Dyspnea experience and management strategies in patients with lung cancer

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Abstract

Objective: The aim of this paper was to describe lung cancer patients’ experience of dyspnea and their strategies for managing the dyspnea.

Methods: Semi-structured interviews with two main questions about dyspnea experiences and management were conducted with 20 patients with lung cancer, not amenable to curative treatment, who had completed life prolonging treatments. Data analysis was made with a descriptive, qualitative content analysis.

Results: The two questions resulted in two domains with 7 categories and subcategories. The experience of dyspnea included four categories: ‘Triggering factors’ included circumstances contributing to dyspnea, which comprised physical, psychosocial and environmental triggers. Bodily manifestations were considered to be the core of the experience. ‘Immediate reactions’ concerned physical and psychological impact. The long-term reactions included limitations, increased dependence and existential impact concerning hope, hopelessness and thoughts of death. The experience of managing dyspnea included three categories: ‘Bodily strategies’, ‘psychological strategies’ and ‘medical strategies’.

Conclusion: Dyspnea experience is a complex experience which influences the life of the patients both with immediate reactions and long-term reactions concerning physical, emotional and existential issues in life and patients address this experience with managing strategies in order to take control of their situation, although they do not seem to be able to meet the existential distress they experience.

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Background

Dyspnea is a common and distressing symptom in patients with lung cancer and decreases quality of life [1]. It has been acknowledged that symptom experience consists of several components, such as intensity, frequency, duration, affective impact and the threat posed by the symptom [2]. Dyspnea has been defined as a subjective, multidimensional experience of breathing discomfort influenced by physiological, psychological, social and environmental factors, and including secondary physiological and behavioral responses and cannot be defined only by physical objective abnormalities [3]. It has been further shown that patients with COPD were able to distinguish between dyspnea and its affective components [4]. Discrepancies have also been found between symptom intensity and symptom distress in patients with lung cancer [5]. Although fatigue was the most intensely experienced symptom, dyspnea, pain and fatigue were all very distressful. Furthermore, dyspnea has been found to create barriers in daily life among patients with advanced cancer [6] and to interfere with physical activities such as walking and work and psychological activities such as disposition, taking pleasure in life, relations with others and sleep in patients with advanced lung cancer [7]. This requires a comprehensive approach to be able to understand patients’ symptom experience.

The dyspnea experience compels patients to take steps to manage the symptom. In a qualitative study from visits to breathlessness clinics, it was shown that dyspnea descriptions included both physical and emotional sensations, such as the feeling of not getting enough breath, panic or impending death, but patients’ management strategies mostly concerned physical strategies, as slowing down and deep breathing [8]. Brown and colleagues [9] used quantitative and qualitative methods to obtain patterns of descriptions of the dyspnea sensation from lung cancer patients and to identify adapting and coping strategies. The patients used an average of 13 strategies to cope with dyspnea, including both immediate and long-term strategies. These strategies were self-taught and only some patients had received
instructions from healthcare professionals. There is a need to gain a deeper understanding of dyspnea experience and its congruence with patients’ own management strategies through their own descriptions. The aim of the present study was therefore to describe lung cancer patients’ experience of dyspnea and their strategies for managing the dyspnea.

Method

Semi-structured interviews were conducted and analyzed descriptively with qualitative content analysis [10].

Participants and setting

The participants were selected from a larger study about the dyspnea experiences of patients with lung cancer, who were not amenable to curative treatment and had completed life-prolonging treatments [11]. The main methods used in the larger study were quantitative analyses based on questionnaires regarding symptoms, especially dyspnea, quality of life, social support and coping strategies. Inclusion criteria were as follows:

- a diagnosis of lung cancer, not amenable to curative treatment;
- all treatments with a life-prolonging intent had been completed;
- reported dyspnea, as measured by any of the quantitative questionnaires used in the main study [11];
- ability to speak and read Swedish; and
- informed consent.

Exclusion criterion was:

- severe mental and cognitive impairment, based on clinical judgments by the nurses involved in the care of the patients.

The patients were approached at the lung oncology out-patient clinic at a University Hospital in West Sweden. Twenty-one patients who fulfilled the inclusion criteria and were considered representative for the study population of the main study [11] were asked to participate in the interview study. One patient declined to participate. The participants comprise 11 men and 9 women, demographic and medical characteristics of whom are shown in Table 1. Sixteen of the patients were retired and three were born abroad.

Interviews

The interviews were semi-structured, open of narrative character with two main questions:

1. Tell me what it is like when you experience dyspnea.
2. Tell me what you do to manage the dyspnea.

The open questioning gave opportunities for additional questions to gain a deeper understanding of the bodily, emotional and cognitive experiences of dyspnea and how it affects daily life; about the patients’ own dyspnea management strategies; about help from others; the helpfulness of the strategies and additional needs.

Procedure

The study was approved by the Ethical Committee at Göteborg University, Göteborg (S 112-03). Once the first author had identified eligible subjects, they were contacted by telephone and provided with information regarding the study. If they were willing to participate, an appointment was made for the interview. Prior to the interview the patients received further verbal and written information about the study and written informed consent was obtained. The interviews were conducted by the first author, during the period September 2003 to November 2004. Most of the interviews took place in the patients’ homes, one at the participant’s work place and three at the out-patient lung cancer clinic. The interviews lasted for 10–45 min (median = 18) and were tape-recorded and transcribed verbatim by the interviewer.

Analysis

The interviews were analyzed by using qualitative content analysis with the aim of identifying categories in the data [10]. The transcribed interviews were read thoroughly several times. Thereafter, the texts were organized into meaning units, which are words or statements referring to some central meaning. Then the meaning units were condensed into codes. Codes with similar content were grouped into subcategories and categories.

| Table 1. Demographic and medical characteristics of the patients (n = 20) |
|-----------------|-----------------|-----------------|
| Age, median (range) | 68.5 (56–79) | Men 68 (56–79) |
| Women | 69 (59–76) | Marital status |
| Married, living with partner | 12 | Living alone, widowed, divorced |
| 8 | Highest educational level |
| Elementary school | 10 | Senior high school |
| 6 | Academic education |
| 3 | Other |
| 1 | Time since diagnosis in months, median (range) |
| 7 (4–141) | Lung cancer histology |
| Non-small cell lung cancer (NSCLC) | 14 | Small cell lung cancer (SCLC) |
| 6 | Number of patients with metastases |
| 11 | Reported dyspnea intensity by the Dyspnea Visual Analogue Scale (VAS-D), median (range) |
| 46 (6–73) |
The category system was defined and revised by the first and third authors until all codes were categorized and the categories were mutually exclusive [10]. Content analysis is presented in the two domains with categories and subcategories.

Results

The results are presented in the domains ‘patients’ experience of dyspnea’ and ‘patients’ experience of managing dyspnea’. The following presentation of results is illustrated with quotations, marked with the patient’s number for this study.

Patients’ experience of dyspnea

Triggering factors

Patients told what either preceded or provoked dyspnea. The category ‘triggering factors’ was either inherent characteristics in the patients or external demands and was divided into the subcategories physical triggers, psychosocial triggers and environmental triggers.

Physical triggers concerned mostly physical strain and also non-demanding activities, such as walking a short distance, eating or even when sedentary:

If I’m walking, I don’t need to walk far before becoming breathless. For example if I brush my teeth or shave it doesn’t matter, whatever I do I become breathless. It doesn’t take much. (5)

Other physical influences were awareness of improper breathing or smoking.

Psychosocial triggers appeared either as personal characteristics, state of mind, excitement or more cognitive features such as expectation of breathlessness. The psychosocial influence also manifested itself as feelings of loneliness or concerns for those near and dear. Anxiety and tension provoked dyspnea could be described in this way: ‘...I tense up and think that I am going to have difficulties in breathing’ (10).

The environmental triggers mostly concerned the weather, but in different ways. The descriptions showed that both warm and cold weather provoked dyspnea and even as is shown in the following quotation, a combination of warm and calm weather as expressed by one participant: ‘Yes, when the weather is warm and calm, I don’t get any real air. But if it becomes windy it is much better, much easier’ (15). Both windy and calm weather were related as being problematic. Other environmental triggers were patients’ experiences of differences in altitude or uphill roads. It was shown that the circumstances which contributed to causing dyspnea could sometimes be avoided, such as bodily exertion. In other cases, some circumstances were inevitable, such as non-demanding activities or environmental influences.

Bodily manifestations

The category ‘bodily manifestations’ concerned being unable to breathe properly, the strain caused by breathing, inability to get enough air, but also an assessment of the frequency and duration of dyspnea and progress of symptom severity. Being unable to breathe properly was expressed as: ‘The short breathing is inside me all the time...’ (11). Strain caused by breathing was described as a heavy feeling in the chest. The inability to get enough air was verbalized as: ‘the air that enters my body is not sufficient to enable me to breathe properly’ (9). Other bodily symptoms were symptoms that either occurred as a result of the lung cancer disease or because they prevailed with dyspnea. These symptoms were airway symptoms, pain, palpitations, general symptoms and some specific symptoms: ‘I cough a lot. I cough when I become strained due to my breathing difficulties’ (8). The bodily manifestations only concerned the body. There were other non-physical symptoms prevailing with dyspnea, but in the analysis they were considered as being reactions to the dyspnea experience.

Immediate reactions

The category ‘immediate reactions’ was divided into the subcategories physical impact and psychological impact. These reactions were effects of the bodily manifestations and occurred immediately, without any reflection.

Physical impact concerned the weakness and fatigue caused by dyspnea, and the awareness of lost strength. Most of the codes categorized as physical impact involved the patients being forced to recover from the dyspnea, which could be recounted as follows: ‘I have to sit down and take a proper break to make my body work again, and that is not easy’ (9).

Psychological impact dealt with varying intensities of emotional reactions to the dyspnea, from expressions that the experiences were unpleasant or troublesome and caused stress, to creating worry and anxiety. One participant described the emotional impact as: ‘You do get a bit agitated when you can’t get any air...’ (4). When asked what it is like being out of breath, another participant expressed a higher intensity of the emotional impact: ‘It produces feelings of panic and anxiety. Yes, that’s how I should describe it. You become worried’ (6). The patients gave no positive descriptions of their feelings regarding the dyspnea, but some patients denied experiencing a negative impact and expressed that they did not panic, feel afraid or worried. Psychological impact also concerned an awareness of the disease and its
progress and the fact that the dyspnea was of not of a temporary nature. The dyspnea was a reminder of the lung cancer disease and of the serious consequences of being stricken by a life-threatening disease. Dyspnea created a state of vigilance and had a negative influence on concentration.

But of course you sit and pay attention to your breathing and wonder if you are going to experience a spate of breathlessness, this is what you do all the time. Things are bad enough as they are without having to worry about anything else. (8)

Psychological impact also referred to becoming restless and lacking initiative because of dyspnea. Both the dyspnea and the disease sometimes promoted combinations of physical and psychological impact expressed as

My body seems to be in a state of anxiousness, I feel worried and restless. I find it difficult to tackle anything.

Lose concentration to some extent. ... When this happens it is very obvious. (7)

The content in immediate reactions could be distinguished from later consequences as limitations and existential thoughts in that these became apparent to the patients after some reflection on their situation.

**Long-term reactions**

The category ‘long-term reactions’ included the subcategories *limitations, increased dependence* and *existential impact*.

*Limitations* disclosed how life became limited, to a greater or lesser extent. Some patients only described the changes while others expressed the limitations more explicitly, i.e. that dyspnea dominated their whole life and they consequently lost the desire to partake in any activity

You think it is awful to be so disabled, that you can’t live as normal. I have somehow lost the desire to do other things too. During spring time I usually sort photographs into albums and things like that, but now I have lost heart in that too. I don’t want... I used to enjoy needlework—I embroidered. But I have lost my desire for this, actually I do nothing. (3)

Limitations included both physical and social limitations as expressed by one participant: ‘There are also physical limitations, so you become ... isolated in some way.’ (12)

*Increased dependence* referred to both being dependent on help from family and those near and dear to one as well as using various aid equipment and assistance. An example of this could be for example bringing a chair to sit and rest when washing the car or adapting a certain environment to the demands of resting. Being dependent on other people included both needing help with practical things such as shopping and need for care and comfort when things become a strain, as described by one participant: ‘...she treats me by massaging my back a little which is comforting and helps to calm me’. (13)

*Existential impact* disclosed mostly as reflections of dyspnea experience, but could not be totally separated from reflections of the experience of an incurable disease. The subcategory existential impact appeared to be in progression as hope decreasing; from hope, through hopelessness, when positive outcomes were finally abandoned and the consequently final step was reached, i.e. thoughts of death. It was noted that patients could give statements categorized to more than one of the parts belonging to existential impact.

Only a few of the patients’ descriptions concerned hope, which were statements about hope of recovery and help. The patients also mentioned that they have learned what is important in life in a difficult life situation with incurable cancer. As expressed by one participant:

All these experiences teach you to appreciate what is important in life—especially things like good friends, books, good TV programmes and yes, what is important. (18)

Hopelessness included feelings of uncertainty regarding the disease, its cause and the symptoms; duration; thoughts of if and when the disease will proceed and about the future, as expressed by one participant: ‘So far I can still get air, but I don’t know what it will be like in the future’ (3). The hopelessness also refers to acknowledging that there is no longer any hope, no possible positive outcome. When the situation is deemed as being hopeless, thoughts of death consequently appeared. For example, as expressed by one participant:

All I can think about is that I don’t want to die. That is what I think about when things are as difficult as that specific time. I thought that if I lie down and fall asleep, I will not wake up again. That is what I think most of the time that I will not get any air and suffocate. (21)

**Patients’ experience of managing dyspnea**

**Bodily strategies**

The category ‘bodily strategies’ included descriptions about planning one’s life to avoid bodily exertion that induces dyspnea or the use of physical activities to relieve dyspnea. The physical activities consisted of different kinds of exercises, such as active breathing exercises or positioning to reduce dyspnea. The patients often used more than one of the bodily strategies:

I try not to exert myself, because that’s when I become breathless. So I try not to exert myself, but I realise that I still have to exercise. So when the weather is good I can go out and walk back and forward and when I have walked for a while, I notice that I can walk longer distances without becoming breathless.—I know when I have to sit down and try to breathe calmly and deeply. (11)
The bodily strategies became integrated in life and new habits were introduced into their life. These habits included knowledge of what provokes dyspnea, what ought to be avoided and what was helpful or not helpful to manage dyspnea: ‘...I am so used to living with it, that’s all. I can’t go shopping and carry heavy things that just doesn’t work’ (4). Bodily strategies could be distinguished from physical impact in that the bodily strategies included planning and deliberate action, while the physical impact only included steps that were unconditional and unavoidable.

**Psychological strategies**

The category ‘psychological strategies’ included descriptions about procedures that were both cognitive and involved deliberate actions. These psychological strategies to alleviate dyspnea were not mutually exclusive and could therefore not be divided into subcategories. Some strategies were using repression and explaining away the dyspnea as being caused by something other than the lung cancer. Usual explanations for dyspnea were age, smoking and being unfit. As one of the patients explained:

In my club with an average age of 78, I am not the only one panting. Everyone has some problems with their mobility and breathing. (17)

Other psychological strategies were to ignore the situation, to endure, distract, accept or protect oneself. A few patients tried to see things positively to manage dyspnea. Further steps were to involve deliberate psychological actions in order to manage dyspnea, such as relaxation or taking control of the situation, to plan activities and to split up activities. Concentration was the another psychological procedure that was used:

I can feel it coming, and then it is possible to control it to a certain extent, breathe, not deeply, but ... I concentrate on just breathing.’ (19)

**Medical strategies**

The category ‘medical strategies’ included descriptions about the use of drugs, including oxygen, and statements of how they helped, or that the patients had turned to healthcare professionals for advice. Medical strategies had also been combined with other strategies, which were described in this way: ‘And when I have inhaled a few doses and rested, then of course I notice that it is much better’ (17). Medical strategies were mentioned by less than half of the patients, but they all mentioned other strategies.

**Discussion**

In this interview study among patients with lung cancer about dyspnea experience, the patients described the triggering factors, bodily manifestations and both immediate and long-term reactions as well as strategies to manage dyspnea. The immediate reactions concerned activities that appeared without patients’ deliberate intentions, although some of them were mentioned earlier as coping strategies [9]. The immediate reactions in the present study were considered as unconditional, i.e. patients could not choose to adopt them. In contrast, the strategies for managing dyspnea were deliberate actions or thoughts. Management strategies has earlier been categorized in short-term strategies used to manage acute dyspnoeic episodes and long-term adaptive strategies, which included activities of daily living, general activities, other behaviors, social isolation and emotional strategies [9]. In this study, both short- and long-term strategies could be categorized in bodily and psychological strategies, although some of the strategies that Brown and colleagues [9] grouped as short term were grouped in this study as immediate reactions, e.g. slowing down. The avoidance or pacing of straining activities have been encouraged in nursing interventions [12], which were strategies patients in this study adopted by themselves. In order to respect patients’ autonomy their apprehension of what triggers dyspnea, should be focused on and used in individual care plans to manage dyspnea. Patients’ own management strategies have to be supported and suggestions of other combinations of strategies should be supplied. Concerning the medical strategies, patients’ long-term medications were not included in the study. Therefore, the medical strategies that the patients mentioned included short-term strategies, as the medical strategies used by the patients were requested medication, some of which did not help; and advice sought in acute situations. An unexpected result was that only a few of the patients mentioned medical strategies and all of them had to combine them with other strategies. This needs further examination.

Regarding the triggering factors the patients were aware of what provoked dyspnea and recounted this. The triggering factors were categorized after their characteristics as physical, psychosocial and environmental triggers. The result of the categorization is congruent with results in other studies, which showed that precipitants of dyspnea were physical behaviors, social isolation and emotional strategies [9]. In this study, both short- and long-term strategies could be categorized in bodily and psychological strategies, although some of the strategies that Brown and colleagues [9] grouped as short term were grouped in this study as immediate reactions, e.g. slowing down. The avoidance or pacing of straining activities have been encouraged in nursing interventions [12], which were strategies patients in this study adopted by themselves. In order to respect patients’ autonomy their apprehension of what triggers dyspnea, should be focused on and used in individual care plans to manage dyspnea. Patients’ own management strategies have to be supported and suggestions of other combinations of strategies should be supplied. Concerning the medical strategies, patients’ long-term medications were not included in the study. Therefore, the medical strategies that the patients mentioned included short-term strategies, as the medical strategies used by the patients were requested medication, some of which did not help; and advice sought in acute situations. An unexpected result was that only a few of the patients mentioned medical strategies and all of them had to combine them with other strategies. This needs further examination.
**Bodily manifestations** only included bodily sensations and were distinguished from the immediate reactions with physical and psychological impacts. Attempts have been made to distinguish between descriptions of dyspnea which are assumed to refer to different origins of dyspnea [13,14]. Wilcock and colleagues [14] examined the descriptors of dyspnea in lung cancer patients, with different manifestations of the disease, and patients with other pulmonary diseases. The descriptors connected with lung cancer patients, regardless of manifestations, were ‘out of breath’ and ‘not having enough air’, which is congruent with the characteristic bodily manifestations in this study. Skevington and colleagues [13] clustered the descriptors of dyspnea into four classes, physical sensation, affective/evaluative, low energy and a fourth class which was divided in two subclasses, hyperventilation and speechless. This is comparable with this study’s results regarding bodily manifestations, although Skevington and colleagues’ cluster of affective/evaluative sensations [13] is more congruent with ‘psychological impact’ in this study.

In this study discrimination was shown between the manifestations of dyspnea and the reactions to the manifestation, this is an important prerequisite to be able to distinguish descriptors of dyspnea. The immediate reactions were responses appearing without any reflection and included physical and psychological impacts. These results lend support to others who found that dyspnea is both a physical and an emotional experience [8], and includes an affective component [4] as well as distress [5]. The importance of including several aspects when evaluating symptoms [2] was confirmed by this study, although the aspects proposed by Dodd and colleagues [2] were not acknowledged by the patients.

The immediate reactions occurred without reflection, but the long-term reactions appeared after conscious considerations of health. The long-term reactions concerned how dyspnea experiences influence life in a comprehensive way, by changing life with restrictions in living, loss of autonomy with subsequent dependence on others and by threatening the entire existence. That dyspnea limited activities and produced social isolation strengthens the results from Roberts and colleagues [6] who found that dyspnea created barriers in aspects of living and that patients coped in isolation and Tanaka and colleagues [7] who found that dyspnea interfered with daily life. In this study patients’ descriptions regarding the existential impact included hope, hopelessness and thoughts of death. Only a few patients made statements belonging to hope, while most of the patients described hopelessness and thoughts of death, which indicates that negative prospects are inherent in these patients. Fear of death during breathlessness was also found by O’Driscoll and colleagues [8], although highlighted as emotional reactions. These results highlight the patients’ need of support and acknowledgment of their worries about the future, which quite possibly can only occur in a caring model where there is a partnership with reciprocity and mutual inquiry between a patient and a healthcare professional [15]. Communication between patients and healthcare professionals is essential in the care of patients with incurable disease and patients need to be confirmed [16] and to experience confirming relationships [17]. Existential impact in this study seems to be the reality for this group of patients and is important for healthcare professionals to acknowledge. When comparing dyspnea experiences and strategies in this study, there were bodily, psychological and existential experiences but only bodily, including medical, and psychological strategies. Consequently, the existential impact was not met by any strategies by the patients. This discrepancy needs to be acknowledged by healthcare professionals and could be addressed with planned group sessions about life changes and existential issues. In a part of a nursing intervention study Bredin and colleagues [18] provided the patients opportunity to express the meaning of breathlessness, disease and future. The intervention resulted in improvement in breathlessness and decreased depression. In the light of this study such intervention strategies seem to be most appropriate. However, it is needed for further investigation in order to assert if the total dyspnea experience, as described in the present study, could be influenced by interventions.

**Methodological considerations**

Qualitative research is useful to develop new knowledge about humans’ experiences and thoughts. Credibility in this study has been established through the choice of patients with an experience of dyspnea and with various ages and a mix of men and women [19,20]. The variation in time since diagnosis could be seen as a strength because manifestations of temporary nature, connected with shorter or longer time since diagnosis, would also have been illuminated. The interview questions were formulated in congruence with the aim, although some of the answers to the question regarding experience were unexpected. Most of the interviews took place in the patients’ home, although three took place in the out-patient clinic for lung cancer patients and one in the participant’s workplace. The other places (i.e. the out-patient clinic for lung cancer patients and one in the participant’s workplace) were both familiar to the patients. Although these interviews were somewhat shorter (median 15 vs 18 min), the variation in categories that emerged was similar to the variation in the other interviews. During the analysis,
similarities and differences of the categories were discussed continuously between two of the authors, until consensus was reached [19]. Dependability, referring to the fact that the research method should be stable over time, was established as the main procedures and questions were used in all interviews [19]. Confirmability refers to the procedure of analyzing trends and patterns in the analysis, when defining and revising the category scheme [10]. Transferability is possible by the description of the procedure and analysis [19,20].

Conclusions

The study describes the patients’ experience of dyspnea, which included triggering factors, bodily manifestations, immediate and long-term reactions. The study also shows that dyspnea can seldom be avoided. The triggers of dyspnea can sometimes be avoided among patients, but the immediate reactions cannot, they are unconditional. The long-term reactions were illuminated with limitations, dependence and existential impact and in that mostly hopelessness and thoughts about death. Further, the study illuminates the need for these patients to use several strategies of bodily, psychological and medical nature in order to manage their dyspnea. The patients’ awareness of what triggers dyspnea as well as helpful strategies to manage should be considered before designing interventions. Before implementing care plans for patients with dyspnea, it is important to listen to their own experiences and take into consideration their management strategies. Patients’ existential distress needs special attention from healthcare professionals.

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References