	0.91**	1.00				0.76**	0.75**	0.64**	0.06	0.45**	-0.30**
F2	0.93**	0.81**	1.00			0.77**	0.72**	0.73**	0.07	0.46**	-0.27**
F3	0.79**	0.59**	0.65**	1.00		0.69**	0.55**	0.77**	0.05	0.58**	-0.50**
F4	0.76**	0.59**	0.62**	0.57**	1.00	0.64**	0.63**	0.56**	0.06	0.32**	-0.18*

Note. COPDSS = COPD-related Stigma Scale; F1 = social stigma subscale; F2 = self-blame subscale; F3 = physical limitation subscale; F4 = self-inflicted disease subscale; SSCI-8 = Stigma Scale for Chronic Illness 8-item version; HADS = Hospital Anxiety and Depression Scale; PROMIS Physical Function = Patient-Reported Outcomes Measurement Information System Physical Function Short-Form 10a

**$p < 0.01$, *$p < 0.05$

Table 4-6. Group comparisons of 28-item COPD-related Stigma Scale scores

	Gender [Mean (SD)]					
	Total (n = 148)	Female (n = 73)	Male (n = 75)		*F*(1, 146)	*p*-value
28-item COPDSS	2.24 (0.55)	2.38 (0.59)	2.11 (0.48)		9.25	0.003
Social Stigma	1.91 (0.59)	2.04 (0.63)	1.78 (0.52)		7.34	0.008
Self-blame	2.21 (0.62)	2.35 (0.69)	2.07 (0.52)		7.94	0.006
Physical Limitation	2.57 (0.71)	2.68 (0.73)	2.46 (0.67)		3.47	0.064
Self-inflicted disease	2.74 (0.67)	2.93 (0.67)	2.57 (0.61)		11.64	0.001
	Age [Mean (SD)]					
	Total (n = 148)	50 – 59 years (n = 45)	60 – 69 years (n = 66)	70 – 79 years (n = 34)	≥ 80 years (n = 3)	*F*(3, 144)	*p*-value
28-item COPDSS	2.24 (0.55)	2.34 (0.60)	2.26 (0.52)	2.07 (0.53)	2.37 (0.23)	1.67	0.176
Social Stigma	1.91 (0.59)	1.99 (0.64)	1.91 (0.59)	1.79 (0.54)	1.83 (0.40)	0.71	0.546
Self-blame	2.21 (0.62)	2.30 (0.65)	2.22 (0.62)	2.05 (0.58)	2.35 (0.89)	1.06	0.368
Physical Limitation	2.57 (0.71)	2.71 (0.74)	2.60 (0.69)	2.29 (0.67)	2.87 (0.12)	2.73	0.046
Self-inflicted disease	2.74 (0.67)	2.84 (0.64)	2.77 (0.66)	2.51 (0.69)	3.25 (0.25)	2.40	0.071
	Education [Mean (SD)]					
	Total (n = 148)	≤ 12th grade (n = 65)	Some college (n = 58)	College degree (n = 17)	Advanced degree (n = 8)	*F*(3, 144)	*p*-value
28-item COPDSS	2.24 (0.55)	2.14 (0.43)	2.41 (0.62)	2.11 (0.63)	2.15 (0.55)	2.97	0.034
Social Stigma	1.91 (0.59)	1.80 (0.49)	2.05 (0.62)	1.87 (0.75)	1.80 (0.59)	2.10	0.103
Self-blame	2.21 (0.62)	2.09 (0.52)	2.38 (0.70)	2.05 (0.63)	2.21 (0.57)	2.67	0.050
Physical Limitation	2.57 (0.71)	2.48 (0.60)	2.76 (0.70)	2.31 (0.80)	2.40 (1.10)	2.88	0.038
Self-inflicted disease	2.74 (0.67)	2.68 (0.65)	2.89 (0.69)	2.60 (0.70)	2.56 (0.42)	1.57	0.199
	Race/Ethnicity [Mean (SD)]					
	Total (n = 147)	Black / African American (n = 8)	Caucasian / White (n = 134)	Other (n = 5)		*F*(2, 144)	*p*-value
28-item COPDSS	2.24 (0.55)	2.05 (0.40)	2.24 (0.56)	2.47 (0.47)		0.93	0.395
Social Stigma	1.91 (0.59)	1.74 (0.41)	1.90 (0.60)	2.32 (0.33)		1.57	0.213
Self-blame	2.20 (0.62)	2.03 (0.45)	2.21 (0.63)	2.36 (0.52)		0.47	0.627

Physical Limitation	2.56 (0.70)		2.40 (0.53)	2.57 (0.71)	2.55 (0.79)			0.22	0.805
Self-inflicted disease	2.74 (0.67)		2.31 (0.44)	2.76 (0.67)	3.00 (0.61)			2.12	0.124
	Relationship status [Mean (SD)]								
	Total (n = 147)	Never married (n = 22)	Married (n = 57)	Partnered (n = 6)	Separated (n = 6)	Divorced (n = 44)	Widowed (n = 12)	*F*(5, 141)	*p*-value
28-item COPDSS	2.24 (0.55)	2.21 (0.39)	2.12 (0.58)	2.52 (0.54)	2.55 (0.84)	2.32 (0.55)	2.25 (0.35)	1.46	0.207
Social Stigma	1.90 (0.58)	1.90 (0.48)	1.77 (0.61)	2.01 (0.54)	2.37 (0.93)	1.96 (0.59)	2.03 (0.26)	1.60	0.163
Self-blame	2.20 (0.62)	2.15 (0.45)	2.10 (0.64)	2.56 (0.58)	2.35 (0.97)	2.31 (0.65)	2.15 (0.45)	1.10	0.364
Physical Limitation	2.56 (0.71)	2.63 (0.59)	2.39 (0.75)	3.07 (0.62)	2.90 (0.65)	2.64 (0.72)	2.50 (0.52)	1.75	0.126
Self-inflicted disease	2.73 (0.66)	2.58 (0.61)	2.71 (0.72)	3.00 (0.69)	3.00 (0.94)	2.78 (0.60)	2.71 (0.52)	0.68	0.641
	Living arrangement Mean (SD)]								
	Total (n = 146)	Alone (n = 37)	No dependents (n = 2)	With other adults (n = 82)	With dependents only (n = 8)	With other adult(s) with dependent(s) (n = 17)		*F*(4, 141)	*p*-value
28-item COPDSS	2.24 (0.55)	2.23 (0.51)	2.07 (0.15)	2.2 (0.57)	2.44 (0.67)	2.43 (0.51)		0.93	0.450
Social Stigma	1.91 (0.59)	1.89 (0.56)	2.05 (0.07)	1.87 (0.61)	2.18 (0.83)	2.00 (0.50)		0.62	0.651
Self-blame	2.21 (0.63)	2.22 (0.62)	2.06 (0.08)	2.15 (0.64)	2.47 (0.63)	2.35 (0.60)		0.77	0.549
Physical Limitation	2.56 (0.71)	2.61 (0.67)	1.90 (0.14)	2.47 (0.70)	2.6 (0.74)	2.94 (0.74)		2.04	0.091
Self-inflicted disease	2.75 (0.66)	2.59 (0.62)	2.38 (0.53)	2.76 (0.67)	2.81 (0.75)	3.07 (0.63)		1.74	0.144
	Occupational status Mean (SD)]								
	Total (n = 148)	Home-maker (n = 5)	Un-employed (n = 6)	Retired (n = 60)	Disability (n = 51)	Leave of absence (n = 2)	Part-time employed (n = 4)	Full-time employed (n = 15)	Self-employed (n = 5)	*F*(7, 140)	*p*-value
28-item COPDSS	2.24 (0.55)	2.55 (0.47)	2.36 (0.74)	2.19 (0.60)	2.29 (0.53)	1.75 (0.15)	2.28 (0.30)	2.21 (0.49)	2.25 (0.35)	0.63	0.734
Social Stigma	1.91 (0.59)	2.18 (0.35)	2.06 (0.77)	1.86 (0.66)	1.96 (0.55)	1.25 (0.35)	2.10 (0.14)	1.84 (0.55)	1.86 (0.38)	0.75	0.630
Self-blame	2.21 (0.62)	2.49 (0.57)	2.43 (0.65)	2.18 (0.68)	2.19 (0.64)	1.56 (0.47)	2.31 (0.43)	2.25 (0.48)	2.22 (0.34)	0.60	0.754
Physical Limitation	2.57 (0.71)	2.64 (0.70)	2.50 (1.06)	2.47 (0.72)	2.74 (0.69)	2.50 (0.71)	2.30 (0.35)	2.44 (0.66)	2.60 (0.68)	0.74	0.636
Self-inflicted disease	2.74 (0.67)	3.53 (0.47)	2.79 (0.97)	2.64 (0.69)	2.78 (0.60)	2.5 (0)	2.63 (0.60)	2.75 (0.70)	2.85 (0.45)	1.32	0.244

	Smoking status [Mean (SD)]					
	Total (n = 148)	Yes, regularly (n = 91)	Yes, occasionally (n = 22)	Not anymore (n = 35)	*F*(2, 145)	*p*-value
28-item COPDSS	2.24 (0.55)	2.23 (0.57)	2.15 (0.50)	2.34 (0.54)	0.86	0.426
Social Stigma	1.91 (0.59)	1.90 (0.59)	1.86 (0.58)	1.96 (0.61)	0.24	0.786
Self-blame	2.21 (0.62)	2.22 (0.63)	2.04 (0.48)	2.29 (0.68)	1.17	0.313
Physical Limitation	2.57 (0.71)	2.50 (0.75)	2.49 (0.60)	2.80 (0.62)	2.46	0.089
Self-inflicted disease	2.74 (0.67)	2.75 (0.70)	2.69 (0.68)	2.75 (0.56)	0.10	0.908
	Supplemental Oxygen use [Mean (SD)]					
	Total (n = 148)	Yes (n = 32)	No (n = 116)		*F*(1, 146)	*p*-value
28-item COPDSS	2.24 (0.55)	2.36 (0.58)	2.21 (0.54)		1.96	0.164
Social Stigma	1.91 (0.59)	1.92 (0.67)	1.90 (0.57)		0.02	0.899
Self-blame	2.21 (0.62)	2.30 (0.69)	2.18 (0.60)		0.80	0.372
Physical Limitation	2.57 (0.71)	2.96 (0.56)	2.46 (0.71)		13.72	0.000
Self-inflicted disease	2.74 (0.67)	2.88 (0.70)	2.71 (0.65)		1.74	0.189
	Inhaler use [Mean (SD)]					
	Total (n = 148)	Yes (n = 123)	No (n = 25)		*F*(1, 146)	*p*-value
28-item COPDSS	2.24 (0.55)	2.28 (0.57)	2.08 (0.40)		2.64	0.106
Social Stigma	1.91 (0.59)	1.92 (0.61)	1.83 (0.45)		0.54	0.462
Self-blame	2.21 (0.62)	2.23 (0.66)	2.09 (0.41)		1.09	0.298
Physical Limitation	2.57 (0.71)	2.66 (0.67)	2.10 (0.72)		14.04	0.000
Self-inflicted disease	2.74 (0.67)	2.76 (0.69)	2.64 (0.52)		0.72	0.396
	COPD Symptoms [Mean (SD)]					
	Total (n = 148)	Yes (n = 129)	No (n = 19)		*F*(1, 146)	*p*-value
28-item COPDSS	2.24 (0.55)	2.24 (0.55)	2.27 (0.58)		0.04	0.848
Social Stigma	1.91 (0.59)	1.91 (0.58)	1.91 (0.67)		0.00	0.987
Self-blame	2.21 (0.62)	2.20 (0.62)	2.27 (0.68)		0.21	0.644
Physical Limitation	2.57 (0.71)	2.58 (0.69)	2.44 (0.80)		0.67	0.413
Self-inflicted disease	2.74 (0.67)	2.72 (0.66)	2.91 (0.68)		1.34	0.249

Note. SD = Standard Deviation; COPDSS = COPD-related Stigma Scale; Social Stigma = Factor 1; Self-blame = Factor 3; Physical Limitation = Factor 3; Self-inflicted disease = Factor 4

Table 4-7. Multivariate Regression Analysis

	Model 1			Model 2			Model 3			Model 4			Model 5		
	28-item COPDSS			Social Stigma			Self-blame			Physical Limitation			Self-inflicted disease		
Variables	B	SE B	Sig.	B	SE B	Sig.	B	SE B	Sig.	B	SE B	Sig.	B	SE B	Sig.
Age															
[50 – 59 years]	-0.59	0.34	0.082	-0.42	0.40	0.295	-0.66	0.41	0.110	-0.66	0.39	0.096	-0.95	0.44	0.032
[60 – 69 years]	-0.47	0.31	0.135	-0.31	0.37	0.392	-0.48	0.38	0.207	-0.59	0.36	0.105	-0.84	0.40	0.040
[70 – 79 years]	-0.58	0.31	0.067	-0.36	0.37	0.333	-0.58	0.38	0.131	-0.83	0.36	0.023	-0.94	0.40	0.022
[≥ 80 years]	0			0			0			0			0		
Gender															
Female	0.20	0.10	0.046	0.19	0.12	0.117	0.31	0.12	0.012	0.09	0.12	0.454	0.16	0.13	0.212
Male	0			0			0			0			0		
Race/Ethnicity															
African American	-0.70	0.34	0.044	0.19	0.12	0.117	-0.63	0.42	0.136	-0.33	0.39	0.410	-1.08	0.44	0.016
Caucasian	-0.15	0.31	0.630	0.19	0.12	0.117	-0.14	0.37	0.702	0.27	0.35	0.450	-0.33	0.40	0.409
Other	0			0			0			0			0		
Education															
≤ 12th grade	0.09	0.20	0.650	-0.01	0.24	0.955	0.10	0.25	0.678	0.17	0.24	0.475	0.17	0.26	0.528
Some college	0.29	0.20	0.145	0.20	0.24	0.394	0.30	0.24	0.228	0.38	0.23	0.102	0.38	0.26	0.149
College degree	0.04	0.24	0.874	0.10	0.29	0.716	0.00	0.30	0.998	0.05	0.28	0.872	-0.02	0.32	0.947
Advanced degree	0			0			0			0			0		
Relationship status															
Never married	0.36	0.25	0.148	0.30	0.29	0.298	0.44	0.30	0.145	0.32	0.29	0.272	0.34	0.32	0.285
Married	-0.07	0.19	0.712	-0.19	0.22	0.397	0.03	0.23	0.909	-0.18	0.22	0.404	0.12	0.25	0.634
Partnered	0.52	0.30	0.086	0.21	0.35	0.557	0.64	0.36	0.080	0.64	0.34	0.064	0.75	0.38	0.053
Separated	0.27	0.28	0.336	0.42	0.33	0.208	0.29	0.34	0.399	-0.17	0.32	0.605	0.43	0.36	0.242
Divorced	0.31	0.19	0.113	0.18	0.22	0.434	0.43	0.23	0.068	0.19	0.22	0.390	0.40	0.25	0.108
Widowed	0			0			0			0			0		
Living arrangement															

	Model 1			Model 2			Model 3			Model 4			Model 5		
	28-item COPDSS			Social Stigma			Self-blame			Physical Limitation			Self-inflicted disease		
Variables	B	SE B	Sig.	B	SE B	Sig.	B	SE B	Sig.	B	SE B	Sig.	B	SE B	Sig.
Alone	-0.18	0.20	0.360	-0.15	0.23	0.512	-0.17	0.24	0.490	-0.22	0.23	0.348	-0.32	0.26	0.209
No dependents	-0.66	0.42	0.117	-0.26	0.49	0.599	-0.67	0.51	0.192	-1.12	0.48	0.023	-1.10	0.54	0.044
With other adults	0.05	0.18	0.789	0.11	0.21	0.593	0.02	0.22	0.913	-0.02	0.20	0.912	-0.04	0.23	0.849
With dependents only	0.55	0.26	0.039	0.71	0.31	0.023	0.57	0.32	0.073	0.24	0.30	0.429	0.40	0.34	0.242
With other adult(s) and dependent(s)	0			0			0			0			0		
Occupational status															
Homemaker	0.47	0.35	0.179	0.51	0.41	0.220	0.51	0.43	0.230	0.17	0.40	0.671	0.76	0.45	0.096
Unemployed	0.07	0.32	0.840	0.16	0.38	0.673	0.32	0.39	0.411	-0.44	0.37	0.235	-0.11	0.41	0.799
Retired	0.11	0.24	0.638	0.12	0.28	0.660	0.24	0.29	0.421	-0.02	0.28	0.932	-0.04	0.31	0.910
Disability	0.10	0.24	0.682	0.22	0.28	0.430	0.13	0.29	0.652	-0.13	0.28	0.634	0.05	0.31	0.861
Leave of absence	-0.52	0.54	0.338	-0.40	0.64	0.533	-0.34	0.66	0.614	-1.15	0.63	0.070	-0.28	0.70	0.689
Part-time employed	0.37	0.37	0.316	0.48	0.44	0.273	0.56	0.45	0.216	0.13	0.43	0.761	0.02	0.48	0.964
Full-time employed	0.29	0.27	0.284	0.33	0.32	0.304	0.49	0.33	0.138	0.08	0.31	0.804	0.08	0.35	0.820
Self-employed	0			0			0			0			0		
Tobacco use															
Yes, regularly	-0.02	0.12	0.836	0.01	0.14	0.964	0.07	0.14	0.600	-0.22	0.13	0.099	0.01	0.15	0.941
Yes, occasionally	-0.23	0.16	0.154	-0.13	0.19	0.480	-0.25	0.19	0.195	-0.40	0.18	0.034	-0.12	0.21	0.553
Not anymore	0			0			0			0			0		
Oxygen use															
No	0.03	0.13	0.795	0.13	0.15	0.399	-0.02	0.16	0.905	-0.06	0.15	0.694	-0.02	0.17	0.900
Yes	0			0			0			0			0		
Inhaler use															
No	-0.02	0.14	0.866	0.00	0.17	0.998	-0.02	0.17	0.916	-0.21	0.16	0.198	0.15	0.18	0.421
Yes	0			0			0			0			0		

	Model 1			Model 2			Model 3			Model 4			Model 5		
	28-item COPDSS			Social Stigma			Self-blame			Physical Limitation			Self-inflicted disease		
Variables	B	SE B	Sig.	B	SE B	Sig.	B	SE B	Sig.	B	SE B	Sig.	B	SE B	Sig.
Having COPD symptoms															
No	0.10	0.14	0.463	0.09	0.16	0.599	0.19	0.17	0.268	-0.04	0.16	0.790	-0.14	0.14	0.325
Yes	0			0			0			0			0		
Duration of having COPD	0.00	0.01	0.552	0.00	0.01	0.853	-0.01	0.01	0.127	0.00	0.01	0.825	0.00	0.01	0.658
CCI	0.26	0.28	0.354	0.18	0.33	0.575	0.36	0.34	0.288	-0.10	0.32	0.746	0.60	0.36	0.098
HADS	0.39	0.10	0.000	0.32	0.12	0.008	0.37	0.12	0.004	0.54	0.12	0.000	0.37	0.13	0.006
PROMIS Physical	-0.10	0.08	0.233	-0.12	0.09	0.224	-0.09	0.10	0.380	-0.22	0.09	0.020	0.07	0.10	0.510
Function															
R^2	0.54			0.44			0.46			0.63			0.44		
Adjusted R^2	0.35			0.22			0.24			0.48			0.22		

Note. DV = dependent variable; DV in Model 1 = 28-item COPDSS; DV in Model 2 = Social Stigma; DV in Model 3 = Self-blame; DV in Model 4 = Physical Limitation; DV in Model 5 = Self-inflicted disease; COPDSS = COPD-related Stigma Scale; HADS = Hospital Anxiety and Depression Scale; PROMIS Physical Function = Patient-Reported Outcomes Measurement Information System Physical Function Short-Form 10a

Chapter 5

Conclusion

Chronic obstructive pulmonary disease (COPD) affects many major aspects of health, including physical functions, psychological functions and overall quality of life. Studies have shown that people with COPD often experience stigma due to their history of smoking and the perception that they caused the COPD within their bodies (Arne et al., 2007; Berger et al., 2011; Halding et al., 2011). COPD and smoking are stigmatized by the public and by health-care providers, which negatively impacts help-seeking behaviors (Gysels & Higginson, 2008; Partridge et al., 2011). Experiencing these stigmas may cause psychological distress in people with COPD and affect their health-related behaviors, which will consequently affect their ability to function physically and their quality of life.

From the systematic review, we found that although people with COPD have similar perceptions of stigma to those with lung cancer, there is a lack of evidence about the dimensions that constitute COPD-related stigma and how these dimensions are related to health outcomes. The fact that there is no existing measure of COPD-related stigma may be partly responsible for the delays in advancing science. Seeking to fill this gap, we interviewed people with COPD in order to develop a valid stigma scale for this population and revised the scale items and response options based on the interview findings. While interviewing people about the COPD-related Stigma Scale items, we found that most participants were aware of COPD-related stigmas, but there were differences in the way they perceived and coped with stigma. We also found that there was a tendency to take a neutral attitude toward the scale items that were challenging to

answer. This tendency influenced participants to select the mid-point option. Further evaluation showed that the frequency of the mid-point responses was decreased when participants were required to explain reasons to choose the mid-point option. After the interview data analysis, we dropped one item and revised eleven items. We also decided to drop the mid-point option from the five-point Likert response options.

Then, we administered the revised version of the COPD-related Stigma Scale (i.e., the 51-item COPD-related Stigma Scale with a four-point Likert scale) to a large number of people with COPD. Findings support the assertion that the COPD-related Stigma Scale has four underlying constructs—social stigma subscale, physical limitations subscale, self-blame subscale, and smoking subscale—and is a reliable, valid measure for people with COPD. Findings also indicate that experiencing COPD-related stigma is associated with psychological distress and physical-function decline. Overall, the findings of the scale development study suggest that further evaluation may be required to confirm the derived factor structure and develop strategies to lessen the impact of COPD-related stigma on disease management and quality of life.

This study had limitations in some respects. First, our systematic review aimed to identify similarities and differences between COPD-related stigma and lung cancer-related stigma. Due to the complexity of stigma associated with COPD or lung cancer, we limited the scope of this review to six domains that cover the pathway from stigma to health (Major et al., 2018). Second, we only included people with COPD who were 50 years old or older in order to rule out the stigma experiences of people with COPD caused by a genetic condition (e.g., alpha-1 antitrypsin deficiency [AATD]). Stigma experiences in those with AATD are attributed to "carrying a genetic condition" (Campos, Alazemi, Zhang, Wanner, & Sandhaus, 2009).

However, considering the increasing awareness of COPD, excluding people with COPD under 50 years old may limit the generalizability of the findings. Finally, we conducted a factor analysis test, excluding eight items that inquired about specific triggers for COPD-related stigma, the use of inhalers and supplemental oxygen. Despite the potential stigma associated with using these treatment devices, the issue of the eight items was not addressed in this study because many subjects were not receiving supplemental oxygen and/or using inhalers. The inclusion of these items will need to be evaluated in future research where there are larger numbers of subjects receiving supplemental oxygen and/or using inhalers.

Directions for future research include confirming the factor structure (i.e., the four-factor structure) as well as establishing measurement invariance across demographic groups, such as those based on gender, culture and geography. In the process of establishing the construct validity of the COPD-related Stigma Scale, we found strong associations between stigma experiences and psychological distress as well as reduced physical function. Future studies may investigate the impact of COPD-related stigma on self-management and healthcare use as well as quality of life. Based on the findings in the studies discussed above and literature reviews, researchers may consider designing and implementing stigma reduction interventions as a part of a psychological support plan for people with COPD.

References

Arne, M., Emtner, M., Janson, S., & Wilde-Larsson, B. (2007). COPD patients' perspectives at the time of diagnosis: a qualitative study. *Primary Care Respiratory Journal, 16*(4), 215-221.

Berger, B. E., Kapella, M. C., & Larson, J. L. (2011). The experience of stigma in chronic obstructive pulmonary disease. *Western journal of nursing research, 33*(7), 916-932.

Campos, M. A., Alazemi, S., Zhang, G., Wanner, A., & Sandhaus, R. A. (2009). Effects of a disease management program in individuals with alpha-1 antitrypsin deficiency. *COPD: Journal of Chronic Obstructive Pulmonary Disease, 6*(1), 31-40.

Gysels, M., & Higginson, I. J. (2008). Access to services for patients with chronic obstructive pulmonary disease: the invisibility of breathlessness. *Journal of pain and symptom management, 36*(5), 451-460.

Halding, A. G., Heggdal, K., & Wahl, A. (2011). Experiences of self-blame and stigmatisation for self-infliction among individuals living with COPD. *Scandinavian journal of caring sciences, 25*(1), 100-107.

Major, B., Dovidio, J. F., & Link, B. G. (2018). *The Oxford Handbook of Stigma, Discrimination, and Health*: Oxford University Press.

Partridge, M. R., Dal Negro, R. W., & Olivieri, D. (2011). Understanding patients with asthma and COPD: insights from a European study. *Prim Care Respir J, 20*(3), 315-323.

Appendices

Appendix A. Shaw et al. (2009) quality assessment checklist for quantitative studies

Criteria	Yes (2/good)	Partial (1/fair)	No (0/poor)	N/A
Study aims				
1. Is the hypothesis/aim/ objective of the study clearly and sufficiently described?	Easily identified in introduction/methods. Specifies: purpose; subjects/target population; and specific interventions/associations under investigation	Vague/incomplete reporting or some information has to be gathered from parts of the paper other than the introduction/ background/objective sections	Question or objective not reported/incomprehensible	
Study design and sample characteristics				
2. Is the study design well described and appropriate? (If study question not given, infer from conclusions)	Design easily identified, well described and appropriate	Design and/or study question not clearly described or design only partially addresses study question	Design does not answer study question or design is poorly described	
3. Is the method of patient/control group selection described and appropriate?	Described and appropriate. Inclusion/exclusion criteria described and defined	Selection methods (and inclusion/ exclusion criteria) not completely described but no obvious inappropriateness or selection strategy likely introduces bias but not enough to seriously distort results	No information/ inappropriate information provided or selection bias that likely distorts results	
4. Are the characteristics of patient/control group(s) clearly described (i.e. age range, health characteristic/s)?	Sufficient relevant demographic information. Reproducible criteria used to categorize participants clearly defined	Poorly defined criteria or incomplete demographic information	No baseline/demographic information provided	

	Criteria	Yes (2/good)	Partial (1/fair)	No (0/poor)	N/A
5.	Are caregiver characteristics clearly described (i.e. age, gender, relationship to care recipient, time spent caring)?	Sufficient relevant demographic information. Reproducible criteria used to categorize participants clearly defined	Poorly defined criteria or incomplete demographic information	No baseline/demographic information provided	
6.	Were patients/participants randomized to intervention groups?	If randomization appropriate: evidence of randomization with a description of the method used (e.g. random number tables, block design)	Randomization mentioned but method is not (i.e. may be possible that randomization was not carried out)	Random allocation not mentioned although it would have been feasible and appropriate (and was possibly carried out)	Study has no control group, i.e. observational/ survey/case–control study, or adequate justification for non-randomization given
7.	For RCTs only Was randomization/ allocation concealed from patients?	Evidence that next allocation was concealed from both parties (recruiter and patient/carer) at the point of consent (e.g. remote randomization)	Allocation concealment reported but not described	Allocation concealment would have been possible (and was possibly carried out) but not reported	Allocation concealment not possible because of study design (e.g. cluster randomized trial)
8.	Have the characteristics of patients lost to follow-up been described?	Losses adequately reported and not likely to affect results	Losses not well reported, but small and not likely to affect results	No information or losses large and likely to affect results	No patients lost to follow-up
9.	Are intervention(s) clearly described?	Defined and reproducible	Partially defined but insufficient detail to reproduce design	Not described	
	Data analysis and results				
10.	Are the main outcomes to be measured clearly described in the introduction/methods?	Defined and measured according to reproducible criteria	Definition leaves room for subjectivity or not sure (i.e. not reported in detail, but probably acceptable) or precise definition(s) are missing, but no evidence of major problems or instrument/mode of assessment(s) not reported	Main outcomes first mentioned in results section or measures not defined/inconsistent/poorly defined	
11.	If possible, was an attempt made to blind those measuring the main	Assessor blind to intervention/study group	Inadequate blinding, i.e. assessor may have been	No attempt made to blind assessor	Not possible/ appropriate, e.g.

Criteria	Yes (2/good)	Partial (1/fair)	No (0/poor)	N/A
outcomes of the intervention?		aware of the group that the participant was assigned to		observational/before-and-after study
12. Are population characteristics (if measured and described) controlled for and adequately described?	Appropriate control at design/ analysis stage or randomized study with comparable baseline characteristics	Incomplete control/description or not considered but unlikely to seriously influence results	Not controlled for and likely to seriously influence results	
13. Are the main findings clearly described?	Simple outcome data (e.g. mean/ prevalence) reported for all major findings	Incomplete or inappropriate descriptive statistics	No/inadequate descriptive statistics	
14. Are methods of analysis adequately described and appropriate?	Described and appropriate	Not reported but probably appropriate or some tests appropriate, some not	Methods not described and cannot be determined	
15. Are estimates of variance reported for the main results?	Appropriate estimates provided (SD/SE, confidence intervals)	Undefined or estimates provided for some but not all outcomes	No information	
16. In trials/cohort studies do analyses adjust for different lengths of follow-up, or in case–control studies is the time between intervention and outcome the same for cases/ controls?	Different lengths of follow-up adjusted for (e.g. survival analysis) and adequately described	Different lengths of follow-up probably adjusted for but not adequately described	Differences in follow-up ignored	Cross-sectional design or same length of follow-up
17. If appropriate, were data analyzed according to ITT (intention to treat) principle?	All participant data analyzed regardless of adherence to protocol or continuation in trial	Attempt made to analyze data according to ITT principle, but inappropriate method or some participants not included	No attempt made to carry out ITT analysis	Design not appropriate for ITT (e.g. cross-sectional data)
Conclusions				
18. Are the conclusions supported by the results?	All conclusions supported by data	Some of the major conclusions supported by data, some not or speculative interpretations are not indicated as such	None/few of the major conclusions supported by the data	

Note. Adapted from “Systematic review of respite care in the frail elderly,” by C. Shaw, R. McNamara, K. Abrams, R. L. Cannings-John, K. Hood, M. Longo, ... & K. Williams, 2009, *Health Technology Assessment, 13*(20), pp. 107-110.

Appendix B. Shaw et al. (2009) quality assessment checklist for qualitative studies

Criteria	Yes (2/good)	Partial (1/fair)	No (0/poor)
Study aims and context			
1. Is the research question sufficiently described?	Research question clearly identified by the end of the research process, if not at the outset	Research question or objective is vaguely/incompletely reported	Question or objective is not reported or is incomprehensible
2. Is qualitative method appropriate?	Qualitative method is appropriate for the aims and the qualitative framework is identified and justified	Qualitative method appropriate but the methodological framework unclear or not adequately justified	Qualitative methods inappropriate for the aims
3. Is the setting/context clearly described?	*Context/setting is clearly described, permitting the reader to relate the findings to other settings	The context/setting is partially described	The context/setting is not described
Sampling			
4. Is the sampling strategy clearly described?	Sampling strategy and rationale clearly described and justified	Sampling strategy not clearly described or not fully justified	Sampling not described
5. Is sampling method likely to recruit all relevant cases? (purposive, theoretical sampling)	Sample includes the full range of relevant, possible cases (more than simple convenience sample) permitting conceptual (rather than statistical) generalizations	Sampling was purposive but does not include the full range of possible cases	No attempt made to sample purposively or theoretically or sampling strategy not described
6. Are relevant characteristics of the sample given?	Relevant details of the characteristics of the sample given	Incomplete details of sample characteristics given	No details of sample characteristics given
7. Is rationale for sample size (e.g. data saturation) given	Gives rationale for termination of data collection, e.g. data saturation	Reasons for sample size implied or no firm rationale	No reason given for sample size

Criteria	Yes (2/good)	Partial (1/fair)	No (0/poor)
Data collection			
8. Are methods of data collection clearly described?	Data collection methods are systematic and clearly described allowing an audit trail such that procedures could be replicated	Data collection methods not clearly described. Difficult to determine if systematic or replicable	Data collection procedures are not described
9. Is method of data collection appropriate for the research question and paradigm?	Data collection methods are appropriate for the research aims and the methodological and analytical framework	The appropriateness of the data collection methods is unclear	Data collection inappropriate for the aims and methodological framework
10. Has the researcher verified the data (e.g. by triangulation)?	More than one method of data collection carried out or more than one analyst involved or other methods of verification employed (e.g. member checking or line of questioning during interview)	Unclear whether triangulation or other types of verification used	No triangulation or other methods of verification described
Data analysis			
11. Are data analysis methods clearly described?	Systematic analytic method clearly described such that procedures could be replicated	Analytic methods not clearly described	Analytic methods not described
12. Are data analysis methods appropriate?	Analytic methods seem appropriate and are well described	Analytic methods only partially described and/or some concerns about appropriateness	Analytic methods not described and/or appropriate
13. Are competing accounts/deviant data taken into account?	Account given of negative or deviant cases in the analysis	Analysis of deviant or negative cases not clearly described	No account given of negative or deviant cases
Reflexivity			
14. To what extent is the researcher reflective?	The researcher explicitly assessed the likely impact of their own personal characteristics and the methods used on the data obtained	Possible sources of influence on the data obtained were mentioned, but the likely impact of the influence was not discussed	No evidence of reflexivity in the report
Conclusions			
15. Are the interpretations and conclusions supported by the data?	The interpretations are clearly described and supported by the data and are evidenced by sufficient participant quotes	The conclusions are unclear or only partially supported by the data or there are insufficient raw data to support conclusions	Conclusions are not identified or are felt not to be supported by the data or conclusions are absent

Note. Adapted from “Systematic review of respite care in the frail elderly,” by C. Shaw, R. McNamara, K. Abrams, R. L. Cannings-John, K. Hood, M. Longo, ... & K. Williams, 2009, *Health Technology Assessment, 13*(20), pp. 111-113.

Appendix C. The 52-item COPD-related Stigma Scale

Thank you for participating in this study. I am a doctoral student at the University of Michigan School of Nursing. This study is a part of my dissertation research to develop a stigma scale for people with COPD. Stigma can be defined as making someone seem less important or valuable because of his/her illness. Many people with COPD have suffered from stigma because of their history of smoking. Stigma experiences can affect people's mental health, such as anxiety and depression, as well as the quality of life. However, there is no well-established measure to show the extent to which people experience stigma.

This interview will help improve our questionnaire. We have a number of questions to describe how people with COPD feel and how they are treated. This questionnaire has 52 items and each item has five answer choices. Today, we want to talk with you about the questionnaire. You may choose one of five answer choices: "Strongly Disagree (SD)," "Disagree (D)." "Neutral (N)," "Agree (A)," or "Strongly Agree (SA)." Then, I will ask some questions related to a given item. There are no right or wrong answers.

This interview will take about 1-1.5 hours. During the interview, I will make notes and audiotape our conversation to capture your opinions without any omissions. I would like to confirm that you are okay with having this interview recorded. All records from this interview will be confidential and will only be identified by a study number.

Before starting, do you have any questions?

1	People shy away from me when they see I'm wearing oxygen.	SD	D	N	A	SA
2	No one seems embarrassed by my coughing.	SD	D	N	A	SA
3	My family doesn't like me to use my inhaler in public.	SD	D	N	A	SA
4	People who were good friends before I got COPD are still good friends.	SD	D	N	A	SA
5	It's embarrassing not to be able to keep up with others when we're walking.	SD	D	N	A	SA
6	I avoid using my oxygen in public so others won't think I'm ill.	SD	D	N	A	SA
7	It embarrasses me to use the inhaler in front of other people.	SD	D	N	A	SA
8	When I'm with friends, I don't feel embarrassed about having COPD.	SD	D	N	A	SA
9	I'm more likely to be embarrassed by my symptoms when I'm among strangers.	SD	D	N	A	SA
10	Others blame a person with COPD for having smoked.	SD	D	N	A	SA
11	Others think people with COPD are idiots for having smoked.	SD	D	N	A	SA

12	People think of COPD as a dirty disease.	SD	D	N	A	SA
13	I've been told not to come back to the doctor until I quit smoking.	SD	D	N	A	SA
14	Health care providers have been abrupt with me about smoking.	SD	D	N	A	SA
15	I feel flawed because I have COPD.	SD	D	N	A	SA
16	Having COPD has changed my view of what I can do.	SD	D	N	A	SA
17	My COPD puts a burden on my friends and loved ones.	SD	D	N	A	SA
18	I avoid using oxygen in front of other people.	SD	D	N	A	SA
19	I plan my activities carefully so others won't notice I can't do as much as I used to.	SD	D	N	A	SA
20	I blame myself for having COPD.	SD	D	N	A	SA
21	Others are put off by my coughing and sputum.	SD	D	N	A	SA
22	In many areas of my life, no one knows that I have COPD.	SD	D	N	A	SA
23	I feel guilty because I have COPD.	SD	D	N	A	SA
24	People's attitudes about COPD make me feel worse about myself.	SD	D	N	A	SA
25	Telling someone I have COPD is risky.	SD	D	N	A	SA
26	People with COPD lose their jobs when their employers find out.	SD	D	N	A	SA
27	I work hard to keep my COPD a secret.	SD	D	N	A	SA
28	I feel I am not as good a person as others because I have COPD.	SD	D	N	A	SA
29	I never feel ashamed of having COPD.	SD	D	N	A	SA
30	People with COPD are treated like outcasts.	SD	D	N	A	SA
31	Most people believe that a person who has COPD is dirty.	SD	D	N	A	SA
32	It is easier to avoid new friendships than worry about telling someone that I have COPD.	SD	D	N	A	SA
33	Having COPD makes me feel unclean.	SD	D	N	A	SA

34	Since learning I have COPD, I feel set apart and isolated from the rest of the world.	SD	D	N	A	SA
35	Most people think that a person with COPD is disgusting.	SD	D	N	A	SA
36	Most people with COPD are rejected when others find out.	SD	D	N	A	SA
37	I am very careful who I tell that I have COPD.	SD	D	N	A	SA
38	Some people who know I have COPD have grown more distant.	SD	D	N	A	SA
39	If they learn I have COPD, I worry about people discriminating against me.	SD	D	N	A	SA
40	Most people are uncomfortable around someone with COPD.	SD	D	N	A	SA
41	I never feel the need to hide the fact that I have COPD.	SD	D	N	A	SA
42	I worry that people may judge me when they learn I have COPD.	SD	D	N	A	SA
43	Having COPD is disgusting to me.	SD	D	N	A	SA
44	I have been hurt by how people reacted to learning I have COPD.	SD	D	N	A	SA
45	I regret having told some people that I have COPD.	SD	D	N	A	SA
46	People have told me that getting COPD is what I deserve for having smoked cigarettes.	SD	D	N	A	SA
47	Some people act as though it's my fault I have COPD.	SD	D	N	A	SA
48	I have stopped socializing with some people because of their reactions to my having COPD.	SD	D	N	A	SA
49	I have lost friends by telling them I have COPD.	SD	D	N	A	SA
50	I have told people close to me to keep the fact that I have COPD a secret.	SD	D	N	A	SA
51	People who know I have COPD tend to ignore my good points.	SD	D	N	A	SA
52	People seem uneasy around me once they learn I have COPD.	SD	D	N	A	SA

Appendix D. COPD-related Stigma Scale

This study asks about some of the social and emotional aspects of having COPD. For most of the questions, just circle the letters or numbers that go with your answer. There are no right or wrong answers. Feel free to write in comments as you go through the questions.

This first set of questions asks about some of your experiences, feelings, and opinions as to how people with COPD feel and how they are treated. Please do your best to answer each question.

For each item, mark your answer: Strongly Disagree (SD), Disagree (D), Agree (A), or Strongly Agree (SA).

		Strongly Disagree (SD)	Disagree (D)	Agree (A)	Strongly Agree (SA)
1	Do you use a supplemental oxygen for COPD? □ Yes => *Please go to No.2* □ No => *Please go to No.3*				
2	**People shy away from me when they see I'm wearing oxygen.**	SD□	D□	A□	SA□
3	Do you have a cough with COPD? □ Yes => *Please go to No.4* □ No => *Please go to No.5*				
4	**No one seems embarrassed by my coughing.**	SD□	D□	A□	SA□
5	Do you use an inhaler for COPD? □ Yes => *Please go to No.6* □ No => *Please go to No.7*				
6	**My family doesn't like me to use my inhaler in public.**	SD□	D□	A□	SA□
7	**People who were good friends before I got COPD are still good friends.**	SD□	D□	A□	SA□
8	**It's embarrassing not to be able to keep up with others when we're walking.**	SD□	D□	A□	SA□
9	Do you use a supplemental oxygen for COPD? □ Yes => *Please go to No.10* □ No => *Please go to No.11*				
10	**I avoid using my oxygen in public so others won't think I'm ill.**	SD□	D□	A□	SA□
11	Do you use an inhaler for COPD? □ Yes => *Please go to No.12*				

		Strongly Disagree (SD)	Disagree (D)	Agree (A)	Strongly Agree (SA)
	□ No => *Please go to No.13*				
12	**It embarrasses me to use the inhaler in front of other people.**	SD□	D□	A□	SA□
13	**When I'm with friends, I don't feel embarrassed about having COPD.**	SD□	D□	A□	SA□
14	Do you have symptoms with COPD such as a cough, phlegm, or shortness of breath? □ Yes => *Please go to No.15* □ No => *Please go to No.16*				
15	**I'm more likely to be embarrassed by my symptoms when I'm among strangers.**	SD□	D□	A□	SA□
16	**Others blame a person with COPD for having smoked.**	SD□	D□	A□	SA□
17	**Others think people with COPD are idiots for having smoked.**	SD□	D□	A□	SA□
18	**I've been told not to come back to the doctor until I quit smoking.**	SD□	D□	A□	SA□
19	**Some health care providers have been abrupt with me about smoking.**	SD□	D□	A□	SA□
20	**I feel flawed because I have COPD.**	SD□	D□	A□	SA□
21	**Having COPD has changed my view of what I can do.**	SD□	D□	A□	SA□
22	**My COPD puts a burden on my friends and loved ones.**	SD□	D□	A□	SA□
23	Do you use a supplemental oxygen for COPD? □ Yes => *Please go to No.24* □ No => *Please go to No.25*				
24	**I avoid using oxygen in front of other people.**	SD□	D□	A□	SA□
25	**I plan my activities carefully so others won't notice I can't do as much as I used to.**	SD□	D□	A□	SA□
26	**I blame myself for having COPD.**	SD□	D□	A□	SA□
27	Do you have either a cough or phlegm with COPD? □ Yes => *Please go to No.28* □ No => *Please go to No.29*				
28	**Others are put off by my coughing and sputum.**	SD□	D□	A□	SA□

		Strongly Disagree (SD)	Disagree (D)	Agree (A)	Strongly Agree (SA)
29	**In many areas of my life, no one knows that I have COPD.**	SD☐	D☐	A☐	SA☐
30	**I feel guilty because I have COPD.**	SD☐	D☐	A☐	SA☐
31	**People's attitudes about COPD make me feel worse about myself.**	SD☐	D☐	A☐	SA☐
32	**Telling someone I have COPD is risky.**	SD☐	D☐	A☐	SA☐
33	**People with COPD lose their jobs when their employers find out.**	SD☐	D☐	A☐	SA☐
34	**I work hard to keep my COPD a secret.**	SD☐	D☐	A☐	SA☐
35	**I feel I am not as good a person as others because I have COPD.**	SD☐	D☐	A☐	SA☐
36	**I never feel ashamed of having COPD.**	SD☐	D☐	A☐	SA☐
37	**People with COPD are treated like outcasts.**	SD☐	D☐	A☐	SA☐
38	**Most people believe that a person who has COPD is unclean.**	SD☐	D☐	A☐	SA☐
39	**It is easier to avoid new friendships than worry about telling someone that I have COPD.**	SD☐	D☐	A☐	SA☐
40	**Having COPD makes me feel unclean.**	SD☐	D☐	A☐	SA☐
41	**Since learning I have COPD, I feel singled out and isolated from the rest of the world.**	SD☐	D☐	A☐	SA☐
42	**Most people think that a person with COPD is disgusting.**	SD☐	D☐	A☐	SA☐
43	**Most people with COPD are rejected when others find out.**	SD☐	D☐	A☐	SA☐
44	**I am very careful who I tell that I have COPD.**	SD☐	D☐	A☐	SA☐
45	**Some people who know I have COPD have grown more distant.**	SD☐	D☐	A☐	SA☐
46	**If they learn I have COPD, I worry about people discriminating against me.**	SD☐	D☐	A☐	SA☐
47	**Most people are uncomfortable around someone with COPD.**	SD☐	D☐	A☐	SA☐

		Strongly Disagree (SD)	Disagree (D)	Agree (A)	Strongly Agree (SA)
48	**I never feel the need to hide the fact that I have COPD.**	SD☐	D☐	A☐	SA☐
49	**I worry that people may judge me when they learn I have COPD.**	SD☐	D☐	A☐	SA☐
50	**Having COPD is disgusting to me.**	SD☐	D☐	A☐	SA☐
51	**I have been hurt by how people reacted to learning I have COPD.**	SD☐	D☐	A☐	SA☐
52	**I regret having told some people that I have COPD.**	SD☐	D☐	A☐	SA☐
53	**People have told me that getting COPD is what I deserve for having smoked cigarettes.**	SD☐	D☐	A☐	SA☐
54	**Some people act as though it's my fault I have COPD.**	SD☐	D☐	A☐	SA☐
55	**I have stopped socializing with some people because of their reactions to my having COPD.**	SD☐	D☐	A☐	SA☐
56	**I have lost friends by telling them I have COPD.**	SD☐	D☐	A☐	SA☐
57	**I have told people close to me to keep the fact that I have COPD a secret.**	SD☐	D☐	A☐	SA☐
58	**People who know I have COPD tend to ignore my good points.**	SD☐	D☐	A☐	SA☐
59	**People seem uneasy around me once they learn I have COPD.**	SD☐	D☐	A☐	SA☐

Appendix E. Stigma Scale for Chronic Illness 8 items (SSCI-8)

Please respond to each question or statement by marking one box per row.

	Lately…	Never	Rarely	Sometimes	Often	Always
1.	Because of my illness, some people avoided me.	1☐	2☐	3☐	4☐	5☐
2.	Because of my illness, I felt left out of things.	1☐	2☐	3☐	4☐	5☐
3.	Because of my illness, people avoided looking at me.	1☐	2☐	3☐	4☐	5☐
4.	I felt embarrassed about my illness.	1☐	2☐	3☐	4☐	5☐
5.	Because of my illness, some people seemed uncomfortable with me.	1☐	2☐	3☐	4☐	5☐
6.	I felt embarrassed because of my physical limitations.	1☐	2☐	3☐	4☐	5☐
7.	Because of my illness, people were unkind to me.	1☐	2☐	3☐	4☐	5☐
8.	Some people acted as though it was my fault I have this illness.	1☐	2☐	3☐	4☐	5☐

Appendix F. Charlson Comorbidity Index (CCI)

Please respond to each item by marking one box per row.

	No	Yes
1. Have you had a myocardial infarction (MI)?	0☐	1☐
2. Have you been hospitalized or treated for heart failure (CHF)?	0☐	1☐
3. Do you have peripheral vascular disease (PVD)?	0☐	1☐
4. Have you had a cerebrovascular disease (CVA) or transient ischemic disease?	0☐	1☐
5. Do you have hemiplegia?	0☐	1☐
6. Do you have asthma, chronic lung disease, chronic bronchitis or emphysema (COPD)?	0☐	1☐
7. Do you have diabetes that requires treatment?	0☐	1☐
8. Do you have end organ damage from diabetes? *(For example, retinopathy, neuropathy, or nephropathy attributable to diabetes.)*	0☐	1☐
9. Do you have moderate or severe renal disease?	0☐	1☐
10. Do you have a chronic liver disease? (*For example, chronic hepatitis B or C*)	0☐	1☐
11. Do you have moderate to severe liver disease?	0☐	1☐
12. Have you had gastric or peptic ulcers?	0☐	1☐
13. Have you had cancer (other than basal cell skin cancer)?	0☐	1☐
14. If you have cancer, have you had a lymphoma? (*For example, Hodgkin's, lymphosarcoma, or myeloma*)	0☐	1☐

	No	Yes
15. If you have cancer, have you had a leukemia?	0☐	1☐
16. If you have cancer, have you had a solid tumor (without metastases)?	0☐	1☐
If yes, which solid tumor have you had? (please specify) _____		
17. Have you had a metastatic solid tumor?	0☐	1☐
If yes, which metastatic solid tumor have you had? ☐ Breast ☐ Colon ☐ Prostate ☐ Lung ☐ Melanoma ☐ Other: (please specify) _____		
18. Do you have Alzheimer's dementia from any etiology or any serious cognitive impairment?	0☐	1☐
19. Do you have any rheumatic or connective tissue disease?	0☐	1☐
20. Do you have HIV or AIDS?	0☐	1☐

Appendix G. Hospital Anxiety and Depression Scale (HADS)

Tick the box beside the reply that is closest to how you have been feeling in the past week.
Don't take too long over your replies: your immediate is best.

1. I feel tense or 'wound up':

3☐ Most of the time
2☐ A lot of the time
1☐ From time to time, occasionally
0☐ Not at all

2. I still enjoy the things I used to enjoy:

0☐ Definitely as much
1☐ Not quite so much
2☐ Only a little
3☐ Hardly at all

3. I get a sort of frightened feeling as if something awful is about to happen:

3☐ Very definitely and quite badly
2☐ Yes, but not too badly
1☐ A little, but it doesn't worry me
0☐ Not at all

4. I can laugh and see the funny side of things:

0☐ As much as I always could
1☐ Not quite so much now
2☐ Definitely not so much now
3☐ Not at all

5. Worrying thoughts go through my mind:

3☐ A great deal of the time
2☐ A lot of the time
1☐ From time to time, but not too often
0☐ Only occasionally

6. I feel cheerful:

3☐ Not at all
2☐ Not often
1☐ Sometimes
0☐ Most of the time

7. I can sit at ease and feel relaxed:

0☐ Definitely
1☐ Usually
2☐ Not often
3☐ Not at all

8. I feel as if I am slowed down:

3☐ Nearly all the time
2☐ Very often
1☐ Sometimes
0☐ Not at all

9. I get a sort of frightened feeling like 'butterflies' in the stomach:

0☐ Not at all
1☐ Occasionally
2☐ Quite often
3☐ Very often

10. I have lost interest in my appearance:

3☐ Definitely
2☐ I don't take as much care as I should
1☐ I may not take quite as much care
0☐ I take just as much care as ever

11. I feel restless as I have to be on the move:

3 Very much indeed
2 Quite a lot
1 Not very much
0 Not at all

12. I look forward with enjoyment to things:

0 As much as I ever did
1 Rather less than I used to
2 Definitely less than I used to
3 Hardly at all

13. I get sudden feelings of panic:

3 Very often indeed
2 Quite often
1 Not very often
0 Not at all

14. I can enjoy a good book or radio or TV program:

0 Often
1 Sometimes
2 Not often
3 Very seldom

Please check you have answered all the questions.

Appendix H. PROMIS Physical Function (Short Form-10a)

Please respond to each item by marking one box per row.

		Not at all	Very little	Somewhat	Quite a lot	Cannot do
1.	Does your health now limit you in doing vigorous activities, such as running, lifting heavy objects, participating in strenuous sports?	5☐	4☐	3☐	2☐	1☐
2.	Does your health now limit you in walking more than a mile?	5☐	4☐	3☐	2☐	1☐
3.	Does your health now limit you in climbing one flight of stairs?	5☐	4☐	3☐	2☐	1☐
4.	Does your health now limit you in lifting or carrying groceries?	5☐	4☐	3☐	2☐	1☐
5.	Does your health now limit you in bending, kneeling, or stooping?	5☐	4☐	3☐	2☐	1☐

		Without any difficulty	With a little difficulty	With some difficulty	With much difficulty	Unable to do
6.	Are you able to do chores such as vacuuming or yard work?	5☐	4☐	3☐	2☐	1☐
7.	Are you able to dress yourself, including tying shoelaces and doing buttons?	5☐	4☐	3☐	2☐	1☐
8.	Are you able to shampoo your hair?	5☐	4☐	3☐	2☐	1☐
9.	Are you able to wash and dry your body?	5☐	4☐	3☐	2☐	1☐

10. Are you able to get on and off the toilet?	5☐	4☐	3☐	2☐	1☐

Appendix I. Descriptive Statistics of the 51-item COPD-related Stigma Scale

	N	Mean	SD	Minimum	Maximum	% at Floor	% at Ceiling
10. Others blame a person with COPD for having smoked. *d*	145	3.09	0.87	1	4	6.8	35.1
15. Having COPD has changed my view of what I can do. *c*	148	2.96	0.88	1	4	8.1	28.4
11. Others think people with COPD are idiots for having smoked. *d*	147	2.93	0.92	1	4	8.1	30.4
19. I blame myself for having COPD.	145	2.93	0.77	1	4	4.7	20.9
5. It's embarrassing not to be able to keep up with others when we're walking. *c*	148	2.85	0.94	1	4	12.2	25.0
2. No one seems embarrassed by my coughing.	112	2.64	0.78	1	4	4.7	9.5
21. In many areas of my life, no one knows that I have COPD.	145	2.63	0.79	1	4	9.5	9.5
13. Some health care providers have been abrupt with me about smoking. *d*	148	2.56	0.94	1	4	16.9	14.9
20. Others are put off by my coughing and sputum.	130	2.56	0.82	1	4	8.8	9.5
46. Some people act as though it's my fault I have COPD. *b*	147	2.56	0.9	1	4	14.2	13.5
28. I never feel ashamed of having COPD	146	2.45	0.86	1	4	13.5	10.8
9. I'm more likely to be embarrassed by my symptoms when I'm among strangers.	142	2.44	0.93	1	4	16.9	12.2
22. I feel guilty because I have COPD. *b*	146	2.43	0.87	1	4	13.5	11.5
14. I feel flawed because I have COPD. *c*	148	2.42	0.99	1	4	20.9	15.5
45. People have told me that getting COPD is what I deserve for having smoked cigarettes. *d*	146	2.38	0.96	1	4	20.3	12.8
18. I plan my activities carefully so others won't notice I can't do as much as I used to. *c*	145	2.3	0.85	1	4	18.9	6.1
6. I avoid using my oxygen in public so others won't think I'm ill.	30	2.27	0.98	1	4	4.7	2.7
16. My COPD puts a burden on my friends and loved ones. *c*	142	2.27	0.92	1	4	22.3	8.1
23. People's attitudes about COPD make me feel worse about myself. *b*	146	2.26	0.92	1	4	20.3	11.5
17. I avoid using oxygen in front of other people.	36	2.22	0.9	1	4	4.7	2.7
40. I never feel the need to hide the fact that I have COPD. *b*	147	2.2	0.82	1	4	18.2	7.4
42. Having COPD is disgusting to me. *b*	147	2.2	0.79	1	4	16.9	6.1
8. When I'm with friends, I don't feel embarrassed about having COPD.	147	2.18	0.92	1	4	25.7	8.8
1. People shy away from me when they see I'm wearing oxygen.	25	2.16	0.75	1	4	2.7	0.7
41. I worry that people may judge me when they learn I have COPD. *b*	146	2.12	0.76	1	4	19.6	3.4
27. I feel I am not as good a person as others because I have COPD. *b*	147	2.11	0.89	1	4	27.0	7.4

	N	Mean	SD	Minimum	Maximum	% at Floor	% at Ceiling
29. People with COPD are treated like outcasts. *a*	144	2.1	0.72	1	4	17.6	3.4
24. Telling someone I have COPD is risky.	146	2.08	0.75	1	4	20.3	3.4
36. I am very careful who I tell that I have COPD.	145	2.08	0.79	1	4	23.0	4.1
25. People with COPD lose their jobs when their employers find out.	133	2.04	0.68	1	4	16.2	2.7
44. I regret having told some people that I have COPD. *b*	146	2.01	0.75	1	4	23.6	3.4
39. Most people are uncomfortable around someone with COPD. *a*	143	1.99	0.74	1	4	23.6	2.7
38. If they learn I have COPD, I worry about people discriminating against me. *a*	145	1.98	0.78	1	4	27.7	2.7
26. I work hard to keep my COPD a secret. *b*	146	1.97	0.78	1	4	26.4	5.4
43. I have been hurt by how people reacted to learning I have COPD. *a*	146	1.96	0.77	1	4	26.4	4.7
47. I have stopped socializing with some people because of their reactions to my having COPD. *a*	145	1.93	0.76	1	4	27.7	4.1
7. It embarrasses me to use the inhaler in front of other people.	120	1.91	0.88	1	4	31.8	3.4
37. Some people who know I have COPD have grown more distant.	145	1.9	0.73	1	4	29.1	2.0
31. It is easier to avoid new friendships than worry about telling someone that I have COPD. *a*	145	1.89	0.72	1	4	29.1	2.0
30. Most people believe that a person who has COPD is unclean. *a*	144	1.88	0.66	1	4	25.0	2.7
51. People seem uneasy around me once they learn I have COPD.	147	1.86	0.67	1	4	29.1	1.4
33. Since learning I have COPD, I feel singled out and isolated from the rest of the world.	147	1.84	0.76	1	4	34.5	3.4
34. Most people think that a person with COPD is disgusting. *a*	146	1.81	0.69	1	4	32.4	2.0
35. Most people with COPD are rejected when others find out. *a*	146	1.79	0.63	1	4	30.4	1.4
50. People who know I have COPD tend to ignore my good points. *a*	147	1.78	0.66	1	4	32.4	2.0
48. I have lost friends by telling them I have COPD.	145	1.75	0.64	1	4	33.8	1.4
49. I have told people close to me to keep the fact that I have COPD a secret.	147	1.74	0.62	1	4	33.8	1.4
32. Having COPD makes me feel unclean.	146	1.65	0.64	1	4	42.6	0.7
4. People who were good friends before I got COPD are still good friends.	148	1.63	0.83	1	4	54.1	5.4
12. I've been told not to come back to the doctor until I quit smoking.	146	1.55	0.75	1	4	56.8	3.4
3. My family doesn't like me to use my inhaler in public.	118	1.5	0.74	1	4	48.6	2.7

Note. SD = Standard Deviation; a = Social Stigma subscale; b = Self-blame subscale; c = Physical Limitation subscale; d = Self-inflicted disease subscale