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Breathlessness in everyday life from a patient perspective: A qualitative study using diaries

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ABSTRACT

Objective: Breathlessness is a subjective symptom, which makes it difficult to define and understand. The aim of the present study was to illuminate how patients suffering from breathlessness experience their everyday life.

Method: The study was a qualitative study, and the focus of the analysis was the patients' descriptions of their experiences of breathlessness using a diary with two unstructured questions for a period of 7 consecutive days. Sixteen participants: 7 men, mean age 65 ± 7 (range 55–73 years old), and 9 women, mean age 65 ± 9 (range 50–72 years old) participated in the study.

Results: Two themes emerged from the analysis: 1) Impaired quality of life and 2) symptom tolerance and adaptation. The theme “impaired quality of life” included the categories limited physical ability, psychological burdens, and social life barriers. The theme “symptom tolerance and adaptation” included importance of health care, social support, hobbies and leisure activities, and coping strategies.

Significance of results: The findings in our study showed that patients, in spite of considerable difficulties with shortness of breath, found relief in several types of activities, in addition to drug therapy. The result indicates that the “biopsychosocial model” is an appealing approach that should be discussed further to gain a better understanding of breathlessness.

KEYWORDS: Breathlessness, Chronic obstructive pulmonary disease, Diary, Dyspnea, Heart failure, Primary healthcare

INTRODUCTION

Breathlessness, or dyspnea, is a common symptom among patients in primary healthcare (Huijnen et al., 2006) and has been ranked fifth among the top 10 differential diagnoses in family medicine (Ponka & Kirlew, 2007). The underlying causes are mostly cardiopulmonary diseases such as heart failure (CHF), ischemic heart disease (IHD), asthma, and chronic obstructive pulmonary disease (COPD). However, obesity, anxiety, anemia, and advanced cancer can also cause breathlessness. Breathlessness

has been difficult to quantify, and in that respect, it may be compared to pain and fatigue as a highly subjective symptom.

Breathlessness can be measured either using one-dimensional scales such as the Visual Analogue Scale-Dyspnea (VAS-D), Medical Research Council (MRC) Breathlessness Scale, modified Borg scale (Stenton, 2008; Johnson et al., 2010; Saracino et al., 2010) or by means of questions about the degree of breathlessness in connection with activities (Bestall et al., 1999; Mahler et al., 2004) or by measuring the impact of breathlessness on health related quality of life (Guyatt et al., 1987; Jones et al., 1992). In the latter case, multidimensional scales or questionnaires are often used. Despite all efforts and because of the complexity of breathlessness, it has been

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difficult to find an accepted method to quantify breathlessness in a clinical setting (Bausewein et al., 2007).

Understanding breathlessness from the patients' point of view gives us valuable insight about what impact it has in patients' day-to-day life; furthermore, the fact that it is a subjective symptom makes it a suitable study object in a qualitative investigation. In previous qualitative studies, breathlessness was studied in light of underlying disease (Gysels et al., 2007); therefore, we wanted to collect data about breathlessness regardless of any underlying disease (Booth et al., 2003; Edmonds et al., 2005; Arne et al., 2007; Mahler et al., 2007; Roche, 2009). The aim of the study was to illuminate how patients suffering from breathlessness experience their everyday life.

METHOD

Design and Participants

The study uses qualitative content analysis. The selection of participants took place at a health center when patients came to their ordinary check-ups asked by their regular physician. Twenty patients were included voluntarily. The inclusion criteria were the presentation of breathlessness and adult age. Patients were excluded if they had a history of malignant disease, dementia, or panic disorder.

Data Collection and Analysis

We used an inductive content analysis method by using diaries as a tool for data collection (Elo & Kynas, 2008). Diaries have been used extensively in research (Freer, 1980), but not as a qualitative data collection instrument about breathlessness. Therefore, we used a diary as a tool for data collection consisting of two open-ended questions. The participants were instructed to complete the diaries for each day

in the evening. They were asked to take notes about their feelings and experience with breathlessness every day for 7 days. The patients were able to free associate when writing about their breathlessness. The two questions were:

1. Please state if you have experienced breathlessness during the past 24 hours or felt unwell for some reason. Has your sleep been affected by your breathlessness? Please describe how you manage everyday life (work/leisure) despite your breathlessness.
2. Did you talk to any other people during the day about your health problems or did someone give you advice or help, for example, your family, friends, telephone-based care, nurses, pharmacies, or alternative medical practitioners (Table 1)?

We used VAS-D as an instrument for repeated measurements in order to describe the health state of the population on an everyday basis (Parkin et al., 2004).

The diaries were coded, and only the researcher knew the participants' identities. Diaries were tested on four participants in the beginning of the study. We found that it would be difficult for participants to keep a diary for more than 7 days.

We transcribed all collected diaries in a word processor. When analyzing the diaries, we followed the steps for analyzing qualitative data described by Graneheim and Lundmann (2004). The diaries were read through repeatedly in order to get a feeling for the whole. Sentences that were relevant to the issue were selected. Meaning-bearing units were identified and coded and then categorization of texts was made. The approach was patient centered and more holistic, not just individual parts of tales. All researchers were involved in the interpretation and categorization of the text, and the process continued

Table 1. *The model of the diary*

Quantitative part	Qualitative part
VAS Please put a cross on the line at the point that best describes how you felt today: Not well at all OK Very well	The questions 1. Please state if you have experienced breathlessness during the past 24 hours or felt unwell for some reason. Has your sleep been affected by your breathlessness? Please describe how you manage everyday life (work/leisure) despite your breathlessness. 2. Did you talk to any other people during the day about your health problems or did someone give you advice or help, for example, your family, friends, telephone based care, nurses, pharmacies or alternative medical practitioner?

until agreement on categories was reached. Two themes emerged when we evaluated the data further.

Ethical Consideration

The Regional Ethical Review Board in Gothenburg (Sweden), Dnr 157/11 approved the study. Instructions and purpose of the study was given to the participants in both written and oral form. The study was conducted in accordance with the Helsinki declaration (Williams, 2008). Written informed consent was obtained from all participants.

RESULTS

Twenty patients agreed to participate in the study. However, four of the patients did not continue their participation. Two of the patients reported that they were no longer breathless, and the other two were not able to fulfil the task with recording diaries. They were, therefore, excluded from the study. However, 16 patients: 7 men, mean age 65 ± 7 (range 55–73 years old) and 9 women, mean age 65 ± 9 (range 50–72 years old) completed the study.

Five of the participants had a diagnosis of COPD (four women, one man), six had a CHF diagnosis (one woman, five men), three had anxiety disorder (all female), one had aorta stenosis (male) and one had an asthma diagnosis (female). Five participants were smokers (four had COPD and one had anxiety disorder), whereas two of the patients were former smokers (one had COPD and the other had anxiety disorder).

Participants marked the state of their health one time a day on the VAS. Seven observations equal to

the number of days they participated were then done.

Minimum, maximum, mean, and standard deviation were calculated as shown in Figure 1.

We found 21 subcategories and 8 categories, and after analyzing the content further, two themes emerged: (1) Impaired quality of life and (2) symptom tolerance and adaptation.

Impaired Quality of Life

Breathlessness had a negative impact on how everyday life was experienced by the patients; moreover, they described it in different terms such as weakness, tiredness, fatigue, feeling run-down, having insomnia, stress, or anxiety. They even mentioned problems in their social life such as difficulty talking with others about their problem and inability to play with their grandchildren. All these complications had consequences for their social life. The following categories are included in the theme: limited physical ability, psychological burdens, and social life barriers.

Limited Physical Ability

The most common consequence of breathlessness was activity limitation and tiredness. Participants mentioned weakness doing or inability to do common daily tasks as being major limitations in daily life. Several patients had problems with heavy lifting or performing other physically demanding activities because they could cause breathlessness. One patient said: “I have difficulties to go more than 12 metres sometimes.” Some avoided physical activities because of the burden of the persistent breathlessness.

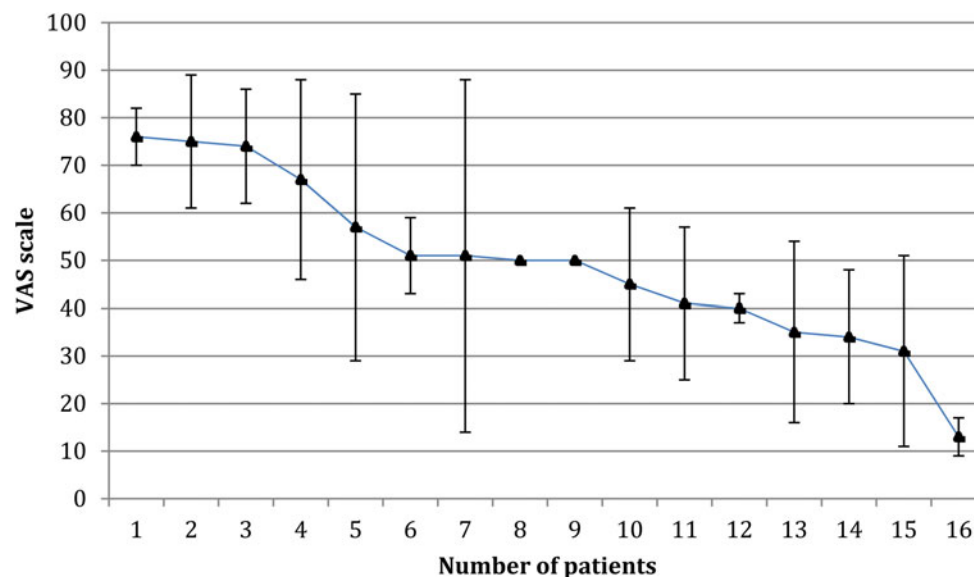


Fig. 1. Daily VAS-D score for participants (n = 16): mean, minimum and maximum values

Psychological Burdens

Breathlessness caused emotional problems and vulnerability. Some participants mentioned sleep disturbances and stress as major psychological burdens. Seven of the participants had some kind of sleeping problems either difficulty in falling asleep or poor sleep quality. One patient said: "I am awake most of the night because of my breathlessness."

For some patients, their symptoms of breathlessness were characterized by anxiety. The problem could be mild or severe and sometimes caused inability to cope with daily life's demands. One participant said: "Sometimes I feel that I walk beside myself."

Social Life Barriers

Breathlessness was an obstacle to the patients' social life and a significant cause of reduced quality of life. The symptoms had a negative influence on social relationships. One participant puts it this way: "Today, I thought life was hard when I could not be with whom I wanted to be with." Lack of confidence made it difficult for them to participate in many of the activities they most desired. One participant said: "My problem stops me in my social life. I am not sure anymore. Can I do this? Can I do that?" Some participants wrote about their loneliness and the unwanted isolation they had to endure because of their breathlessness.

Symptom Tolerance And Adaptation

The participants indicated that they were able to tolerate the severity of their symptoms with appropriate medication and/or if they had support from their family or if they were involved in some kinds of activities. They had developed different coping strategies. The following categories were finally considered: importance of healthcare, social support, hobbies and leisure activities, and coping strategies.

Importance of Healthcare

Several patients mentioned the importance of medication. Some felt anxious if they did not have their inhalators nearby prior to going out and shopping. Others mentioned the importance of check-ups at the health center. They relied very much on their regular controls. One patient said "Everything is easier and gets a little more positive after my check-up today. It has probably helped a bit with the higher dose of medicine."

Social Support

The support they got from family members and friends allowed patients to feel better. One patient

said: "I have met and spoken with some friends today who know well my problems. . . . that simplifies a lot."

The support could be physical assistance, for example, helping them with cleaning their home or washing dishes, but it could also be emotional support. It could be talking on the telephone with an adult child or going out with relatives or friends.

Hobbies and Leisure Activities

Eight of the patients mentioned the importance of mental and physical activities. Walking alone or with a dog was something that was appreciated by many. Dancing, painting, gardening, and cooking were also activities mentioned by the participants. These activities often helped them to forget their problems. One of the participants mentioned: "Walking with my dog is something I like, easy to breathe and I feel good afterwards." Another participant said: "Easier gardening today. A positive day."

Coping Strategies

The patients exhibited various forms of coping that helped them get through everyday life with their breathlessness. Denial, reflection, planning, and adaptation were some of these strategies.

Denial and refusal are examples of negative coping that may be important for some patients. "When I am better I don't want to think about my disease."

One of the patients put it this way: "When I read what I wrote, I realise that I should work out and begin to exercise more. I have actually wanted to do it for a long time, but it becomes so clear here."

Some of the participants mentioned how they plan their days in order to be able to get things done. One said: "I plan my actions as good as possible, breathe deeply, resting and so on." And yet another said: "I have changed my lifestyle slightly and I work less than before, otherwise I cannot handle my situation." Symptoms get worse gradually, which makes adaptation possible.

As one mentioned: "It is so gradual that you learn to live with it." And another said: "Living with health problems for a long time makes you eventually get used to it. The abnormal becomes normal in the end."

DISCUSSION

The findings in our study showed that patients, in spite of considerable difficulties with shortness of breath, found relief in several types of activities, in addition to drug therapy. Hobbies and leisure activities were sources of recreation and vitality. Support from family members and friends were also crucial to enable patients to get through the times when the breathlessness was at its worst[R1]. Patients

had a variety of different psychological tools to cope with their symptoms on a daily basis (Fig. 2). The physical, Psychological and social dimensions of patients' lives were affected by breathlessness to different degrees. However, this was compensated for by factors that improved day-to-day life for participants. Some of them developed new ideas about how they experienced life with their symptom. Some patients mentioned that keeping a diary during the study period had helped them to reflect on their situation and that they could see their problems much more clearly as a result.

The strength of our study was that the study engaged all the participants to tell as much about their symptoms as they wanted. We felt that it was valuable for patients with breathlessness to write in diaries. Diaries have demonstrated their research potential in many studies, and it appears that they may have particular value in data collection on common health problems and the psychosocial dimensions of these problems (Freer, 1980). Using a diary in the investigation of breathlessness was, to our knowledge, new; both researchers and patients obtained new insights about the participants' day-to-day life with breathlessness.

However, the challenge in our study was the low number of patients who participated in the study. Some participants seemed to lose focus on the issue in longer follow-ups, something we noticed in the beginning of the study. This allowed us to determine on a length of 2 weeks for data collection.

The fact that the daily life of patients was affected in all three areas—physical, psychological, and social—as a consequence of breathlessness could

raise the question whether a biopsychosocial model (Engel, 1977,1983) could ease the understanding of this highly subjective symptom. Engel highlighted the framework of the biopsychosocial model for a new understanding of a variety of illnesses (Engel, 1977). The model has been used for a better understanding of the symptom pain (Lumley et al., 2011). The results of the study indicate that the biopsychosocial model described by Engel is an appealing approach, which should be discussed further to gain a better understanding of the symptom of breathlessness.

Restriction in everyday life and limitation in physical activity have been described earlier both in patients with CHF (Edmonds et al., 2005) and COPD (Roche, 2009). In their article, Baily et al. highlighted the importance of nonpharmacological management of breathlessness (Bailey et al., 2010) and in our study we could see how participants told about their different strategies coping with breathlessness in daily life.

Diaries as a data-collecting tool among patients with breathlessness may carry information about the immanent potential patients have to handle the everyday life. It could also be used for monitoring the progression of breathlessness or the effect of medication. More research should be conducted about how diaries could be used in an effective way in primary care as both diagnostic and monitoring tools. Developing a biopsychosocial perspective is important in primary healthcare when meeting with patients with breathlessness.

Efforts should be made to deal with breathlessness from a biopsychosocial perspective when meeting patients with breathlessness in primary care.

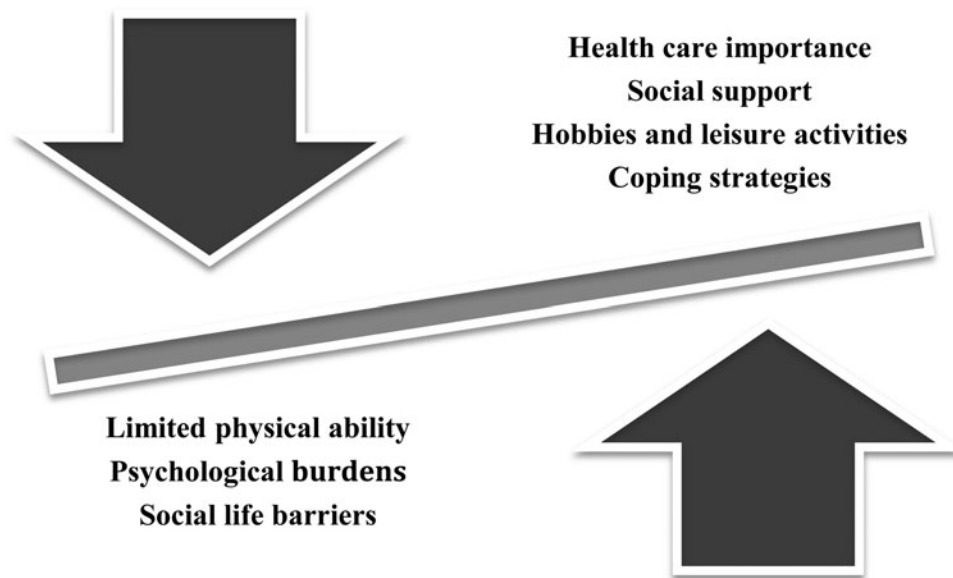


Fig. 2. Categories illuminating how patients suffering from breathlessness experience their everyday life

This could lead to a better understanding of not only the specific symptoms but also of the patient with the symptom. Use of diaries by patients with breathlessness can lead to greater motivation and ability to reflect by the diary keeper.

Because patients have different types of activity limitation, it is important to offer them activities and exercise in different forms. Cognitive behavioral therapy could also be considered as part of the treatment of breathlessness, especially among patients with anxiety or even other disorders such as underlying diseases.

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REFERENCES

- Arne, M., Emtner, M., Janson, S., et al. (2007). COPD patients perspectives at the time of diagnosis: A qualitative study. *Primary Care Respiratory Journal: Journal of the General Practice Airways Group*, *16*, 215–221.
- Bailey, C.D., Wagland, R., Dabbour, R., et al. (2010). An integrative review of systematic reviews related to the management of breathlessness in respiratory illnesses. *BMC Pulmonary Medicine*, *10*, 63.
- Bausewein, C., Farquhar, M., Booth, S., et al. (2007). Measurement of breathlessness in advanced disease: A systematic review. *Respiratory Medicine*, *101*, 399–410.
- Bestall, J.C., Paul, E.A., Garrod, R., et al. (1999). Usefulness of the Medical Research Council (MRC) dyspnoea scale as a measure of disability in patients with chronic obstructive pulmonary disease. *Thorax*, *54*, 581–586.
- Booth, S., Silvester, S. & Todd, C. (2003). Breathlessness in cancer and chronic obstructive pulmonary disease: Using a qualitative approach to describe the experience of patients and carers. *Palliative & Supportive Care*, *1*, 337–344.
- Edmonds, P.M., Rogers, A., Addington-Hall, J.M., et al. (2005). Patient descriptions of breathlessness in heart failure. *International Journal of Cardiology*, *98*, 61–66.
- Elo, S. & Kyngas, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, *62*, 107–115.
- Engel, G.L. (1977). The need for a new medical model: A challenge for biomedicine. *Science*, *196*, 129–136.
- Engel, G.L. (1983). The biopsychosocial model and family medicine. *The Journal of Family Practice*, *16*, 409, 412–403.
- Freer, C.B. (1980). Health diaries: A method of collecting health information. *The Journal of the Royal College of General Practitioners*, *30*, 279–282.
- Graneheim, U.H. & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, *24*, 105–112.
- Guyatt, G.H., Berman, L.B. & Townsend, M. (1987). Long-term outcome after respiratory rehabilitation. *CMAJ*, *137*, 1089–1095.
- Gysels, M., Bausewein, C. & Higginson, I.J. (2007). Experiences of breathlessness: a systematic review of the qualitative literature. *Palliative & Supportive Care*, *5*, 281–302.
- Huijnen, B., van der Horst, F., van Amelsvoort, L., et al. (2006). Dyspnea in elderly family practice patients. Occurrence, severity, quality of life and mortality over an 8-year period. *Family Practice*, *23*, 34–39.
- Johnson, M.J., Oxberry, S.G., Cleland, J.G., et al. (2010). Measurement of breathlessness in clinical trials in patients with chronic heart failure: The need for a standardized approach: A systematic review. *European Journal of Heart Failure*, *12*, 137–147.
- Jones, P.W., Quirk, F.H., Baveystock, C.M., et al. (1992). A self-complete measure of health status for chronic airflow limitation. The St. George's Respiratory Questionnaire. *American Review of Respiratory Disease*, *145*, 1321–1327.
- Lumley, M.A., Cohen, J.L., Borszcz, G.S., et al. (2011). Pain and emotion: A biopsychosocial review of recent research. *Journal of Clinical Psychology*, *67*, 942–968.
- Mahler, D.A., Ward, J., Fierro-Carrion, G., et al. (2004). Development of self-administered versions of modified baseline and transition dyspnea indexes in COPD. *COPD*, *1*, 165–172.
- Mahler, D.A., Waterman, L.A., Ward, J., et al. (2007). Responsiveness of patient-reported breathlessness during exercise in persistent asthma. *Chest*, *131*, 195–200.
- Parkin, D., Rice, N., Jacoby, A., et al. (2004). Use of a visual analogue scale in a daily patient diary: Modelling cross-sectional time-series data on health-related quality of life. *Social Science & Medicine*, *59*, 351–360.
- Ponka, D. & Kirlew, M. (2007). Top 10 differential diagnoses in family medicine: Dyspnea. *Canadian Family Physician*, *53*, 1333.
- Roche, N. (2009). Activity limitation: A major consequence of dyspnoea in COPD. *European Respiratory Review: An Official Journal of the European Respiratory Society*, *18*, 54–57.
- Saracino, A., Weiland, T.J., Jolly, B., et al. (2010). Verbal dyspnoea score predicts emergency department departure status in patients with shortness of breath. *Emergency Medicine Australasia*, *22*, 21–29.
- Stenton, C. (2008). The MRC breathlessness scale. *Occupational Medicine*, *58*, 226–227.
- Williams, J.R. (2008). The Declaration of Helsinki and public health. *Bulletin of the World Health Organization*, *86*, 650–652.