



ORIGINAL ARTICLE

Mirror of shame: Patients experiences of late-stage COPD. A qualitative study

Heidi Jerpseth RN, PhD, Associate Professor¹  | Ingrid R. Knutsen RN, PhD, Professor¹ |
Kari T. Jensen RN, PhD, Associate Professor² | Kristin Halvorsen RN, PhD, Professor¹ 

¹Faculty of Health Science, Institute of Nursing and Health Promotion, Oslo Metropolitan University, Oslo, Norway

²Institute of Nursing and Health Promotion, Faculty of Health Science, Oslo Metropolitan University, Oslo, Norway

Correspondence

Heidi Jerpseth, Faculty of Health Science, Institute of Nursing and Health Promotion, Oslo Metropolitan University, Pb 4, St Olavs Plass, 0130 Oslo, Norway.
Email: heidi.jerpseth@oslomet.no

Aims and objectives: This study aims to shed light on patients with late-stage COPD and their experiences of shame.

Background: Patients with COPD often experience shame for bringing the disease into their lives due to smoking. Knowledge about patients with COPD and their feelings of shame is crucial, but limited, however.

Design: The study has a qualitative and explorative design. We interviewed twelve patients with late-stage COPD. The data were analysed using Kvale and Brinkmann's three interpretative contexts. The COREQ checklist was used.

Results: Three main themes were defined; the body as a mirror of shame; a sense of being unworthy, invisible and powerless; and that sharing the burden is too difficult. The participants experienced that the disease defined their value as human beings and that made them feel vulnerable, ashamed and more socially isolated.

Conclusions: The participants experienced feelings of shame, guilt and self-blame due to their own perceptions of themselves. They were in doubt about whether they were worthy to receive care and comfort from both health professionals and, their family and friends. The participants seemed to have internalised the moral norms of contemporary society and the understanding that the disease, and especially a 'self-inflicted' disease, is a personal weakness.

Relevance for clinical practice: Findings from this study show that patients struggle with feelings such as shame and misery. The nurses who work bedside are in continuous contact with the patients and have an opportunity to gain knowledge of these feelings in order to meet the patients' needs for comfort and care. They have an obligation to ask patients about their feelings and meet them with empathy and respect. Moreover, it is necessary to have interdisciplinary fora in clinical practice where health professionals reflect, discuss and challenge themselves according to attitudes towards patients with so-called 'self-inflicted' diseases.

KEYWORDS

care, chronic obstructive pulmonary disease, nursing, shame, stigma

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2021 The Authors. *Journal of Clinical Nursing* published by John Wiley & Sons Ltd.

What does this paper contribute to the wider global clinical community?

- Knowledge of how patients with late-stage COPD experience a feeling of stigma and shame
- Insight in how patients with late-stage COPD experience the feeling of being unworthy of receiving care from healthcare personnel, family and friends.
- Highlights nurses' role in meeting patients with late-stage COPD with empathy, to ensure care which correlate with patients' needs and interests.

1 | INTRODUCTION

Chronic Obstructive Pulmonary Disease (COPD) is a growing and large health problem worldwide and it is estimated that the disease is present in about 11.8% of men and 8.5% of women across the world. The cardinal symptoms of COPD are dyspnoea, chronic cough and/or sputum production. The disease develops progressively and gradually increases in severity (Global Initiative for Chronic Obstructive Lung Disease, 2020). Many patients with COPD experience several physical and psychological symptoms that leads to a reduction in quality of life. The most common symptoms are breathing problems, exhaustion and pain, compounded by comorbidity and psychological distress (Ahmadi et al., 2016; Disler et al., 2014; Kendall et al., 2018).

The risk factors for contracting COPD are tobacco smoking, smoke from home cooking, heating fuels, occupational dusts, chemicals and a familial history of COPD. Although tobacco smoking is the best-studied COPD risk factor, there also seems to be a complicated gene-environment interaction (Global Initiative for Chronic Obstructive Lung Disease, 2020). The link between socioeconomic status and COPD through smoking habits is important. However, research has shown that socioeconomic factors also have a strong independent effect on the prevalence and severity of COPD (Danielsson et al., 2012; Halvorsen & Martinussen, 2014).

The general public seems to know little about COPD, despite campaigns to increase COPD awareness (de Queiroz et al., 2015; Miravittles et al., 2006). However, it is difficult to know whether it is the public health campaigns that stigmatise the smoking behaviour, or the smokers themselves. Studies show that patients with COPD frequently perceive a health-related stigma because of the link to smoking (Bragadottir et al., 2018; Halding et al., 2011; Rose et al., 2017; Svedsater et al., 2017).

Given that tobacco smoking is the main modifiable risk factor for COPD, the perceived controllability of an individual's smoking behaviour may influence social reactions to onset of the disease. A common view in the population is that smoking is a personal choice rather than an addiction. Many people with COPD therefore hold themselves responsible for the disease (Plaufcan et al., 2012; Rose et al., 2017). This understanding is often followed by an underlying moral obligation on the person him- or herself to change his/her lifestyle habit to improve his/her situation.

Experiences of shame for having what we understand as a 'self-inflicted' disease may delay the information-seeking process, reduce active engagement in interventions and contribute to poor self-management (Gysels & Higginson, 2010). In addition, studies show

that it is important for healthcare professionals to understand the patients' experiences of shame, because shame and depression often delayed the patients contacting the healthcare system and reduced adherence to oxygen therapy (Arne et al., 2007; Harrison et al., 2015).

In this study, our aim is to shed light on patients with late-stage COPD and explore their experiences of shame due to their perception of being ill.

2 | THEORETICAL BACKGROUND

The study takes a theoretical approach to stigma and shame. Goffman's understanding of the concept of stigma will form the starting point for understanding the themes. Goffman describes stigma as an attribute that is deeply discrediting (Goffman, 1986). Stigma is constructed in society, imposing attitudes on individuals. Stigma's moral nature as a mark of shame is linked to a belief in the weakness of the stigmatised individual's character. Stigmatisation threatens an individual's social identity, and embarrassment impacts on a person's self-identity and self-evaluation (Goffman, 1986). In this way, an individual can be overwhelmed by stigmatisation, which might become a master status in their life and a persistent source of shame.

As regards health and health challenges, stigma is connected to many chronic health problems, which are understood to be 'lifestyle related' or 'self-inflicted' in contemporary societies (Weiss et al., 2006). Such understandings hold the individual responsible, which contributes to a hidden burden of illness. Social understandings differ between different societies and change over time. A condition that is related to stigma in one society, time or context may not be so in another (Goffman, 1986). When it comes to attitudes to smoking habits, during the last fifty years smoking has changed from being associated with elegance and being cultivated to being a habit associated with low education and lower socioeconomic status (Rose et al., 2017). Shame is linked to a person's being or identity and can be triggered by experiences of not being worthy. Another way to describe shame is that shame arises from the tension between how I want to be seen and how I experience being seen, implying an assumed powerlessness to reach the requirements of one's ideal self (Miceli & Castelfranchi, 2018).

Shame can be induced by failing and feeling guilty about failure (the smoking habit) and it is a prototypical response to devaluation of the social self, which leads to hiding and nondisclosure because of overwhelming feelings of low self-worth (Dirkse et al., 2014). Few studies have focussed on shame in patients with COPD according to our knowledge. What has been shown in these few studies is that

the feeling of shame among patients with COPD influences their contact with healthcare professionals in a negative way (Arne et al., 2007; Halding et al., 2011; Lindgren et al., 2014; Odencrants et al., 2007). The patients' experiences of shame may be reinforced by the interactions with healthcare professionals, who might blame patients with COPD, resulting in patients feeling stigmatised (Jerpseth et al., 2016; Winstanley, 2008). Talking about COPD can therefore make people think about the patient's smoking habit, not just the state of his or her lung function. Identifying, assessing and understanding these patients' experiences of shame is necessary in order to support and care for these patients, who might sometimes hide their needs because of social stigma.

3 | AIM

This study aims to draw attention to the circumstances of older patients with late-stage COPD and explore their experiences of shame and feelings of stigma due to their illness.

4 | METHODS

In line with the aim, we have applied a study with a qualitative and explorative design with a phenomenological and hermeneutical approach. Phenomenology is both a theoretical and methodological approach. As a method it contributes in developing detailed and nuanced descriptions about the lived experience with illness. Moreover, phenomenology gives insight into relations and other phenomena that contributes to a better and deeper understanding of the patients' situation and needs, based on an embodied experience (Finlay, 2011). In our study, this reflects the patient with late-stage COPD's embodied experiences of shame related to the illness. Hermeneutic addresses the interpretation of meaning (Brinkmann & Kvale, 2015). The objective was to gain a deeper understanding of the phenomena shame and stigma experienced by people living with COPD. To ensure reflexivity during the research process, a consolidated criteria for reporting qualitative research (COREQ) 32-item checklist were used (File S1) (Tong et al., 2007).

4.1 | Recruitment and participants

Nurses who worked in outpatient clinics at one university hospital and two district hospitals recruited the patients and made the initial

contact. The nurses who knew the patients asked those who met the inclusion criteria (see Table 1). Twelve older patients diagnosed with late-stage COPD were recruited. The nurses gave the patients written and oral information about what taking part in the interviews entailed. One week after the initial contact was made, the first author, who is an experienced researcher, RN and PhD, contacted patients who had agreed to participate in the study and gave them further information. All the contacted patients (five from district hospitals and seven from university hospital) were willing to take part in the study; however, we were not informed of the number of patients asked by the nurses at the first time. Voluntary informed consent was obtained prior to the interviews.

4.2 | Ethics

The Regional Committee for Medical Research Ethics (REK, ref.2012/618) granted permission to conduct the interviews. At the time the interviews were conducted, the participants were characterised by late-stage illness, which made them particularly vulnerable. However, they did not have any difficulty giving free and informed consent or making personal decisions. We regarded the potential harm in this study to be minimal. Before and during the interviews, the participants were informed about their right to decide what they wanted to share in the interviews. The first author made an appointment with the nurses who knew the patients, to ensure that the patients could contact them if they felt a need for a follow-up conversation due to worries about the sensitive themes and their health situation. The patients were informed of the opportunity to contact the nurses.

All personal information was stored confidentially and processed in accordance with the General Data Protection Regulation (GDPR), and the analyses were carried out using de-identified transcripts.

4.3 | Interviews

Ten interviews were conducted in the participant's home ($n = 10$), and two of the interviews were conducted in a nursing home ($n = 2$). The first author carried out the interviews. All participants were interviewed once.

The interviews were conducted using a semi-structured interview guide with open-ended questions. The first and last authors developed the interview guide (Table 2). The first author followed up participants' statements with questions in order to go deeper

TABLE 1 Overview of inclusion criteria

Inclusion criteria	Exclusion criteria
Older patients (≥ 63 years old) diagnosed with late-stage COPD (GOLD III-IV)	
Not hospitalised when the interviews take place	
Able to write and speak Norwegian	Cognitive impairment

into the patients' experiences. The questions were asked openly and encouraging the participants to share their stories, and the answers therefore varied widely.

The meaning and structure of the conversations were jointly created by the participant and the researcher in line with Brinkmann & Kvale (2015) understanding of qualitative interviews. When no additional information was uncovered during the interviews, the researchers agreed that enough information power had been achieved (Braun & Clarke, 2019). The interviews had an average duration of 65 minutes.

4.4 | Analysis

The data were analysed manually. The analysis is a cyclical process as well as a reflexive activity, starting with the collection of data, the writing of summaries after the interviews and listening to and transcribing the interviews. The goal was to identify the participants' experiences of living with COPD and their thoughts about the stigma and shame associated with having a 'self-inflicted' disease.

The interviews were transcribed verbatim and unidentified. The participants were not offered an opportunity to read the transcripts and were not able to respond to the findings. This was decided due to the participants' fragile health condition. The data analysis was inspired by Brinkmann & Kvale (2015) three interpretative contexts: self-understanding, critical understanding or common sense level, and theoretical level. The coding was data-driven, whereby the text

was organised and reorganised based on codes developed from the data in an inductive process (Brinkmann & Kvale, 2015). Taking the self-understanding context as an example, we marked all the statements about the participants' experiences of visible bodily changes because of the disease. In the commonsense context, we went beyond the participants' statements and included a wider framework of understanding. In the coding process, we created an overview of codes. We analysed the content of the statements by including general knowledge of the phenomena of shame and stigma. In the third context, a theoretical framework for interpreting the meaning of the statement was applied (Brinkmann & Kvale, 2015). In this study, we applied Goffman's theoretical approaches in order to understand the participants' experiences of a disease that has been historically and socially stigmatised.

The analyses were conducted in cooperation between all the authors.

5 | FINDINGS

The findings described the participants' embodied experiences of the disease as characteristic of themselves as human beings. They experienced that their physical impairments made them feel vulnerable, ashamed and that, as a result, they became more socially isolated. They blamed themselves for bringing COPD into their lives because of their former smoking habits.

They felt like second-class people and most of them perceived feelings such as shame and stigma. The three main themes that reflect the patients' experiences were identified: the body as a mirror of shame, a sense of being unworthy, invisible and powerless, and sharing the burden is too difficult.

Demographic and medical characteristics are presented in Table 3. Half of the participants were married, the rest were either divorced, widowers/widows or lived alone.

5.1 | The body as a mirror of shame

The participants experienced their own bodies as disgusting, a tragedy, deceitful and shameful. Their worries were linked to their loss of a body that they once could trust in and gave them an identity

TABLE 2 Interview guide

1. How does COPD affect your daily life?
2. How does your physical condition affect your social interaction? Follow up questions related to: Pain, anxiety, breathlessness, use of oxygen
1. How do you feel about being a part of the social community due to your disease?
2. What are your thoughts regarding your own disease?
3. If this is ok for you, can you tell me if you know the reason why you got COPD?
4. How do you experience that other people react when you tell them that you have COPD?
5. Have you given any thoughts to what you like to ask or discuss with the nurses or physicians regarding your disease?

TABLE 3 Demographic and medical characteristics of the participants.

Characteristics	1	2	3	4	5	6	7	8	9	10	11	12
Age	63	87	71	65	64	67	68	70	74	82	64	67
Gender	F	F	M	F	F	M	M	M	M	F	F	F
Disease years	7	5	15	10	8	5	10	10	14	20	15	15
Used to smoke/still smoke	x	x	s	x	x	x	x	x	x	x	x	x
Supplemental oxygen	x	x		x	x	x		X		x		x

Abbreviations: F, female; M, male; s, still smoke; x, used to smoke.

of being strong and healthy. Their self-image had become completely different from what it used to be, as one of the participants elucidated:

Once I used to be healthy and strong. People were always contacting me in the communal back garden if they wanted somebody to help them with practical things. Now, I am nothing, my body is weak, and I find it disgusting (M 71).

The most eye-catching symptom of the disease was experienced as the everlasting coughing and the use of supplemental oxygen. This functional impairment was impossible to hide, and the participants considered this as a sign of their disability and that made them feel ashamed. However, the expression of the disease was impossible to hide, and for the participants, this made them feel stigmatised, not only because of their smoking habits, but because of the disease itself. One of the participants experienced that she represented disease and death and, people do not like to be reminded of such matters.

I think it is embarrassing to be ill. In a way, I believe that my body is disgusting. Everyone is in a way perfect, except me, because I am ill. People see that there is something wrong with me. The coughing and shortness of breath and the oxygen equipment make me feel like an outsider. People who are well and healthy do not want to be with someone like me who is ugly and halfway to death (F65).

The participants were exposed to stigmatising attitudes in social contexts. They experienced being visible in public places, but in the 'wrong way'. Their visibility was linked to the clear signs that their bodies were ill, which put them in a situation where they wanted to be invisible instead. This urge to hide from others led to social distancing and isolation. They talked about feelings of not being accepted as ill, and as someone who did not deserve sympathy.

Once, I took the oxygen equipment with me and tried to find a chair to rest on. Then a man came across to me and said: 'You get what you deserve because of your smoking habit.' I felt like I was shrinking and felt so humiliated. I wondered if I could make myself invisible (F64).

They experienced that not thinking about the disease or tell people that they suffered from COPD was considered as the best strategy to keep distance to the overwhelming feelings of shame. Instead, they told themselves and other people that they suffered from asthma or had some trouble with their legs, since it was impossible for them to walk as far as they used to do. Even though the participants tried to keep the disease a secret, their bodies failed them and revealed that they were seriously ill.

I believe I have had COPD for quite a while, but I felt ashamed and told my family and myself that I had asthma. I did not want to see the doctor, because I did not want him to say what I already knew: You have COPD (F 65).

This response to the disease led to nondisclosure and displacement. Even though most of them had been heavy smokers, some of the participants perceived that it was another reason for why they became ill.

The doctor told me that I got COPD because of my smoking habit. However, I think that the reason why I got COPD must be more complex than just smoking. Maybe it is just bad luck. If I tell the doctor that, he will tell me that I am wrong (M67).

5.2 | A sense of being unworthy, invisible and powerless

The participants evaluated the disease as a weakness in themselves as human beings. They took it for granted that the disease was proof that they had done something wrong (like smoking), and that they thereby got what they deserved. In this scenario, they felt as if they had no right to complain and or make any requirements or demands.

I used to smoke about forty cigarettes a day. No wonder I became ill. I hate myself for not quitting the day I was diagnosed with asthma. Now I am reduced to zero, and I am the one to blame. When you are old and ill and have COPD, you do not count anymore (M 70).

They perceived a feeling of not being worthy and not deserving help and care from either family and friends or health professionals. A sense of being unimportant and invisible to other people because of the disease that affected all aspects of their lives was common among the participants.

My life does not matter, because I am a little dot. Others who are healthy do not care that I am ill. The world becomes so small when you are ill, and friends and family do not think you are good enough anymore (F64).

They experienced strong feelings of powerlessness. This sense of powerlessness was perceived as a feeling of grief and loneliness, and lack of confidence that their needs would be met. They lived in constant fear of getting worse and not being able to handle their bodily limitations.

I do nothing on my own anymore. I am one hundred percent dependent on other people. I feel this is embarrassing and that I am a burden on my husband and on society (F64).

5.3 | Sharing the burden is too difficult

Repeated episodes of exacerbation made the participants feel concerned about their bodily signals and gave them a feeling of loss of control and solitude. Some of them experienced that they had no one to talk to, or to share their burden with. The participants wanted to share their burden, but that they experienced uncertainty if someone wanted to comfort them. The expectation of not being welcomed or comforted by friends, family or healthcare professionals when they showed their vulnerability led to avoidance of sharing their worries and anxiety. However, being rejected by family, friends and healthcare professionals made them believe that they might deserve such rejection because of the nature of their disease.

They felt underprivileged when it came to resources from the healthcare system, and one of the participants characterised this feeling as like being 'second-class people'. However, he said that he did not deserve any better.

The nurses and the doctors are too busy, and they do not seem to have time to talk to me about my worries. In a way, I think the doctors and nurses are tired of me because I have been hospitalised so many times. However, I think that I am not worthy of their time even though I want to know about my disease (M 74).

The participants experienced that their smoking habit had served as a comfort. In the 1950s when they were young, smoking was a way of being regarded as an adult. Commonly, the participants perceived that they were not accepted because of how they had lived. They experienced feelings of loneliness and stigmatisation because of choices they had made when they were young and in a difficult situation.

I had a very difficult upbringing. I grew up in poor economic and social conditions, so my goal was to grow up fast. Being an adult at that time meant that you had to smoke (F65).

Others used cigarettes in order to cope with a difficult everyday life. Cigarettes also provided a break and a kind of emotional distance from a demanding job or an exhausting everyday life.

I became a widow when the children were in their teens. I had to work two jobs to manage the expenses. The cigarettes gave me a break, they gave me time for myself (F82).

Even though the participants experienced that their lives had become difficult, they still wanted to live and sometimes they perceived that life was good. The participants still had hope for the future, not only related to the disease but also what they defined as good experiences in their lives. What they found hard to accept was that other people did not find them worthy.

I still want to live. Sometimes I find the way I live good enough. I still have my cats and I have my husband. My hope for the future is to see the island where I grew up once again. I know that I have a limited time left to live, but I hope that a medicine will make my life better (F67).

6 | DISCUSSION

The study's findings show that the participants have a burdensome life with late-stage COPD. The burden of the disease was further reinforced by their experiences of shame due to the disease itself and as a result of bodily deterioration. The participants characterised themselves as 'a little dot, a burden, reduced to zero', which underlines their views of themselves as not being worthy. These feelings might be reinforced by experiences of self-criticism among the participants used as a form of problem-solving strategy, whereby the emotions may be regulated if they tell themselves that the feeling of shame is justified. Shame is an experience of being unworthy, and the vicious circle of shame is related to the fact that it is shameful to show one's own shame to other people (Miceli & Castelfranchi, 2018). Feeling stigmatised can affect individuals deeply and reinforce their contribution to their social isolation and depression (Earnest, 2002). Individuals may self-blame on account of their behaviour, which can fuel feelings of shame about their condition (Rose et al., 2017). The findings show that the participants often experienced self-blame, low self-control and social isolation, which reinforces their experience of being stigmatised.

The participants experienced that visible signs such as coughing, and sputum production were difficult to handle. They told about their bodies, which used to be trustworthy and strong, which the disease had turned into a stranger. This strangeness was experienced as a threat to hope for the future. In line with other studies, we will argue that the findings show that stigma may be associated with the disease COPD and the ensuing bodily disabilities (Halding et al., 2011; Kendall et al., 2018; Lundell et al., 2020).

The patients' experiences of self are shaped by feelings such as shame, guilt and self-blame that could not exist without others' perceptions and evaluations of them (Harrison et al., 2016). This corresponds to Goffman's characterisation of stigma, which is experienced as the difference between a person's expected social identity or 'virtual social identity' and his or her actual identity (Goffman, 1986). We will argue that the visible signs of the participants' disease could be the reason why some people with COPD see themselves

as being less worthy and therefore stigmatised. The participants told about social isolation because of their experiences of not being like other people, who were healthy and strong as they once were. Goffman described this behaviour as 'cover'. The term describes the mechanisms a person with a stigma can use to hide or cover up the disadvantageous feature. The use of such strategies enables people who feel stigmatised to cope with various challenges when interacting with others who do not know about their stigma (Goffman, 1986).

The findings showed that the participants held themselves personally responsible for their health and disease, and some of them agreed that they were in doubt about whether they deserved what they needed in terms of health care and support. They told about their experiences of being given low priority and little time by healthcare professionals. However, they blamed themselves for this low priority. One of them said that she believed that the healthcare professionals were tired of her. In this way, feelings of shame were reinforced by their experience of their vulnerabilities not being acknowledged by healthcare professionals. Asking someone else for help might feel like a kind of humiliation, and the participants described that the disease gave rise to anxiety, shame and pain. A common aspect of contact between patients and healthcare professionals is an asymmetric relationship and power imbalance (Tuttle, 2007). The patient is the vulnerable one because he/she is the one that needs help, and this help is dependent on the healthcare professionals' willingness to offer help.

Patients, physicians and nurses may be at the extremes of the continuum of vulnerability. The significance of vulnerability, understood as a deep-seated, non-optional feature of being human, should ideally be a shared feeling between healthcare professionals and patient. It can be argued that understanding a patient's vulnerability is a prerequisite if healthcare professionals are to understand the patients' situation when it comes to illness and other concerns (Tuttle, 2007). Several studies have shown that patients who used to smoke have felt the opposite, that is, discrimination by health professionals (Bragadottir et al., 2018; Ek et al., 2014; Halding et al., 2011). In this perspective, it is natural to bring the concept of "deserving" into the discussion. This notion arises when we consider whether people with a former or current smoking habit deserve the available healthcare, and, if not, who shall decide who deserves what? The International Council of Nurses (ICN) first code says that 'The nurse's primary professional responsibility is to people requiring nursing care' (International Council of Nurses, 2012). This means that it is the needs of the patients that are the nurses' priority, irrespective of the reasons why they need nursing care. The same is true of the principle of justice as a core value in medical ethics. The ICN has said that nurses must advocate for equity and social justice (Beauchamp & Childress, 2019; International Council of Nurses, 2012). However, studies show that there is a clear tendency for healthcare professionals to give patients with chronic 'self-inflicted' diseases lower priority than other patients when it comes to treatment and care (Barr et al., 2005; Halvorsen et al., 2009; Meijer et al., 2018; Pedersen, 2010).

One reason for healthcare professionals not prioritising patients with 'self-inflicted' diseases might be healthcare professionals' lack of identification with patients with COPD. COPD is more frequent among people of low socioeconomic status (Halvorsen & Martinussen, 2014). Differences in social status and culture may lead to a weaker understanding of and engagement with these patients' situations by healthcare professionals. Thoughts like 'it could have been me', which are a prerequisite for empathy, perhaps seem to be too far away, both because of the nature of the illness and the perceived distance between the patients and the healthcare professionals. Studies show that some patients with COPD felt more ashamed and stigmatised, due to their diagnosis because healthcare professionals express that they are to blame for their disease (Bragadottir et al., 2018; Lindgren et al., 2014; Odencrants et al., 2007; Winstanley, 2008). The findings showed that some of the participants worried about and avoided using the diagnosis and being associated with the group of patients who suffer from COPD and are former smokers. Instead, they used a strategy whereby they tried to convince themselves and others that they struggle with asthma or have trouble with their legs and, for that reason, postponed seeing their doctor and seeking help. The experience of shame can be understood in different ways, but one common description is linked to a wish to be invisible and to hide (Gilbert & Woodyatt, 2017). This avoidance behaviour might be a reason for delaying taking the initiative to seek medical advice (Arne et al., 2007; Lindgren et al., 2014).

In medical culture, diagnoses are meaningful, and their meaning is not limited to the strictly medical aspect, neither for lay people nor for healthcare professionals. A diagnosis can also have a judgemental aspect as the disease is like a judgement over one's way of life. Prestige is a measurement of regard or esteem, and, together with power and economic resources, it is one of the three basic forms of social inequality. In a study of physicians' ranking of medical diagnoses, the results showed that so-called 'self-inflicted' diseases, with no chance of being healed, were ranked bottom (Album et al., 2017). This may indicate that patients with late-stage COPD belong at the lower end of the prestige scale and might be underprivileged in the healthcare system.

7 | LIMITATIONS OF THE STUDY

This is a qualitative study, and the number of participants is relatively small. The recruitment area was the area around Norway's capital city, which means that the participants were city residents. Smoking habit was not an inclusion criterion, but as a coincidence, all the participants in this study were former or current smokers. The smoking habit might have reinforced the participants' experiences of shame and stigma. The first author has conducted studies of patients with late-stage COPD before, and, for this reason, preconceptions might have coloured the findings. One limitation was that the data analysis was not submitted to the participants for member checking of its validity or plausibility as an explanation of what was said (Brinkmann & Kvale, 2015). We considered the participants' health status to be

unstable and vulnerable, and a member check would probably have been stressful for them. However, the first and the last author read and reread the transcripts many times to maintain a balance between staying close to the themes and avoiding that preconceptions coloured the interpretation. This to ensure reflexive objectivity (Brinkmann & Kvale, 2015). Another weakness of this study is the choice of theoretical framework. Since Goffman's theory was written 40 years ago, it could be argued that the language and concepts are dated and fall short of contemporary standards of political correctness.

8 | CONCLUSIONS

The findings showed that the participants experienced that their physical impairments made them feel vulnerable, ashamed and that, as a result, they became more socially isolated. Moreover, they felt troubled by the disease itself, and the ensuing bodily impairment seemed to be hard to accept. They perceived that they were in doubt about whether they were worthy to receive care and comfort from both healthcare professionals, family and friends, due to their experiences of shame for bringing the disease into their life. The patients seemed to have internalised the moral norms of contemporary society and culture that tell us that disease, and especially 'self-inflicted' disease, is a weakness relating to the person afflicted.

Patients in this study delayed contacting healthcare due to feelings of not being worthy. The study also shows that the participants felt that they had no one to share their burden with, and no right to bother the healthcare professionals either. It is crucial for patients to have a balanced relationship with their nurses and physicians if they are to get the right help and care at the right time.

9 | RELEVANCE TO CLINICAL PRACTICE

Findings from this study show that patients struggle with feelings such as shame and misery. It is the nurses who work at the bedside and are in continuous contact with the patients and could have an opportunity to gain knowledge of these feelings in order to meet the patients' needs for comfort and care. They have an obligation to ask patients about their feelings and meet them with empathy and respect. Moreover, it is necessary to have interdisciplinary fora in clinical practice where health professionals reflect, discuss and challenge themselves according to attitudes towards patients with so-called 'self-inflicted' diseases. A stronger focus on how attitudes may influence nursing and medical care needs to be emphasised in both nursing and medical education. Additionally, management in clinical practice has responsibility to give time and space for health professionals to mirror own attitudes and to secure equal and good care for all patients.

ACKNOWLEDGEMENTS

We want to thank all the participants for your courage and willingness to share.

CONFLICT OF INTEREST

The authors have no conflict of interest to declare.

AUTHORS CONTRIBUTIONS

HJ and KH designed the study. HJ collected the data. All authors have contributed in analysing of the data and the development of the manuscript. All authors have agreed on the final version of the manuscript.

ORCID

Heidi Jerpseth  <https://orcid.org/0000-0001-9934-4820>

Kristin Halvorsen  <https://orcid.org/0000-0002-8416-1391>

REFERENCES

- Ahmadi, Z., Berneld, E., Currow, D., & Ekström, M. (2016). Prescription of opioids for breathlessness in end-stage COPD: A national population-based study. *International Journal of Chronic Obstructive Pulmonary Disease*, 11(1), 2651–2657. <https://doi.org/10.2147/copd.s112484>
- Album, D., Johannessen, L. E., & Rasmussen, E. B. (2017). Stability and change in disease prestige: A comparative analysis of three surveys spanning a quarter of a century. *Social Science & Medicine*, 180, 45–51. <https://doi.org/10.1016/j.socscimed.2017.03.020>
- 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. <https://doi.org/10.3132/pcrj.2007.00033>
- Barr, R. G., Celli, B. R., Martinez, F. J., Ries, A. L., Rennard, S. I., Reilly, J. J. Jr., Sciruba, F. C., Thomashow, B. M., & Wise, R. A. (2005). Physician and patient perceptions in COPD: The COPD Resource Network Needs Assessment Survey. *The American Journal of Medicine*, 118(12), 1415.e9–1415.e17. <https://doi.org/10.1016/j.amjmed.2005.07.059>
- Beauchamp, T. L., & Childress, J. F. (2019). *Principles of biomedical ethics*, 8th ed. Oxford University Press.
- 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. *Journal of Clinical Nursing*, 27(1–2), 57–64. <https://doi.org/10.1111/jocn.13843>
- Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, 11(4), 589–597. <https://doi.org/10.1080/2159676x.2019.1628806>
- Brinkmann, S., & Kvale, S. (2015). *InterViews: Learning the craft of qualitative research interviewing*, 3rd ed. Sage.
- Danielsson, M., Gilljam, H., & Hemstrom, O. (2012). Tobacco habits and tobacco-related diseases: Health in Sweden: The National Public Health Report 2012. Chapter 10. *Scandinavian Journal of Public Health*, 40(9 Suppl), 197–210. <https://doi.org/10.1177/1403494812459607>
- de Queiroz, M. C., Moreira, M. A., Jardim, J. R., Barbosa, M. A., Minamisava, R., Gondim Hdel, C., Velasco, F. C., & Penhavel, M. V. (2015). Knowledge about COPD among users of primary health care services. *International Journal of Chronic Obstructive Pulmonary Disease*, 10, 1–6. <https://doi.org/10.2147/COPD.S71152>
- Dirkse, D., Lamont, L., Li, Y., Simonič, A., Bebb, G., & Giese-Davis, J. (2014). Shame, guilt, and communication in lung cancer patients and their partners. *Current Oncology*, 21(5), e718–e722. <https://doi.org/10.3747/co.21.2034>
- Disler, R. T., Green, A., Luckett, T., Newton, P. J., Inglis, S., Currow, D. C., & Davidson, P. M. (2014). Experience of advanced chronic obstructive pulmonary disease: Metasynthesis of Qualitative Research. *Journal*

- of *Pain and Symptom Management*, 48(6), 1182–1199. <https://doi.org/10.1016/j.jpainsymman.2014.03.009>
- Earnest, M. A. (2002). Explaining adherence to supplemental oxygen therapy: The patient's perspective. *Journal of General Internal Medicine*, 17(10), 749–755. <https://doi.org/10.1046/j.1525-1497.2002.20218.x>
- Ek, K., Andershed, B., Sahlberg-Blom, E., & Ternstedt, B. M. (2014). "The unpredictable death"—The last year of life for patients with advanced COPD: Relatives' stories. *Palliative and Supportive Care*, 1–10. <https://doi.org/10.1017/s1478951514001151>
- Finlay, L. (2011). *Phenomenology for therapists: Researching the lived world* (1. Aufl. ed.). Wiley-Blackwell.
- Gilbert, P., & Woodyatt, L.L. Woodyatt E. Worthington Jr M. Wenzel & B. Griffin (2017). An Evolutionary Approach to Shame-Based Self-Criticism, Self-Forgiveness, and Compassion. *Handbook of the Psychology of Self-Forgiveness*. Cham: Springer. https://doi.org/10.1007/978-3-319-60573-9_3
- Global Initiative for Chronic Obstructive Lung Disease. (2020). *Global strategy for diagnosis, management, and prevention of chronic obstructive pulmonary disease*. https://goldcopd.org/wp-content/uploads/2019/12/GOLD-2020-FINAL-ver1.2-03Dec19_WMV.pdf
- Goffman, E. (1986). *Stigma: Notes on the management of spoiled identity*. Simon & Schuster.
- Gysels, M., & Higginson, I. J. (2010). The experience of breathlessness: The social course of chronic obstructive pulmonary disease. *Journal of Pain and Symptom Management*, 39(3), 555–563. <https://doi.org/10.1016/j.jpainsymman.2009.08.009>
- 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. <https://doi.org/10.1111/j.1471-6712.2010.00796.x>
- Halvorsen, K., Forde, R., & Nortvedt, P. (2009). Value choices and considerations when limiting intensive care treatment: A qualitative study. *Acta Anaesthesiologica Scandinavica*, 53(1), 10–17. <https://doi.org/10.1111/j.1399-6576.2008.01793.x>
- Halvorsen, T., & Martinussen, P. E. (2014). The geography of chronic obstructive pulmonary disease: A population-based study of Norway. *Social Science and Medicine*, 111, 25–34. <https://doi.org/10.1016/j.socscimed.2014.03.018>
- Harrison, S. L., Robertson, N., Apps, L., C. Steiner, M., Morgan, M. D. L., & 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. <https://doi.org/10.3109/09638288.2014.939770>
- Harrison, S. L., Robertson, N., Goldstein, R. S., & Brooks, D. (2017). Exploring self-conscious emotions in individuals with chronic obstructive pulmonary disease. *Chronic Respiratory Disease*, 14(1), 22–32. <https://doi.org/10.1177/1479972316654284>
- International Council of Nurses. (2012). *The ICN codes of ethics for nurses* (Revised ed.) http://www.icn.ch/images/stories/documents/about/icncode_english.pdf
- Jerpseth, H., Dahl, V., Nortvedt, P., & Halvorsen, K. (2016). Considerations and values in decision making regarding mechanical ventilation for older patients with severe to very severe COPD. *Clinical Ethics*, 11(4), 140–148. <https://doi.org/10.1177/1477750916657657>
- Kendall, M., Buckingham, S., Ferguson, S., MacNee, W., Sheikh, A., White, P., Worth, A., Boyd, K., Murray, S. A., & Pinnock, H. (2018). Exploring the concept of need in people with very severe chronic obstructive pulmonary disease: A qualitative study. *BMJ Supportive & Palliative Care*, 8(4), 468–474. <https://doi.org/10.1136/bmjspcare-2015-000904>
- 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, 441–451. <https://doi.org/10.2147/copd.s60182>
- Lundell, S., Wadell, K., Wiklund, M., & Tistad, M. (2020). Enhancing Confidence and coping with stigma in an ambiguous interaction with primary care: A qualitative study of people with COPD. *Chronic Obstructive Pulmonary Disease*, 17(5), 533–542. <https://doi.org/10.1080/15412555.2020.1824217>
- Miceli, M., & Castelfranchi, C. (2018). Contempt and disgust: the emotions of disrespect. *Journal for the Theory of Social Behaviour*, 48(2), 205–229. <https://doi.org/10.1111/jtsb.12159>
- Meijer, E., Kampman, M., Geisler, M. S., & Chavannes, N. H. (2018). "It's on everyone's plate": A qualitative study into physicians' perceptions of responsibility for smoking cessation. *Substance Abuse Treatment, Prevention, and Policy*, 13(1), 1–9. <https://doi.org/10.1186/s13011-018-0186-x>
- Miravittles, M., de la Roza, C., Morera, J., Montemayor, T., Gobartt, E., Martín, A., & Luis Alvarez-Sala, J. (2006). Chronic respiratory symptoms, spirometry and knowledge of COPD among general population. *Respiratory Medicine*, 100(11), 1973–1980. <https://doi.org/10.1016/j.rmed.2006.02.024>
- Odenrants, 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. <https://doi.org/10.1111/j.1471-6712.2007.00441.x>
- Pedersen, W. (2010). *En fremmed på benken: Essays*. Universitetsforl.
- Plaufcan, M. R., Wamboldt, F. S., & Holm, K. E. (2012). Behavioral and characterological self-blame in chronic obstructive pulmonary disease. *Journal of Psychosomatic Research*, 72(1), 78–83. <https://doi.org/10.1016/j.jpsychores.2011.10.004>
- 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*, 14(3), 199–216. <https://doi.org/10.1177/1479972316680847>
- 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*, 34(6), 1466–1481. <https://doi.org/10.1007/s12325-017-0557-0>
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349–357. <https://doi.org/10.1093/intqhc/mzm042>
- Tuttle, J. P. (2007). The physician's disease: The impact of medical knowledge on personal illness. *Palliative and Supportive Care*, 5(1), 71–76. <https://doi.org/10.1017/S1478951507070095>
- Weiss, M. G., Ramakrishna, J., & Somma, D. (2006). Health-related stigma: Rethinking concepts and interventions. *Psychology, Health & Medicine*, 11(3), 277–287. <https://doi.org/10.1080/13548500600595053>
- Winstanley, L. (2008). Risk assessment documentation in COC prescribing. *Journal of Family Planning and Reproductive Health Care*, 34(2), 137. <https://doi.org/10.1783/jfp.34.2.137d>

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

How to cite this article: Jerpseth H, Knutsen IR, Jensen KT, Halvorsen K. Mirror of shame: Patients experiences of late-stage COPD. A qualitative study. *J Clin Nurs*. 2021;00: 1–9. <https://doi.org/10.1111/jocn.15792>