Conceptions of daily life in men living with a woman suffering from chronic obstructive pulmonary disease

Gunilla Lindqvist¹, Kristiina Heikkilä^{2,3}, Björn Albin⁴ and Katarina Hjelm⁵

Aim: To describe conceptions of daily life in men living with a woman suffering from chronic obstructive pulmonary disease (COPD) in different stages of the disease. Background: A chronic disease like COPD affects not only the person living with the illness, but also the spouse. Significant tasks and demands are placed on husbands. COPD has for a long time been considered more a man's disease than a woman's disease, but according to new evidence COPD is a vast problem in women, which requires support from their spouses. The literature review did not reveal any previous studies concerning conceptions of daily life in men living with women suffering from COPD in different stages. Methods: A phenomenographic study was conducted. Data were collected from October 2008 to October 2009 through semi-structured interviews with 19 men living with a woman suffering from COPD. Findings: Two main descriptive categories were found: (1) unchanged life situation where no support was needed; (2) changed life situation related to severity of COPD, where support was needed. The categories were described from the perspective 'ME and my spouse'. Even in their caregiving situation, the men continued with their own life and activities and did not put themselves in second place. No support was needed from healthcare or municipality when the women had mild COPD, but this changed when the COPD progressed. The men felt that daily life was burdened, restricted and the partner relationship was affected, even if the disease had not reached the final stage. The COPD forced them gradually into a caregiving role, and their daily life changed. They become more of a caregiver than a spouse. The men experienced lack of knowledge and support, and they felt that health professionals and municipality did not care about them.

Key words: COPD; everyday life; male spouses; nursing; phenomenography

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Introduction

Chronic obstructive pulmonary disease (COPD) is a leading cause of morbidity and mortality in

Correspondence to: Gunilla Lindqvist, PhD Candidate, School of Health and Caring Sciences, Linnaeus University, SE-351 95 Växjö, Sweden. Email: gunilla.lindqvist@lnu.se

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the world (Global Initiative for Chronic Obstructive Lung Disease (GOLD), 2011). No previous studies have been found concerning men's conceptions of daily life as the spouse of a woman suffering from COPD in different grades of the disease. Most studies of informal caregiving of COPD patients have investigated the experiences in relation to patients with one of the grades,

¹PhD Candidate, School of Health and Caring Sciences, Linnaeus University, Växjö, Sweden

²Senior Lecturer, School of Health and Caring Sciences, Linnaeus University, Växjö, Sweden

³Senior Lecturer, Department of Neurobiology, Care Sciences and Society, Division of Nursing, Karolinska Institute, Stockholm, Sweden

⁴Associate Professor, School of Health and Caring Sciences, Linnaeus University, Växjö, Sweden

⁵Professor, School of Health and Caring Sciences, Linnaeus University, Växjö, Sweden

mostly severe or very severe COPD (Booth et al., 2003; Ingadóttir and Jonsdottir, 2006; Kanervisto et al., 2007; Ek et al., 2011). COPD is a progressive disease (GOLD, 2011), so it is important to study conceptions related to the different grades, to obtain knowledge and deepen our understanding of men's situation.

During the later part of the 20th century, the prevalence of COPD increased among women in the entire western world (GOLD, 2011). The disease has consequences not only for the ill person, but also impacts on the person giving informal care (Bergs, 2002; Pinto et al., 2007). Most persons living with COPD are cared for in their own home by spouses and have regular follow-ups in primary health care, whereas very severe COPD cases, especially with oxygen therapy, are followed by hospital clinics. The length of hospital stay for patients has decreased in recent years (Heart and Lung Association, 2009). This means that the spouse has to take over more of the care from health professionals.

COPD is a non-reversible illness, affecting about 600 million people in the world (GOLD, 2011). As a result of this, there will be increased costs for healthcare, medications and early retirement (Larsson, 2002) and need of support from the spouse according to the grade of COPD (Lindqvist et al., accepted). The severity of COPD is classified in four grades by spirometry. Grade I, mild, is a condition where the person has minimal shortness of breath with or without cough and/or sputum, and usually it is unrecognized that the lung function is abnormal. In grade II, moderate, the person suffers because of the shortness of breath on exertion, with or without cough, sputum or dyspnoea, and this is often the grade where medical attention is sought because of chronic respiratory symptoms. Grade III, severe, is when the person has more severe shortness of breath, with or without cough, sputum or dyspnoea, often with repeated exacerbations, which have an impact on quality of life. In grade IV, very severe, the airflow limitation and symptoms are severe, and in most cases the person requires oxygen treatment (GOLD, 2011).

The person with severe COPD becomes largely dependent on the spouse in order to manage everyday life at home (Carling Elofsson and Ohlén, 2004; Seamark *et al.*, 2004; Kanervisto *et al.*, 2007). The caregivers experience a reduction in quality of life (Pinto et al., 2007), they lose their self-identity and feel interrupted in their old lifestyle (Bergs, 2002). The caregivers lose their intimate relationship and identity, feel confused and anxious about the future, and their coping strategy is to take one day at a time (Simpson et al., 2010). The caregivers feel helpless when they see their spouse suffering from breathlessness, and they do not know how to act, being poorly prepared to handle acute exacerbations (Booth et al., 2003; Gysels and Higginson, 2009).

Caring for a spouse with COPD can have an impact on physical and mental health (Bergs, 2002; Pinto et al., 2007). The role overload has been shown to cause psychological distress and lower self-perceived health in older caregiving husbands (Ducharme et al., 2007); reducing the caregiving burden improved the mental health of the men assisting spouses with multiple sclerosis (Buchanan et al., 2010). The spouses have to deal with feelings of guilt in the sufferer, as the ill person conceives the COPD as self-inflicted because it is associated with smoking habits; there are also feelings of living in the shadow of the death of the COPD sufferer (Lindqvist and Hallberg, 2010). The worry about the spouse was the most difficult part for the informal caregivers (Gautun et al., 2012). Patients with COPD and their spouses have increased incidents of anxiety and depression (Kühl et al., 2008). Spouses of a patient with very severe COPD received inadequate support from health professionals, and their personal needs were unmet. The caregivers were in emotional distress and they had inadequate knowledge about the COPD and how to handle palliative care (Spence et al., 2008). The informal caregivers take on the caregiving role without little or no training in a very complex situation, especially when the COPD progresses (Lindqvist et al., accepted).

A literature review (Lindqvist et al., 2004) showed that men and women in general experienced informal caregiving differently. Women reported a higher level of burden than men, and women gave significantly more demanding and complex care than men. More negative psychological states were reported by caregiving wives than by husbands. Among caregiving men common themes were a sense of duty: 'you've got to do what you've got to do'. Men approach caregiving as a form of work, a series of tasks that needs to be accomplished (Thompson, 2002).

Aim

The aim of the study was to describe conceptions of daily life in men living with a woman suffering from COPD in different grades of the disease.

Methods

Design

A descriptive study with a phenomenographic method was used. Phenomenography aims to understand, analyse and describe the individual's conceptions of different phenomena, based on qualitative variations in people's ideas about the surrounding world, such as how they conceive, think, conceptualize, understand and remember various aspects of a phenomenon (Marton, 1981; Marton and Booth, 1997). The outcome in phenomenography is the generation of different content-related categories of what is experienced by the participants themselves. The categories can be seen as a structural framework within which various qualitatively dissimilar ways in how people experience the phenomena, the second-order perspective. The perceptions are based on experiences in reality, as humans are aware of and dependent on different social contexts (Marton and Booth, 1997).

Participants

Included in the study were men living with a woman who had been diagnosed with COPD in different grades, mild to severe, described by GOLD (2011). Women were excluded if they had been diagnosed with very severe COPD, the final grade of COPD and being continuously treated with oxygen. Nineteen men, aged 55–85 years (median 74 years), were included (Table 1). The men were recruited from two hospitals, different healthcare centres and patient associations. In line with the phenomenographic method (Marton, 1981; Marton and Booth, 1997), information was given to health professionals and chairpersons stating that it was important that there should be variation in the grade of COPD, from mild to severe, in age, in duration of COPD and in place of residence in order to maximize variation in conceptions. The head physician, managers of the departments and chairpersons of the patient associations received written and oral

Table 1 Description of male participants in the study

Variable	
Age (years) ^a	74 (55–85)
Duration of COPD in female spouse (years) ^a	5 (1–20)
<5 years (<i>n</i>)	8
5–10 years (<i>n</i>)	6
>10 years (<i>n</i>)	5
Reported perceived severity of COPD	
female spouses (n)	
Mild	3
Moderate	5
Severe	11
Years lived together ^a	48 (7–61)
Gainfully employed (n)	1
Early retirement	2
Retired	16
Marital status (n)	
Married	17
Cohabiting	2

COPD = chronic obstructive pulmonary disease. a Values are median (range).

information about the study and gave their written approval. When the women suffering from COPD visited the hospital, the healthcare centre or the patient association, they received a letter of invitation to join the study from the doctor, nurse or chairperson and were asked to invite their spouse to participate in the study. The spouse then sent a letter of consent to the first author.

Data collection

Data were collected through semi-structured interviews, which is the recommended method for collecting data in phenomenography (Marton and Booth, 1997). Data were collected between October 2008 and October 2009. An interview guide was developed based on literature and peer reviewed by researchers/nurses who were experienced in chronic disease management. The entry question was 'How is a typical day for you?', with follow-up questions, for example, 'What effect has it had on your daily life that your wife got COPD?' 'What do you do to manage your life?' Two pilot interviews (included in the study) were conducted and functioned well, which led to no changes in the interview guide. Seventeen interviews took place in the participants' homes, one at a patient association office and another was conducted in a university office. A researcher (first author) experienced in the

Table 2 Description of the data analysis process (Sjöström and Dahlgren, 2002)

- 1. Familiarization: The transcripts were read through to become familiar with the data and correct any errors in transcription.
- 2. Compilation: The most significant statements were identified in the answers given by each informant, and questions were asked about the text. 'What are the different ways of conceiving?' 'How is this conceived?' Statements were marked with coloured pencil.
- 3. Condensation: Longer statements were reduced to find the core of each answer given by the men. The men's expressions were used throughout the analysis to guide the interpretations.
- 4. Grouping or classification: Similar answers were brought together according to their characteristic features in order to obtain a more comprehensive understanding of how they were connected with each other.
- 5. Comparison: The selected statements were compared with find dividing lines between variations, establishing categories, which are distinct from each other and revising the preliminary analysis.
- 6. Labelling: The categories were named to capture the essence of the understanding. The categories were named as close to the text as possible.
- 7. Contrasting: Comparing and contrasting the categories, which cover a description of the unique characteristic of each category, as well as a description of similarities between categories.

field conducted all the interviews. Each interview lasted for 50 to 90 min, and was tape recorded and transcribed verbatim.

Ethical considerations

The study was carried out in accordance with the ethical standards of the Helsinki Declaration, and with written informed consent from the participants (World Medical Association Declaration, 2008). According to Swedish law at the time of the study, approval from an ethics committee was not required for research studies that did not pose a physical or mental risk to the informants (Swedish Health Care Act, 2003).

Data analysis

Data were analysed according to the method of phenomenography described by Sjöström and Dahlgren (2002), which comprises seven steps, shown in Table 2. In a phenomenographic analysis, it is essential to determine what is most important in a particular participant's answer.

The aim in phenomenographic analysis is to find different ways of understanding a phenomenon.

Findings

Two main descriptive categories were found, the 'Unchanged life situation' where no support was needed. 'Changed life situation' related to severity of COPD, where support was needed, with three subcategories: 'daily life is burdened', 'daily life is restricted' and 'partner relationship is affected'. The men's approach is that they continue with their own life and own activities and their approach to their situation are to view themselves as 'ME and my spouse'. They did not put themselves in second place. The outcome space is illustrated in Figure 1.

Unchanged life situation

The men caring for a woman with mild COPD conceived that their daily lives were unchanged from before the woman became ill. The woman's mild symptoms did not affect daily life, and support was not needed from healthcare or the municipality. The men had not taken over any extra tasks because of the COPD, and therefore no extra burden was put on them. They did what they had done in the past and continued with previous routines. They could make their trips as previously without restrictions. Their social life worked as before and there was no need to take into account the woman's condition, and the couple's relationship was not affected because of the COPD. The men lived their lives as before and continued with their own life and own activities.

Nothing in particular has changed for me, perhaps that she can ask me for something and it has to happen immediately and if it isn't done at once she does it herself. The day goes by, ... I cook all the food because I enjoy that, ... we are renovating the house and have various activities going on, ... we manage for ourselves, we carry on with life as it should be, no restrictions,... social life is important. (15)

Changed life situation

The men's daily lives were affected even if the disease had not reached the final grade. The demands increased as the COPD progressed. The

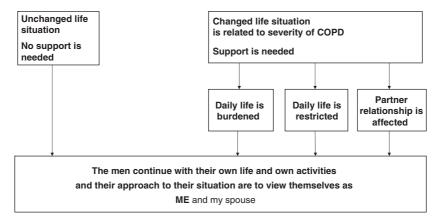


Figure 1 The outcome space. Two descriptive categories, consisting the different conceptions of daily life in men living together with a woman suffering from chronic obstructive pulmonary disease (COPD), and the men's approach to their situation.

disease gradually forced them into a caregiving role, having to take over household duties. The men felt their daily life was burdened, restricted and the COPD had affected the partner relationship. The disease limited their social life gradually and the men felt restricted in what they could do. They experienced an impact on their mental health because of the caregiving. As the COPD progressed the partner relationship became more affected and they became more of a caregiver. However, at the same time the men allowed themselves to continue with their own life and activities. They did not let their own needs and activities take second place.

She has no energy for anything, I have to take over virtually everything, ... I have no problem with that, ... it's mentally stressful, my role is more as a carer, ... day-to-day life is limited and heavy, we can't travel at all, we just have to take it gradually, you take the situation you're in, ... the garden and especially my fishing, that's freedom, and if I wasn't able to do that it would be very heavy indeed. (17)

Daily life is burdened

The men had no problems taking over household tasks, which they felt was a natural thing to do. At the same time they said that they were burdened in their caregiving role. As the COPD progressed the men became more burdened,

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which affected them negatively, mainly mentally. They found it difficult not being able to help when the woman had difficulty breathing. The disease ruled and they adapted to it.

It's difficult for her and it affects me mentally, I get depressed when I see and hear her.

I've had to take over just about everything, but it feels natural, but it is a strain ... the disease dictates and I have to adapt to it. (14)

She finds it really hard to get air, it's difficult to see it and not be able to do anything, ... it affects you, ... it's tough. (10)

Several men were suffering from illness of their own, but no one said that their own physical health had been affected by the caring duties; they only mentioned the mental impact.

... that I hear and see badly and have artificial legs, disk hernia, and an operated knee, but my health is all right, I suppose, ... but her illness makes me depressed, ... it affects me negatively. (14)

The men felt burdened and had to plan their days and take into account how the woman was feeling. As the disease progressed it was not easy to perform activities of their own, but somehow the men tried to continue with these.

... you have to think about the disease night and day, ... you have to plan more, ... we take the day as it comes, I take my bike and go for a ride, a kilometre every day in the morning, and once in the afternoon, ... I go out hunting with my son. (8)

Several men felt uncertain about the disease and how to handle it. They knew it was a disease that could lead to death, and they tried to make the best of the situation, for as long as they could manage. They worried about the progress of the disease and how it would end. The men felt bad about not knowing how long they could manage the heavy workload.

... the diagnosis was heavy because I didn't know how it worked. I keep thinking that it's a deadly disease,... you worry about how it will develop and how far it can go. (8)

I suffer from it ... I don't really know how I should handle it, how much longer she can cope with it ... as long as I have the energy I suppose it will be all right. (10)

The men felt that they did not get any support from health professionals or the municipality; they lacked information and practical support. All the men wished for information, with and without their spouse, given repeatedly, especially as the disease progressed. No one asked them how they managed or if they had the strength or needed support, not even in the severe grade of COPD. At the same time the men seldom accompanied the women to the doctor, and if they did they often sat in the waiting room.

They've never asked me how I am or how it's working out, I haven't been given any help at all. (7)

I don't usually go in with her when she sees the doctor, ... I drive her there, ... they have never turned to me as next of kin, ... I get no information about how to deal with things. (2)

Information is essential, both together and separately and more than once, ... no one has asked how it works at home. I visited her when she was in hospital, but they never turned to me. (13)

Most of the men thought that the smoking had caused the COPD; the men who smoked had difficulties stopping smoking themselves or had failed. They thought it was complex and made demands of them because they could not smoke as before, they had to smoke outside and hide the cigarettes.

... it's the smoking that caused the COPD, I'm absolutely sure of that. (9)

... I can't sit down and smoke, I can't let her see cigarette butts, it drives her crazy, ... I can't smoke in the house any more. (5)

Daily life is restricted

The men experienced restrictions in maintaining their social contacts because of the COPD. Their wives found it demanding when a lot of people came together, so the men refrained from social life to some degree. As time passed, the woman's symptoms made it impossible to do things together. They could not travel as before either in Sweden or abroad. They were restricted in having time to spend with their grandchildren, relatives or friends out of consideration for their women. They also considered the risk of infections.

Social life has been affected, ... we never go out to anything and that's because of the disease, she thinks it's difficult when there are too many people, ... it limits me, ... we can't travel anywhere at all. If the grandson has any infection he can't come. (11)

Several men experienced malaise and depression due to the caregiving strain, which restricted them in their daily life. Some women did not want to be left alone because of respiratory problems and feelings of panic at not getting air. Despite the restrictions the men created opportunities to have their own space to cope mentally by being reachable by phone.

It depresses me and I have to adjust, ... she wants me to be at home as much as possible ... she feels panic when she can't get air, I take the telephone with me so she can reach me. (7)

It affects me mentally, I get depressed when I see that she has difficulty breathing. (8)

The high cost ceiling covered the costs for medication and medical visits so it did not cause any economic problems. However, the men thought that the cost of home help was too high,

which restricted them in their daily life because they had to do everything without assistance.

... we were going to get home help ... but it didn't work out because they charged seven or eight hundred crowns an hour, ... which we thought was too expensive. If I have the strength and can cope without help it won't happen. (16)

Partner relationship is affected

The men balanced between being a spouse and a caregiver, and when the COPD reached the severe grade they felt they were more a caregiver.

I feel more like a carer, ... I was joking with her the other day and said that I ought to get a carer's allowance, ... but as long as I can manage I'll do it. (7)

Husband? More of a carer, you could say. (4)

The men wanted to help and be close to their woman, but they needed their own space. They managed the situation by continuing with previous activities. To have activities of their own allowed recovery and generated energy, this gave a possibility to get a distance to the situation. Some men said it was not their fault that the woman had got COPD.

... of course you have the responsibility ... but you have to be able to do some things of your own as well, ... I have my own activities for relaxation, it's not my fault that she has COPD. (2)

I'm a practical person so I do a lot of things with the house, for example, that's been my salvation. (11)

... but you have to be able to do what you yourself want as well, so I drive out to the boat. (10)

Depending on the woman's symptoms they did things together, such as going to the anti-smoking clinic, bridge, etc. If some of the activities did not work out, they tried to find solutions to the problem, for example, a tandem to ride together if the woman could not manage to walk or cycle.

... we go together to the anti-smoking clinic every Tuesday, and every Thursday we play bridge. (3) We have activities with the Pensioners' Organization, we've been renovating the house, she likes to get exercise, and we've tried various things, I had the brilliant idea of buying a tandem. (11)

When problems occurred, most of the men focused and tried to solve them. They lived in the present, and did not think about any problems in advance. The men's attitude was that what will be will be.

... you have to tackle the problems that arise and take them as you can solve them. (14)

... you put off the hard things, you have to take advantage of the time you have and not get too depressed. (18)

... I feel no worry, what happens will happen. (1)

Some couples could talk about the COPD, whereas others had difficulties. Some men had the same emotional feelings for their woman, and for some the feelings had deepened. They saw it as a part of life to be there for each other, but they found it difficult not to know what to do. They tried to make the wife's life easier by doing something fun.

We can talk, ... it's no problem. (19)

... I find it really hard to talk about illness,... it's easier for women.' (10)

The feelings are deeper but you don't know how to handle it. (2)

... we're just as fond of each other. I try to drive her around in the car because she likes that. (14)

A few couples still had a sex life, but it was adjusted to suit the woman's condition. Several men said that their sex life was affected because of their own health or their wife's health.

... it has no effect on our sex life. (19)

Yes, our sex life is definitely affected by the disease, it doesn't work at all because she could never manage it. (4)

The women's mood swings could be a problem. Most of the men could tell their wife not to demand too much of them.

The worst thing is her mood swings, ... I go around on tiptoe at home. (16)

... there are demands but they're not unreasonable, she is aware and I can protest if I have to. (4)

Discussion

The main findings showed two categories: (1) unchanged life situation where no support was needed; (2) changed life situation related to the severity of COPD, where support was needed. The men felt that daily life was burdened, restricted and the partner relationship was affected. The men's attitude was from the perspective of 'ME and my spouse'. The men did not put themselves in second place. They created opportunities to continue with their own life and activities despite being in a caregiving situation.

The study shows that men living with a woman with mild COPD did not experience changes in their daily life, and support was not needed. This is a new finding in relation to previous studies that have shown no similar results, as only severe and very severe grades have been studied. The men were affected in their daily life when the COPD gradually progressed, even though the COPD had not reached the final grade. The men's life situation changed because of the severity of COPD, which resulted in caregiver strain. They expressed consequences similar to those of a person suffering from COPD (Seamark et al., 2004; Kanervisto et al., 2007), a growing restriction of daily life and adjustments to the condition. Previous studies have shown that persons with COPD become more limited as the disease progresses, and in later grades they need help with everything (Barnett, 2005; Gysels and Higginson, 2009). This study shows that the progress of the disease results in the men experiencing increased demands and responsibilities to take an active part in supporting the daily life of their wives. The men have to take over more household tasks, and in the end they have the responsibility for everything. As the length of hospital stay has decreased during the last few years, and most persons with COPD are cared for in their homes with follow-ups in primary health care or pulmonary departments at the hospital (Heart and Lung Association, 2009), a larger workload and responsibilities is transferred to spouses.

Previous studies show how important spouses are for COPD sufferers to manage their daily life and be able to stay in their home (Kanervisto et al., 2007; Simpson et al., 2010). The Social Services Act (SFS, 2001: 453) clarifies how important it is that county councils and municipalities work together to identify and support informal caregivers. In the present study, the men rejected the home service because of its cost. The men wished for information and support from health professionals, but they conceived that health professionals did not give them what they needed and they felt ignored. They felt they were left alone with the caring, and even when the woman had severe COPD and the caring was intense, no one asked them how they managed or if they had the strength or needed support. People who receive support will be less vulnerable and learn to cope with their situation (Lazarus and Folkman, 1984). The men conceived that they did not receive this support because they had no contact with the health professionals when the woman was treated at the pulmonary department or at the healthcare centre. To have information and knowledge about what they undergo can give a sense of control (Lazarus and Folkman, 1984). At the same time the men seldom accompanied the women to the doctor, and if they did they often sat in the waiting room. There are studies indicating that men complain about the inefficiency and inadequate leadership of the healthcare organization, and that the individual's needs are ignored (Foss, 2004), and they are reluctant to attend to their GP because of the negative response they felt they had from the health service (White, 2001). This should be studied further as there may be other explanations why men do not accompany the women on healthcare visits.

Studies have shown that informal caregivers are at greater risk of ill health (Seamark et al., 2004; Kanervisto et al., 2007; Simpson et al., 2010). This study found that the men felt burdened and restricted, which resulted in caregiver strain. The men balanced between being a spouse and a caregiver, finally becoming more of a caregiver because of the progress of the disease. Several men themselves were suffering from serious diseases. Previous studies show that men have lower levels of somatic symptoms and higher levels of mental ill health than caregiving women

(Thompson et al., 2004). The findings in this study, indicating that men in this situation more often have mental than physical impact, are crucial and need to be considered when trying to support the men, even though they do not ask for support. Females report more somatic symptoms, anxiety and insomnia than men (Nordtug et al., 2011). These differences may be because men and women conceive and deal with the role of caregiver differently (Thompson et al., 2004).

Despite the men's feeling of burden and restriction in their daily life they continued with their own life and refused to take second place, not everything was focused on the caregiving duties. Regardless or independently of the COPD severity, the men in the study kept their coping strategies and handled daily life with an ill spouse by continuing with their lives and activities in the perspective 'ME and my spouse'. Their own activities involved recovery and generated energy and a possibility to distance themselves from the situation. This is in contrast to women giving informal care to men with COPD, who were prisoners of the caregiving situation and did not allow themselves to have their own activities (Lindqvist et al., accepted). Previous studies have shown that emotional care is more likely to be given by women than men, who performed more personal care tasks (Hwang et al., 2010). Men are task oriented in their caregiving duties, and carry out activities in a linear style, whereas women use a parent-child approach and enfold activities in a constant stream of duties (Corcoran, 1992). Women have been shown to be more inclined to caring activities and relationships, whereas men are instrumental, technical and ego oriented (Jakobsen and Karlsson, 1993; Jakobsen, 1999). For men, caregiving was a job that must be performed or a problem to be solved (Calasanti and King, 2007). Men use more problem-focused coping, whereas women use more emotionfocused coping (Folkman and Lazarus, 1980). In the present study, the men focused on practical care as a way of defining the problem with an attempt to handle it; if they have problems they question their tactics and try to find solutions. The men do not complain, they do what needs to be done, but make sure that they have some time for themselves.

Studies from the National Board of Health and Welfare (2010) indicate that support in many

cases is a prerequisite for informal caregivers to cope with their tasks. This study illustrates the complex situation of being a male caregiver with changes in many areas and a need for support from health professionals and the municipality. A multi-professional team could provide a possibility to work effectively with their situation; the team should be coordinated by a COPD nurse familiar with the disease, able to monitor needs and provide sufficient support with help from the multi-professional teamwork, for example, counselling, coping strategies, etc. (Osterlund Efraimsson et al., 2008; Lindqvist et al., accepted). To develop a good structure, a spouse plan should be drawn up by health professionals (Lindqvist et al., accepted). The role of the nurse is to assess the patient's individual needs, and based on the care plan to coordinate the health professionals that need to be involved. The nurse then acts as a coordinator of the multi-professional team (National Board of Health and Welfare, 2005).

Strengths and limitations

An interview-based method was chosen to obtain a deeper insight and understanding in a field where knowledge was lacking. The phenomenographic research method was used, the aim of which is to investigate various ways to conceive a phenomenon (Sjöström and Dahlgren, 2002). Nineteen interviews were conducted, which is considered an adequate number to allow different conceptions (Marton and Booth, 1997; Sjöström and Dahlgren, 2002), and this is considered a strength of the study. A qualitative study does not aim to give a generalized conclusion, but the results can be transferred to other settings or groups with similar characteristics (Sjöström and Dahlgren, 2002). A strength of the study was that men were given the opportunity to describe their conceptions of how they live their daily life. The data material contains of a variety of men's conceptions, with a predominance of spouses having severe COPD, which can be viewed as a strength in relation to the purpose. Sixteen were retired and two had taken early retirement, whereas only one was still working. COPD is mostly diagnosed in middle-aged or older people. Thus, the group represents a broad range of experiences and conceptions, which is the main goal of phenomenographic research (Marton and

Booth, 1997). The core question of credibility is about the relationship between the empirical data and the categories for describing ways of experiencing a certain phenomenon (Marton, 1981; Marton and Booth, 1997). In this study, the credibility is ensured by the way similarities and differences between the participants' conceptions are supported by the empirical data. The coauthors double-checked the content of the categories to verify the relevance. Furthermore, in accordance with Sjöström and Dahlgren (2002), a precise description of each part of the research process is given and quotations from the interviews are provided so that the relevance of the categories can be judged.

Conclusion and implications

There was variation in men's conceptions of their daily life, related to the progress of the COPD. The men living with a woman with mild COPD experienced no changes of their daily life, but this changed when the COPD progressed. The men were affected in their daily life even if the women's COPD was not severe. Men appear to accept and adjust to the caregiving as a broadening of their marital vows. The men are engaged in the caregiving tasks, but at the same time they allow themselves to continue with their own life and activities. The men felt uncertainty in the care, due to lack of knowledge, information and support. Coordination by a COPD nurse monitoring needs and providing sufficient support to the caregiving men with help from a multi-professional team would be a valuable help for them. The men reported no physical impact, only mental impact due to their caregiving, and in order to manage they need support. A spouse plan could be helpful to discover the men's needs to be able to support them in a sufficient way. Further studies are needed to describe in more detail the differences in being a male/female caregiver and how appropriate support can be developed in relation to this.

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References

- **Barnett, M.** 2005: Chronic obstructive pulmonary disease: a phenomenological study of patients' experiences. Journal of Clinical Nursing 14, 805-12.
- Bergs, D. 2002: The hidden client women caring for husbands with COPD: their experience of quality of life. Journal of Clinical Nursing 11, 613-21.
- Booth, S., Silvester, S. and Todd, C. 2003: Breathlessness in cancer and chronic obstructive pulmonary disease: using a qualitative approach to describe the experience of patients and carers. Palliative and Supportive Care 1, 337-44.
- Buchanan, R., Radin, D. and Huang, C. 2010: Burden among male caregivers assisting people with multiple sclerosis. Gender Medicine 7, 637-46.
- Calasanti, T. and King, N. 2007: Taking women's work like a man: husbands' experiences of care work. The Gerontologist 47, 516-27.
- Carling Elofsson, L. and Öhlén, J. 2004: The meaning of being old and with chronic obstructive pulmonary disease. Palliative Medicine 18, 611–18.
- Corcoran, M.A. 1992: Gender differences in dementia management plans of spousal caregivers: implications for occupational therapy. American Journal of Occupational Therapy 46, 1006-12.
- Ducharme, F., Lévesque, L., Lachance, L., Gangbé, M., Zarit, S., Vézina, J. and Caron, C. 2007: Older husbands as caregivers: factors associated with health and the intention to end home caregiving. Research on Aging 29, 3-31.
- Ek, K., Ternestedt, B-M., Andershed, B. and Sahlberg-Blom, E. 2011: Shifting life rhythms: couples' stories about living together when one spouse has advanced chronic obstructive pulmonary disease. Journal of Palliative Care 27, 189-97.
- Folkman, S. and Lazarus, R.S. 1980: An analysis of coping in a middle-aged community sample. Journal of Health and Social Behavior 21, 219-39.
- Foss, C. 2004: Patients' voices on satisfaction: unheeded women and maltreated men? Scandinavian Journal of Caring Sciences 18, 237-80.
- Gautun, H., Werner, A. and Lurås, H. 2012: Care challenges for informal caregivers of chronic ill lung patients: results from a questionnaire survey. Scandinavian Journal of Public Health 40, 18-24.
- Global Initiative for Chronic Obstructive Lung Disease (GOLD). 2011: Global strategy for diagnosis, management,

- and prevention of chronic obstructive pulmonary disease. Retrieved 16 May 2011 from htpp://www.goldcopd.com
- Gysels, M. and Higginson, I. 2009: Caring for a person in advanced illness and suffering from breathlessness at home: threats and resources. Palliative and Supportive Care 7, 153-62.
- Heart and Lung Association. 2009: A report on COPD. The forgotten public health disease. (Hjärt- och Lungsjukas Riksförbund. 2009: En rapport om KOL. Den bortglömda folksjukdomen). Retrieved 31 August 2011 from http:// www.hjart-lung.se/hjartlung/uploads/Dokument/kol_rapport_ webb.pdf.on.
- Hwang, B., Luttik, M.L., Dracup, K. and Jaarsma, T. 2010: Family caregiving for patients with heart failure: Types of care provided and gender differences. Journal of Cardiac Failure 16, 398-403.
- Ingadóttir, T.S. and Jonsdottir, H. 2006: Technological dependency - the experience of using home ventilators and long-term oxygen therapy: patients' and families' perspective. Scandinavian Journal of Caring Sciences 20, 18-25.
- Jakobsen, L. 1999: Livsform, kön och risk: En utveckling och tillämpning av realistisk livsformsanalys. (Life-mode, gender and risk: a development and application of realistic life-mode analysis). Lund: Arkiv Förlag.
- **Jakobsen, L.** and **Karlsson, J.C.H.** 1993: Arbete och kärlek: En utveckling av livsformsanalys. (Work and love: a development of an analysis of life-modes). Lund: Studentlitteratur.
- Kanervisto, M., Kaistila, T. and Paavilainen, E. 2007: Severe chronic obstructive pulmonary disease in a family's everyday life in Finland: perceptions of people with chronic obstructive pulmonary disease and their spouses. Nursing and Health Science 9, 40-47.
- Kanervisto, M., Kaistila, T. and Paavilainen, E. 2007: Family dynamics in families of severe COPD patients. Journal of Clinical Nursing 16, 1498-505.
- Kühl, K., Schürmann, W. and Rief, W. 2008: Mental disorder and quality of life in COPD patients and their spouses. International Journal of COPD 3, 727-36.
- Larsson, K. 2002: Kronisk obstruktiv lungsjukdom. (Chronic obstructive pulmonary lung disease). Stockholm: Boehringer Ingelheim.
- Lazarus, R.S. and Folkman, S. 1984: Stress, appraisal and coping. New York: Springer.
- Lindqvist, G. and Hallberg, R-M.L. 2010: Feelings of guilt due to self-inflicted disease. Journal of Health Psychology 15, 456-66.
- Lindqvist, G., Håkansson, A. and Petersson, K. 2004: Informal home caregivers in a gender perspective: a selected literature review. Vård i Norden 24, 26-30.
- Lindqvist, G., Albin, B., Heikkilä, K. and Hjelm, K. (accepted) Conceptions of daily life in women living with a man suffering from chronic obstructive pulmonary disease (COPD). Primary Health Care Research & Development, 1-1212, doi:10.1017/S146342361200031X.
- Marton, F. 1981: Phenomenography describing conceptions of the world around us. Instructional Science 10, 177-200.
- Marton, F. and Booth, S. 1997: Learning and awareness. Mahwah, New Jersey, USA: Lawrence Erlbaum Associates.

- Nordtug, B., Krokstad, S. and Holen, A. 2011: Personality features, caring burden and mental health of cohabitants of partners with chronic obstructive pulmonary disease or dementia. Aging & Mental Health 15, 318-26.
- Österlund Efraimsson, M., Hillervik, C. and Ehrenberger, A. 2008: Effects of COPD self-care management education at a nurse-led primary health care clinic. Scandinavian Journal of Caring Science 22, 178-85.
- Pinto, R., Holanda, M., Medeiros, M., Mota, R. and Pereira, E. 2007: Assessment of the burden of caregiving for patients with chronic obstructive pulmonary disease. Respiratory Medicine 101, 2402-408.
- Seamark, D.A., Blake, S.D. and Seamark, C.J. 2004: Living with severe chronic obstructive pulmonary disease (COPD): perceptions of patients and their carers. Palliative Medicine 18, 619-25.
- Simpson, C., Young, J., Donahue, M. and Rocker, G. 2010: A day at a time: caregiving on the edge in advanced COPD. International Journal of COPD 5, 141-51.
- Sjöström, B. and Dahlgren, L-O. 2002: Applying phenomenography in nursing research. Journal of Advanced Nursing 7,
- Social Services Act (SFS). 2001: Socialtjänstlagen. Stockholm: Riksdagen, 453 pp.
- Socialstyrelsen (National Board of Health and Welfare). 2005: Kompetensbeskrivning för legitimerad sjuksköterska. (Competence Description for Registered Nurse). Stockholm: Socialstyrelsen.
- Socialstyrelsen (National Board of Health and Welfare). 2010: Meddelandeblad: stöd till anhöriga i form av service eller behovsprövad insats - handläggning och dokumentation. (Information sheet: support for next kin in the form of service or need-tested measures-administration and documentation). Stockholm: Socialstyrelsen.
- Spence, A., Hasson, F., Waldron, M., Kernohan, G., McLaughlin, D., Cochrane, B. and Watson, B. 2008: Active carers: living with chronic obstructive pulmonary disease. International Journal of Palliative Nursing 8, 368–72.
- **Swedish Health Care Act.** 2003: The act concerning the ethical review of research involving humans. Vetting the ethics of research involving humans. Retrieved 3 March 2008 from http://www.epn.se/start.startpage.aspx
- Thompson, E.H. 2002: What's unique about men's caregiving?. In Editor, B.J. Kramer and E.H. Thompson, Men as caregivers. New York: Prometheus Books.
- Thompson, R., Lewis, S., Murphy, M., Hale, J., Blackwell, P., Acton, G., Clough, D., Patrick, G. and Bonner, P. 2004: Are there sex differences in emotional and biological responses in spousal caregivers of patients with Alzheimer's disease? Biological Research for Nursing 5, 319-30.
- White, A. 2001: How men respond to illness. Men's Health Journal 1, 18-19.
- World Medical Association Declaration of Helsinki. 2008. Ethical principles for medical research involving human subjects. Retrieved 21 October 2008 from http://www. wma.net/en/30publications/10policies/b3/index.html