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# 'Feelings of Guilt due to Self-inflicted Disease'

## A Grounded Theory of Suffering from Chronic Obstructive Pulmonary Disease (COPD)

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### Abstract

The aim of this grounded theory study was to illuminate the main concern of people suffering from chronic obstructive pulmonary disease (COPD) and how they handle their everyday life. Data were collected through interviews with 23 people with COPD at different stages, from mild to severe. A substantive theory was generated showing that the main concern was *feelings of guilt due to self-inflicted disease* associated with smoking habits. This core category was related to five managing strategies termed *making sense of existence, adjusting to bodily restrictions, surrendering to fate, making excuses for the smoking-related cause* and *creating compliance with daily medication*.

### Keywords

- *chronic obstructive pulmonary disease*
- *daily life*
- *feelings of guilt*
- *grounded theory*
- *main concerns*

## Introduction

CHRONIC obstructive pulmonary disease (COPD), which is an increasing health problem currently affecting about 600 million people globally, is expected to be the third most common cause of death worldwide in 2020 (GOLD, 2004). Cigarette smoking is by far the most commonly encountered risk factor for COPD, and it has also been shown that passive smoking impairs lung function. A chronic disease such as COPD is a long-term condition that is irrevocable, and people suffering from COPD cannot expect a return to normal lung function. The reduced lung function and the impaired oxygen intake cause damage to several other organs such as the heart, the blood vessels, the kidneys, the skeleton, the muscles, the brain and the digestive tract (Biskobing, 2002; Grönberg, Slinde, Engström, Hulthén, & Larsson, 2005). The periods of deterioration are what people fear most, and lack of breath and impairment in functions lead to difficulties in managing everyday life. Day-to-day activities cannot be carried out, leading to frustration (Haughney et al., 2005; Oliver, 2001). Van den Bemt and co-workers (2009) found an association between COPD and diagnosed depression. In a study by Williams, Bruton, Ellis-Hill and McPherson (2007), the study participants stated that it was important to participate in daily life and to maintain physical and social activities in order to sustain their former roles, despite the breathlessness.

Social isolation is common in people who suffer from severe COPD, and strategies are needed to cope with the situation (Carling Elofsson & Öhlén, 2004; Jonsdottir, 1998). They are ashamed when others see them exposed and vulnerable because of shortage of breath. They worry about the future, and how the disease will develop. They know that the disease is incurable, and that deterioration will occur sooner or later. Thoughts about death and fear of suffocation are never far away; they describe it as living their life on borrowed time. Being forced to ask for help feels demeaning, as if one is a burden (Guthrie, Hill, & Muers, 2001; Oliver, 2001; Seamark, Blake, & Seamark, 2004). People with COPD said that their self-image was challenged and that their emotions vacillated between the idea of having a meaningful and a meaningless life; these feelings could be so strong at times that they had a death wish (Ek & Ternstedt, 2008). Having COPD can be devastating, and it creates a feeling of just existing rather than maintaining a sense of self in living with the effects of COPD (Nicholls, 2003).

The feeling of not being able to control the disease affects life palpably, and causes practical barriers to interacting with people as well as loss of important social roles (Carling Elofsson & Öhlén, 2004; Guthrie et al., 2001; Guyatt, Berman, Townsend, Pugsley, & Chambers, 1987). People suffering from COPD report that they feel worthless when they cannot achieve ordinary tasks, and they prioritize in order to save energy (Guthrie et al., 2001; O'Neill, 2002). Among professionals in healthcare, there is limited knowledge about how people diagnosed with COPD experience their chronic disease, based on their own words, and it is therefore valuable to explore their thoughts about their life situation and how they manage the situation. Exploring people's experiences through their narratives helps us to understand how they present their life stories and give us a deeper insight into their specific problems. Thus, the aim of the study was to generate a theory, grounded in empirical data, to reveal the main concerns of people who suffer from COPD and how they handle their situation.

## Method

The constant comparative method of grounded theory (GT), developed by Glaser and Strauss (1967), was used. This inductive approach encourages the researcher to enter the study with an open mind and to try to take the role of 'the other'. The method attempts to discover the main problem in a given situation and how people handle this problem (Glaser, 1992). Such an inductive method aims to generate a model or theory grounded in empirical data. GT has its theoretical roots in pragmatism and symbolic interactionism, which involves the idea that meaning is constructed and changed in interactions between individuals (Blumer, 1969; Mead, 1967). Glaser's view on qualitative research includes the idea that theory is a process, and can be presented as a momentary product that is still developing. The systematic abstraction and the conceptualization of empirical data constitute the theory-generating process. There are two main characteristics of GT, the systematic methodology and the constant comparative method. The constant comparative method can be seen as the 'core category' of GT, and entails that every part of the data, that is, emerging codes, categories, properties and dimensions, as well as different parts of the data, are constantly compared with all other parts of the data to explore variations,

similarities and differences in the data (Hallberg, 2006, p. 143). It is important that the researcher should keep a rein on his or her prior understanding and reflect on the interpretation of data rather than being directed by preconceptions and earlier theories. Hall and Callery (2001) stress the concept of 'reflexivity' as being an important aspect of openness, and argue that researchers must be self-reflective about how they influence the research process. Grounded theory methodology includes simultaneous collection and analysis of data, open and theoretical sampling, hierarchical analysis processes, constant comparisons, theoretical sensitivity, theoretical saturation and memo writing. Substantive theory concerns, and is applicable to, a delimited and specified area whereas a formal theory is concerned with a more general area. According to Glaser (1992, p. 117), a grounded theory is 'readily modifiable' and generalizable.

### *Participants*

The participants of the study, 13 women and 10 men, were recruited from two hospitals in the southern part of Sweden (see Table 1). The Swedish Federation of People Suffering from Heart and Lung Diseases and one healthcare centre. The 23 participants were between 52 and 82 years of age (mean = 67.8 years; SD = 9.3 years). Twenty-two participants had been heavy smokers for many years and one participant was a passive smoker. Nineteen participants had stopped smoking six weeks to 20 years prior to the interview, and three were still smoking. The inclusion criterion was that the participants were diagnosed with mild to severe COPD (GOLD, 2004). The exclusion criterion was having severe COPD with oxygen treatment. In line with guidelines for GT, the participants were initially selected through an open sampling process in order to maximize variation in experiences. Later in the simultaneous process of collecting and analysing data, theoretical sampling was carried out in order to saturate emerging categories.

### *Data collection*

Data collection was conducted in parallel with analysis of data. The tape-recorded interviews were collected from January 2005 to March 2006. Twenty interviews took place in the participants' homes; the other three were conducted at a university office. Each interview lasted for 30–90 minutes. The first author conducted all interviews using open questions such as: 'Can you tell me what it is

like to live with COPD?' and 'How does COPD affect you?' These open questions were facilitated by relevant follow-up and probing questions, for example, 'What are your concerns?' and 'What do you do about it?' Open sampling was used initially in order to maximize the variation in data, and this was later followed by theoretical sampling, in order to refine emerging theoretical ideas and saturate emerging categories. Accordingly, this sampling process is 'driven by the emerging theory' (Hallberg, 2002, pp. 142–143). After 21 interviews, theoretical saturation was reached, meaning that new data did not seem to add new information. However, two additional interviews were conducted to ensure further that there was saturation. All interviews were conducted, transcribed and analysed in Swedish by Swedish researchers. The result of the analysis was then translated into English for this manuscript.

### *Data analysis*

The interviews were transcribed verbatim and analysed consecutively by the first author, with supervision and support from the second author. This means that both researchers confirmed the codes and categories during analysis. Initially, the analysis consisted of open line-by-line coding of data. This open coding included data being broken apart into pieces and substantive codes being identified and labelled in a concrete fashion. These substantive codes codified the meaning of data. The emerging codes were then clustered into more comprehensive categories, which were labelled on a more abstract level. Each category was saturated with information, and its subcategories or dimensions were identified. Thus, the aim of open coding was to conceptualize the data. The next step of analysis included finding relationships between the categories and their subcategories and to identify the core category. The core category was central to the data and reflected the main concern in the area studied, and could be related to categories explaining how the main concern was managed. In each phase of the analysis, the researchers were constantly moving between inductive and deductive thinking. The technique of questioning and comparing the data strengthened the researchers' theoretical sensitivity. During the entire process of analysis, ideas, preliminary assumptions and theoretical reflections were written down in so-called 'memos' (e.g. Glaser & Strauss, 1967).

Table 1. Description of participants in the study

Participants	Age	Duration of symptoms (years)	Stage	Previously treated in hospital	Education	Employment	Location
1. Female	69	15	Moderate	Yes	Blue collar	Pensioner	Urban
2. Female	56	12	Severe	Yes	Blue collar	Sickness benefit	Rural
3. Female	55	5	Mild	No	Blue collar	Sickness benefit	Rural
4. Male	70	2	Moderate	Yes	Blue collar	Pensioner	Rural
5. Male	60	9	Severe	Yes	Blue collar	Early retirement pension	Rural
6. Female	52	2	Mild	Yes	Blue collar	Sickness benefit	Rural
7. Female	67	9	Severe	Yes	Blue collar	Pensioner	Urban
8. Male	80	13	Severe	Yes	Blue collar	Pensioner	Rural
9. Female	76	5	Moderate	Yes	Employer	Pensioner	Urban
10. Male	79	7	Severe	Yes	Employer	Pensioner	Urban
11. Female	60	8	Severe	No	Blue collar	Unskilled labour	Urban
12. Female	62	8	Mild	Yes	White collar	Early retirement pension	Urban
13. Male	82	12	Severe	Yes	Blue collar	Pensioner	Urban
14. Male	80	4	Severe	Yes	White collar	Pensioner	Rural
15. Male	71	8	Moderate	No	Employer	Pensioner	Rural
16. Female	81	4	Mild	No	Employer	Pensioner	Urban
17. Female	66	19	Severe	Yes	Blue collar	Pensioner	Urban
18. Male	54	6	Severe	Yes	Blue collar	Early retirement pension	Urban
19. Male	68	5	Severe	Yes	Blue collar	Pensioner	Urban
20. Female	73	10	Moderate	Yes	White collar	Pensioner	Urban
21. Male	69	3	Mild	No	Blue collar	Pensioner	Rural
22. Female	71	13	Severe	No	Blue collar	Pensioner	Urban
23. Female	58	1	Severe	Yes	Blue collar	Sickness benefit	Urban

Notes: Stage I: Mild COPD – Mild airflow limitation ( $FEV_1/FVC < 70\%$  but  $FEV_1 > 80\%$  predicted) and usually, but not always, *chronic* cough and sputum production

Stage II: Moderate COPD – Worsening airflow limitation ( $50\% < FEV_1 < 80\%$  predicted) and usually the progression of symptoms, with shortness of breath typically developing on exertion

Stage III: Severe COPD – Further worsening of airflow limitation ( $30\% < FEV_1 < 50\%$  predicted), increased shortness of breath and repeated exacerbations that have an impact on patients' quality of life.

### Methodological quality and rigour

Applicability was assured as the study sample was based on both open and theoretical sampling of individuals diagnosed with COPD until saturation was achieved, in line with grounded theory methodology. Reasonableness was ensured by concordance between the method of data collection and the subject area, and through continuous comparisons of different parts of data, codes and categories during the analysis process. Trustworthiness was optimized by a systematic approach to data collection and analysis to ensure that the emerging results were grounded in the data. Conscientiousness was important from the start of the research process through repeated reflections

and considerations concerning possible emotional and cognitive influence (Fridlund & Hildingh, 2000).

### Ethical considerations

The study was carried out in accordance with the ethical standards of the Helsinki Declaration (World Medical Association Declaration, 2000). Ethical approval of the study was obtained from the committee of FoU-centrum Landstinget Kronoberg LE/071004. Oral and written information about the study was given to the participants, including information on autonomy, informed consent, confidentiality and the right to end the participation at any time without stating any reason.

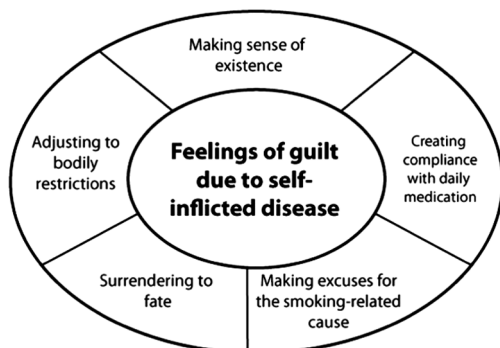


Figure 1. A substantive theory on 'Feelings of guilt due to self-inflicted disease' grounded in empirical data from people suffering from chronic obstructive pulmonary disease (COPD).

The participants were asked to sign a written agreement concerning their participation in the study.

## Results

The analysis generated a substantive theory with a core category illuminating the main concern for people suffering from COPD, which were *feelings of guilt due to self-inflicted disease* associated with smoking habits (Fig. 1). This core category was related to five additional categories forming a pattern of behaviour that would explain how this main concern was handled. The categories included in this pattern of behaviour were *making sense of existence*, *adjusting to bodily restrictions*, *surrendering to fate*, *making excuses for the smoking-related cause* and *creating compliance with daily medication*.

### *Feelings of guilt due to self-inflicted disease*

The core category and the central theme in the data, 'feelings of guilt due to self-inflicted disease', explores the main concern. This includes feelings of living in the 'the shadow of death' due to COPD, and feelings of guilt because of the strong association between the disease and smoking habits. The dimensions of the core category were *living with an incurable disease*, *preparing for an uncertain future*, *feelings of being stigmatized*, *having no rights to complain* and *having to take the consequences of life habits*. Suffering from a self-inflicted disease means that the disease is seen as being caused by the

individual's own behaviour. He or she therefore has to put the blame on himself or herself, and take the consequences. They feel that they have no right to complain because of present or previous smoking habits:

A self-inflicted disease, yes. And I find that difficult, because then there is that thing about the feeling of guilt. Yes, it's not worth complaining, because I have caused it myself; it is my own fault. Guilt, the feeling of guilt, because I know that it was I myself who caused this disease; no-one else did it. (12, 6)

Participants realized that COPD was an incurable disease and that they would have to live with it for the rest of their lives. Having a chronic disease like COPD, which is to a great extent defined in social terms as being self-inflicted, increased the risk of being stigmatized and being seen as an outsider by other people. Participants stated that they were exposed to stigmatizing attitudes, not only in society in general but also within the healthcare system. Their self-inflicted suffering often led to insufficient attention—even from healthcare professionals—and they felt that they ought to be ashamed of their situation and disease-related behaviour. Their experience was that they were not always met with understanding and sympathy; rather negative attitudes could be uncovered, which were particularly noticeable if they had not managed to stop smoking: 'That thing about smoking, then you don't get access to care. You can if you're an alcoholic or a drug abuser' (3).

Feelings of guilt were common in the participants, and were related to their thoughts of having done something they should not have done. This can be seen as the result of the struggle between the ego and the moral values of an individual: the basic conception of what is right and what is wrong. The discrepancy between what one had done and what one ought to have done resulted in strong feelings of responsibility for, and guilt related to, the consequences of their smoking behaviour. In addition, this gave rise to thoughts of being a burden to their family and to society. A kind of self-accusation arose, where the COPD sufferers accused themselves of having been smokers, of not realizing the risks of smoking and of lacking the ability to be responsible and to stop the smoking behaviour. The self-accusation meant that the participants looked at their own worth with self-critical and condemning eyes. Their self-respect was negatively affected.



### *Making sense of existence*

Making sense of existence was a way of being able to continue living with the disease and not to succumb. Participants recognized and gained insight into their disease, embodied it and created a relationship with it. Respectful treatment and adequate information from healthcare professionals supported participants' efforts to make sense of the disease. This does not mean that they had totally accepted the disease, but they had realized that they would have to live with it for the rest of their lives:

I have learnt the disease and learnt to live with it, but that I haven't accepted it is another matter. I am happy in life as it is; you have to make the most of it as far as you can. (5, 7)

Awareness grew that the present structure of life must be gradually replaced by a new structure, adapted to the demands of the sick body. The COPD entailed consequences not only here and now but also in the future, which meant that a new attitude to life must be established. The disease always needed to be handled in such a way as not to exceed the participant's capabilities. If there was a misjudgement, the disease immediately reinforced its grip:

One tries in every way possible. I have started to do pool training. I have joined the heart and lung disease association. And then I have been going to the gym for one year, and that's brilliant. (20)

Acceptance of loss can be just as important in the psychological adjustment to an acquired disease or disability. Participants in the study actively tried to reduce the effect of the disease on their daily life. They strove to rebuild a normal life and did not want to become passive victims of COPD. Instead, they tried to find a way of relating to the disease and of making it a part of their life. They tried to re-establish their own identity, in which the disease played a role: 'Today, I'm proud that I have got as far as I have done, and that I can handle this' (15).

### *Adjusting to bodily restrictions*

The symptoms of cough with a large amount of mucus, shortness of breath and tiredness were very unpleasant and distressing, and the participants had to find ways to cope and not to become inactive and isolated. COPD restricted both their choice of activities and the prerequisites for performing them. Participants had to balance every activity against their physical capacity during the day, and to listen to the signs and symptoms from the body:

Well, the rule of the game is never to hurry; that is number one, I think. Then you learn that you can't do this, because then you lose the rhythm; but if I follow the instructions and take my medication, and then I can make it through the whole day. (15)

Another way of adjusting daily routines to one's physical ability was, for example, to save energy and to choose the escalators instead of the stairs, in order to reduce the demands on the strained breathing capacity. When participants became breathless, feelings of anxiety arose and they lost the ability to do things they had been able to do before: '... and then suddenly become a frail old man' (5). Not having the physical ability to cut the lawn, do the shopping, take long walks, travel and participate in social events added strain to the participants' daily life and they therefore always had to plan in advance:

It is my breathlessness; I can't walk far, so I am very handicapped. I hardly have the strength to walk from the car, but I always used to be busy; you want to do so much and then you have to sit down and rest and take it easy. (8)

In the process of adjusting to the chronic disease, the participants incorporated the COPD into their life: 'I listen to my body; I think it feels like I do. I live one day at a time and I like setting some goals; I set goals I can manage' (12, 15).

### *Surrendering to fate*

It was when the disease took over the participants' lives and when they were afflicted by feelings of hopelessness and depression that it seemed as if death might be close: 'Everything has changed, my whole life has changed. You begin to be so worthless, and as if you should go to the guillotine' (22). The COPD attacked the entirety of the person and threatened their integrity and their whole existence. The participants expressed it as becoming a person other than the one they were before the disease: 'I don't want to realize that I've got this, I want to be the person I was' (6). A feeling of hopelessness and powerlessness arose when personal control was lost and they became dependent on other people. They found it difficult to manage their life situation without assistance. The disease deprived them of their independence and their ability to direct things their own way: 'Well, you feel a bit like—to put it in a nutshell—that it is rather pointless continuing. It is therefore rather a pointless existence' (14). Everyday occupations could no longer be carried out in the same way, for example, cleaning and doing the garden. Shopping for food

required planning; they avoided stairs and crowds, and social isolation was very real:

Sometimes I am so tired that I can't cope with myself; there are many days when I have just lain here on the sofa. I felt very frustrated when I was feeling so ill, I couldn't accept this disease. It was impossible, but in the end I had to. (22, 20)

Being dependent on help from others in daily life became a burden for the participants. This burden increased when the daily life of the family had changed, and the disease was affecting everyone around the sufferer:

If I had been alone I would not have lived, because you can't stand it alone ... and she manages the rest. If she dies tomorrow, my wife, then I'll die too. This is absolutely certain, because I can't manage alone. (8)

Feelings of confusion could arise when the roles in the family became less clear. Feelings of shame occurred when other people had to take into consideration that the participant's strength had diminished, and that things could not be carried out. Participants had difficulties in taking part in social events or journeys; even if the COPD was not visible, it caused existential pain. They felt that they were not respected or taken seriously. Being constantly reminded of the disease sometimes resulted in their sense of control over life being limited or lost. Participants lived in the proximity of death, and felt that changes were occurring in the body. Death felt more tangible and its touch was felt palpably when the breathing difficulties increased:

I am afraid of dying, I am afraid of this. I feel like death is constantly on my heels. I am so frightened that it will catch up with me. I somehow try to run away from it ... I would run any distance. I know that it is stalking me the whole time and one never knows when death will come, and after all it could happen any time. You never know, but the disease is there; it is. (6)

### *Making excuses for the smoking-related cause*

In spite of the evidence for the detrimental effects of smoking, participants tried to justify the cigarettes and the smoking. Psychological reasons for smoking played a significant role in continuing to smoke. Some participants continued to smoke to enhance their feelings of security, well-being and self-esteem—but also to reduce negative feelings and anxiety:

I haven't been smoking like a smoker, you know; smokers breathe in the smoke, but I puff-smoke. But it's not as if I mega-smoke. I must confess that I have inhaled, but I haven't smoked that much. I would say that it might partly be that I have breathed in smoke, but otherwise I have blown it out. (5)

The cigarette was regarded as a best friend and a constant companion involving some kind of ritual behaviour rather than being seen as an addictive drug. There was comfort and companionship in the cigarette, and smoking created a feeling of community: 'The cigarette is a part of my identity because I can hide a lot behind that. You get a mate with a cigarette' (15). Smoking could also facilitate social contacts: there was a feeling of companionship with other smokers; the atmosphere became relaxed and it was easier to make contact and talk:

You have a smoke after coffee, and when your mates smoke, you also have a smoke. Lots of times you wanted that cigarette for the companionship. Really, smoking doesn't taste good, but there was something else in it, the companionship. (18)

The desire to smoke was so strong that the signals of destruction or risk-taking from their bodies meant nothing to them. The psychological effects of smoking were the main obstacle to stopping. They made up excuses for themselves that smoking would not have any negative effects on them: it would happen to others but not to them: 'The doctor said it was COPD, but I didn't pay any attention. No, I wouldn't get it somehow, it wouldn't happen to me' (4). Participants did not start to reflect on smoking seriously until their bodies indicated ill health and deterioration. Some of them had to come face to face with their symptoms and mortality:

I had to sleep sitting up, because I couldn't breathe properly. That frightened me, because I don't want to die. So when I went to the doctor, there was a, well she looked like a typical COPD patient with the oxygen paraphernalia hanging all over. So then I thought that I had probably seen death there, so this was probably a warning to me—that now there wouldn't be any more cigarettes. (3)

### *Creating compliance with daily medication*

The quality of life for people suffering from COPD diminishes as the disease progresses and they definitely need their daily medication to function and to survive:



I wouldn't survive for 10 minutes if I didn't have the medication; I've just got to have it. I use the inhaler before I get out of bed; it's a must. I set the alarm to wake me at eight, because I think the longer I sleep, the worse things are for me in the morning. (22)

Carelessness with medication results in drastic consequences in the form of struggling to breathe and psychological problems, for example, anxiety related to not getting enough air and feelings of being close to death. According to the participants, COPD is a planning disease. They could no longer take unplanned trips as before; instead, meticulous planning was required: all the medications had to be brought along and they were constantly afraid of being ill during the trip. Travelling abroad was out of the question; they neither dared nor had the strength. Participants had to deal with the reality that they had COPD and had to tolerate daily medication and accept the fact that there are medicines that will reduce symptoms, exacerbations and hospitalizations—and improve their quality of life. The medication controlled their lives, as they could not manage without it. This dependency affected their self-esteem and reinforced the feelings of guilt for having brought the disease on themselves:

You have to be a realist. I know that I won't get better; instead, it's more likely going to be downhill. I'm sure I'll end up in bed with oxygen, or I'll have to have oxygen at home. An oxygen cylinder on the walking frame, that's just a fact. You live and learn. (1)

## Discussion

A substantive theory was grounded in the empirical data, showing that the main concern of people living with COPD was *feelings of guilt due to self-inflicted disease* associated with smoking habits. Accordingly, the guilt was related to the participants' awareness of the strong association between smoking behaviour and COPD and they blamed themselves for bringing the disease into their own lives. They found that the life they had planned had been sidelined, and they were preparing for an uncertain future. The participants' basic trust in existence was threatened, and now they had to live in the proximity of death with the incurable disease. They were also exposed to stigmatizing attitudes and felt that they had no right to complain because of the strong association between the disease and smoking. The theory also

illustrates patterns of behaviour that explain how the main concern was handled by people with COPD, that is, making sense of existence, adjusting to bodily restrictions, surrendering to fate, making excuses for the smoking-related cause and creating compliance with daily medication.

A healthy person looks upon the body and its functions in a self-evident way, but being struck by COPD altered their basic trust in existence. They have to adjust to a life with a chronic disease. The verdict of chronic disease was a reminder of how fragile life is, and meant that one's self-image changed and the true self became threatened. The self-accusation meant that they looked differently at their own worth and self-confidence was negatively affected. This is in line with Murphy (2001), who argues that a chronic disease means that the image of one's person changes and is threatened. In order to manage the situation, participants had to make sense of the disease and in some way incorporate the incurable disease into their identity. Whether participants accepted or denied their chronic disease was to a high degree dependent on their inner strength, earlier life experiences, social circumstances and available social support. Inner strength makes one open to life's many possibilities, with its choices and activities. It makes it possible to handle and be open to the many possibilities of one's life; the person can choose to stand up and fight or live in reconciliation (Nygren, Norberg, & Lundman, 2007). Inner strength is a central human resource that creates well-being and healing (Koob, Roux, & Bush, 2002; Roux, Dingley, & Bush, 2002).

Adjusting to bodily restrictions, which was an important strategy for handling life with COPD, included taking an active interest in treatments, being watchful for symptoms and listening carefully to body signals. Compliance with medication is desirable in all medical treatments, and trying to tolerate and be compliant with daily medication was a commonly used strategy for handling COPD. Another strategy was surrendering to fate; however, sometimes feelings arose of being deprived of independence and of the ability to steer things in one's own way due to the disease. Psychological symptoms, such as feelings of hopelessness and powerlessness, anxiety and depression could also arise when personal control was lost and sufferers had to accept being dependent on other people.

Making excuses for or minimizing the smoking behaviour was one way of managing or minimizing feelings of guilt. Stopping smoking was seen as a

long struggle or 'fight', comparable to stopping any other ultimately self-destructive or harmful behaviour. Many smokers and ex-smokers felt guilty about their failure to control themselves. Participants felt that they were a burden on the healthcare system, and that they were weak-willed when they were in some cases unable to stop smoking. Psychological reasons for smoking played a significant role in continuing smoking. If they could not stop smoking, they were met with a noticeably negative attitude from healthcare professionals as well as from society in general, which increased their feelings of guilt. Some participants continued to smoke for psychological reasons, for example to enhance their feelings of security, well-being and self-esteem—and also to reduce negative feelings and anxiety. The denial of their risk-taking behaviour: 'I will not become ill from smoking, but others may', can be seen as a defence mechanism (Lazarus, 1973). Most COPD patients are not prepared to accept any personal responsibility for their medical status. They refuse to see any connection with smoking and prefer to blame exposure to pollution in the work environment or genetic causes (Hansen, Walters, & Wood-Baker, 2007). Patients with COPD may need help and support to get over the denial or the 'unrealistic optimism', and gain insight. Supporting psychotherapy should be of great value to these patients in this process.

Suffering from COPD is strongly associated with smoking habits, and having a chronic disease makes one different from other people, which can create a feeling of stigmatization. According to Goffman, stigmatization may arise when the people around feel that there is a difference between a person's expected social identity and his/her actual identity. In practice, stigmatization means that a person is locked out from a community due to physical or psychological deviation (Goffman, 1990). For many people living with chronic disease, the stigmatization becomes part of life irrespective of their disease, sex or social status (Vickers, 2000). Many times, the stigmatization can be worse than the disease itself. It is difficult for a person living with chronic disease to experience a good quality of life if he or she is subject to stigmatization (Burckhardt, Woods, Schultz, & Ziebarth, 1989). People who experience a high degree of stigmatization often develop poor self-confidence and a low degree of control over their daily life situation (Goffman, 1990). If a person is heard and respected,

their self-confidence increases and it is easier to resist the stigmatization to which they are subjected (Koch & Kraklin, 2001; Vickers, 2000).

Feelings of shame and guilt have been found to influence contacts between healthcare professionals and patients due to their perception of COPD as being a self-inflicted disease (Odencrants, Ehnfors, & Grobe, 2007). It is the task of healthcare professionals to start from the point where the patient is, to listen emphatically to his or her worries and anguish and to help him or her to use their resources to continue and create a life of which COPD is part. Healthcare professionals should encourage patients to make use of their abilities to create meaning in their present life situation. If the patient feels that there is a meaning to life, the ability to handle both the disease and his or her own existence improves (Frankel, 1986). Living with the disease means to know it, and to think and talk about it.

Although COPD is mainly a somatic disease, the consequences of it are highly relevant to clinical psychologists. Supportive individual psychotherapy and cognitive-behavioural therapy would be helpful for this group of patients with a broad range of psychological and psychosocial problems. Issues for therapy could be, for example, limiting stigmatization and disability, reducing loss of autonomy and social roles and adapting to new life goals. Clinically significant depression and anxiety are common among patients with COPD. In a blind, randomized controlled trial (de Godoy & de Godoy, 2003), 30 patients in Brazil with COPD were invited to 12 sessions of psychotherapy included in a pulmonary rehabilitation programme. The results showed that both depression and anxiety were reduced but 'six-minute walking distance' (a test of physical ability) was not modified. Eiser, West, Evans, Jeffers and Quirk (1997) found that six group-sessions of cognitive-behavioural therapy with 10 patients suffering from moderately severe COPD resulted in sustained improvement in exercise tolerance but produced no change in anxiety levels. It was hypothesized by these authors that the anxiety scale used in the study (the Hospital Anxiety and Depression Scale) was not sensitive enough to capture changes in anxiety, and that more prolonged and intensive psychotherapy would give even better results on exercise tolerance as well as on anxiety and quality of life.

Sarbin (1986) suggested narrative psychotherapy as an alternative treatment approach for patients

with COPD, as it deals with a large range of issues. When patients narrate their stories, relief of frustration, guilt and shame can be experienced. According to Sarbin, some specific aims of therapy should be to facilitate acceptance of losses, to delimit social withdrawal and to restructure life goals. Cully, Graham, Stanley and Kunik (2007) argue that in line with other medically ill older patients, patients with COPD are at high risk of insufficient treatment of mental health problems and underuse of mental health services, because of restricted access to care and negative attitudes to mental health. According to these authors, 85 per cent of depressed primary care patients desire treatment for their depression. However, only about 13 per cent of depressed individuals and 25 per cent of anxious individuals actually seek care for their mental health. We consider that psychological support and/or psychotherapeutic treatment would be helpful to patients with disabling COPD, but unfortunately such treatment is seldom offered to patients with COPD in the public healthcare system in Sweden.

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