


Episodes of breathlessness: Types and patterns – a qualitative study exploring experiences of patients with advanced diseases

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Abstract

Background: Despite the high prevalence and impact of episodic breathlessness, information about characteristics and patterns is scarce.

Aim: To explore the experience of patients with advanced disease suffering from episodic breathlessness, in order to describe types and patterns.

Design and participants: Qualitative design using in-depth interviews with patients suffering from advanced stages of chronic heart failure, chronic obstructive pulmonary disease, lung cancer or motor neurone disease. As part of the interviews, patients were asked to draw a graph to illustrate typical patterns of breathlessness episodes. Interviews were tape-recorded, transcribed verbatim and analysed using Framework Analysis. The graphs were grouped according to their patterns.

Results: Fifty-one participants (15 chronic heart failure, 14 chronic obstructive pulmonary disease, 13 lung cancer and 9 motor neurone disease) were included (mean age 68.2 years, 30 of 51 men, mean Karnofsky 63.1, mean breathlessness intensity 3.2 of 10). Five different types of episodic breathlessness were described: triggered with normal level of breathlessness, triggered with predictable response (always related to trigger level, e.g. slight exertion causes severe breathlessness), triggered with unpredictable response (not related to trigger level), non-triggered attack-like (quick onset, often severe) and wave-like (triggered or non-triggered, gradual onset). Four patterns of episodic breathlessness could be identified based on the graphs with differences regarding onset and recovery of episodes. These did not correspond with the types of breathlessness described before.

Conclusion: Patients with advanced disease experience clearly distinguishable types and patterns of episodic breathlessness. The understanding of these will help clinicians to tailor specific management strategies for patients who suffer from episodes of breathlessness.

Keywords

Dyspnoea, episode, types, pattern, qualitative research, palliative care

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Introduction

About half of the patients with advanced and life-limiting diseases experience breathlessness despite optimal treatment of the underlying condition.¹ Some patients suffer from continuous breathlessness (breathlessness all the time), but the majority describe episodes of breathlessness (intermittent breathlessness) or a combination of both.^{2,3} Patients with chronic obstructive pulmonary disease (COPD) or cancer describe that episodic breathlessness triggers anxiety, panic and even the fear to die.⁴ The emotional response to episodic breathlessness (mainly panic) leads to a vicious circle triggering breathlessness itself.⁵ Despite the high prevalence, more detailed information about episodic breathlessness is scarce.⁶ In 70 cancer patients, breathlessness episodes occurred frequently (81%), most often 1–5 times/day and lasted less than 10 min (88%).² Booth et al.⁷ indicated differences between patients with cancer and COPD regarding the patterns and course of episodic breathlessness, for example, the quick onset of an episode without a warning signal was reported only by patients with cancer. Four randomized controlled trials (RCTs) evaluated pharmacological interventions for episodic breathlessness, but only one study provided rather limited information about the frequency (1–2 episodes/day).^{8–11}

Better understanding of patients' experience of episodic breathlessness and its patterns is needed to improve treatment options. Therefore, we aimed to explore the experience of patients with advanced and life-limiting diseases suffering from episodic breathlessness, and describe types and patterns of episodes of breathlessness.

Methods

Design

We used a qualitative study design with in-depth face-to-face interviews. This study followed the consolidated criteria for reporting qualitative research (COREQ) guideline for reporting qualitative research.¹²

Participants and recruitment

A purposive sample of patients aged >18 years, suffering from breathlessness due to COPD (stage III/IV of the Global Initiative for Obstructive Lung Disease (GOLD) classification), chronic heart failure (CHF), stage II-IV of the New York Heart Association (NYHA) classification, lung cancer (LC; primary and secondary LC, all stages), and motor neurone disease (MND; all stages).^{13,14} Patients could be on any treatment with regard to the underlying disease or breathlessness. Lack of capacity to give informed consent and cognitive impairment, as judged by the principal investigator, were exclusion criteria.

Interviews were conducted until no new information was gained, and saturation was achieved. Participants were recruited at five out-patient clinics of two university hospitals in South London over a 6-month period in 2010. Informed consent was obtained from the patients at least 24 h before the interview.

Interview procedure

The in-depth face-to-face interviews were conducted by two trained interviewers (S.T.S. (male, physician), H.B. (male, sociologist)), usually in the participant's home. Demographic and clinical data were obtained before the interview started. We chose a semi-structured approach to explore patients' experiences using a topic guide, including general experience with breathlessness; experiences, characteristics and triggers of episodic breathlessness and its patterns; and impact on daily living, management strategies and health-care use. We defined episodic breathlessness following Reddy's suggestions as 'breathlessness occurring intermittently with and without underlying continuous breathlessness'.²

At the end of the interview, we asked the participant to draw at least one graph to illustrate the pattern of a typical episode of breathlessness. We used a coordinate system with two axes (x = time line, participant defined whether unit was minutes, hours or days; y = severity of breathlessness; see Figure 2).

All interviews were tape-recorded and transcribed verbatim. The interviewers kept field notes of each interview in participant-related memos.

Data analysis

The interviews were analysed using Framework Analysis. This is a matrix-based method using a thematic framework to classify and organize data by key themes, concepts and categories.¹⁵ First, all interviews and memos were read twice by the principal investigator (S.T.S.) to familiarize with the content. The following analytic hierarchy guided the analysis: data management (identifying initial themes, coding), descriptive accounts (sorting, summarizing, identifying dimensions and categories) and explanatory accounts (detecting patterns, identifying clusters, developing explanations and a theory). The stages of descriptive and explanatory accounts were facilitated by creating thematic charts in particular for thematic-related (inter-participant) and participant-related (inter-thematic) analysis. The analysis was conducted by S.T.S. At the beginning, five interviews were coded by two additional researchers (C.B., F.M.) in order to address rigour and trustworthiness. At every analysis stage, findings were discussed and results of these discussions were incorporated. Special attention was paid to deviant cases ('negative cases', which contradicted the emerging explanation) to describe the range of

Table 1. Demographic and clinical characteristics of participants.

Characteristics	n = 51
Age, in years, mean (SD; range)	68.2 (11.6; 39–92)
Gender, n (%): male	30 (59)
Disease group (stage)	
COPD	14 (7 GOLD III, 7 GOLD IV)
LC (entity)	13 (7 primary LC, 4 mesothelioma, 2 secondary LC (breast))
CHF	15 (2 NYHA II, 10 NYHA III, 3 NYHA IV)
MND	9
Ethnicity, n (%)	
White British	32 (63)
White Others	7 (14)
Black African	3 (6)
Black Caribbean	5 (10)
Indian	4 (8)
Living situation, n (%): alone	19 (37)
Karnofsky Index, mean (SD)	63.1 (14.1)
CCI, n (%): missing	4 (8)
No risk	7 (14)
Mild risk	18 (35)
Moderate risk	11 (22)
Severe risk	11 (22)
Smoking, n (%)	
Still smoking	3 (6)
Smoked but stopped	31 (61)
Never smoked	17 (33)
Oxygen supply, n (%)	14 (28)
Severity of breathlessness in general, mod. Borg, mean (SD)	
Average 24 h	3.2 (1.7)
Worst	5.4 (2.4)
Now	1.7 (1.6)
Rest	1.2 (1.2)
On exertion	5.4 (2.1)

SD: standard deviation; CHF: chronic heart failure; COPD: chronic obstructive pulmonary disease; GOLD: global initiative for chronic obstructive lung disease; LC: lung cancer; NYHA: New York Heart Association; CCI: Charlson Comorbidity Index.

experiences and meanings.¹⁶ The computer program NVivo 8 (devised by QSR international in 2008) was used for data management.

The graphs illustrating the pattern of episodes of breathlessness were analysed with a descriptive approach using the following criteria: onset (quick or slow/gradual), recovery (quick or slow/gradual) and presence of a plateau. Similar graphs were grouped in categories.

Ethics approval

The Joint University College London (UCL)/University College London Hospitals (UCLH) Committees on the Ethics of Human Research Alpha (09/H0715/81) provided ethical approval, and the study was registered on ClinicalTrials.gov (NCT01138358) and the National Institute for Health Research Clinical Research Network Portfolio (NIHR CRN Study ID 7859).

Results

Patients' characteristics

Fifty-one participants were interviewed. Demographic and clinical details are shown in Table 1. The majority of interviews (45 of 51) were conducted in participants' homes, two at the recruiting hospital and four at the investigators' institute. Median length of interviews was 55 min (range 17–89 min).

Types of episodic breathlessness

Patients' experiences and descriptions of episodes of breathlessness could be grouped into five main types: Type 1–5 (Figure 1). All types were clearly distinguishable from each other with typical characteristics. However, they were not exclusive, and one patient could experience different types of episodic breathlessness. Eight patients described all types.

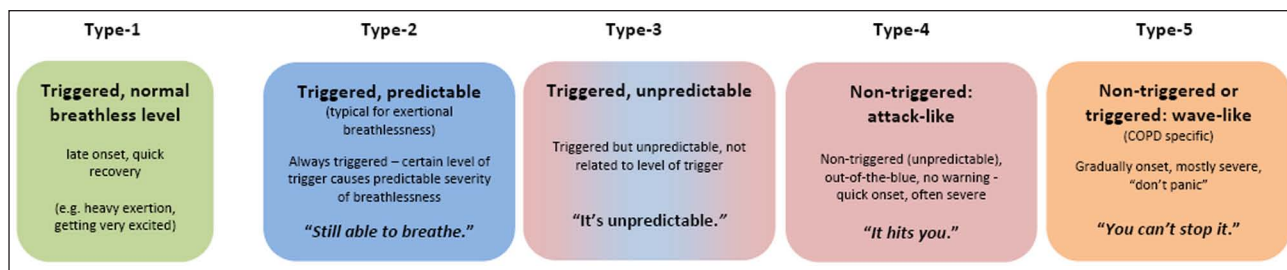


Figure 1. Types of episodic breathlessness.
COPD: chronic obstructive pulmonary disease.

Triggered episodes with normal levels of breathlessness (Type-1)

Five patients complained about episodes of breathlessness by exertion, which was comparable to the level of breathlessness of a healthy person during physical activity (Table 2). The severity of breathlessness was always strongly related to the level of exertion. Overall, patients who experienced this type showed lower severity scores for breathlessness:

I can do long walks but a little bit slower than before. (Male, 71 years, MND)

Triggered episodes with predictable response (Type-2)

Nearly all patients (46 of 51, except those with Type-1) suffered from triggered episodic breathlessness with a predictable response. This was the typical type for exertional breathlessness, such as climbing stairs, talking and emotions (e.g. panic, anger). The trigger was both the activator and worsening factor of episodic breathlessness. A certain level of trigger caused a predictable severity of breathlessness, and even slightest exertion could trigger severe breathlessness: 'It depends what I am doing' (male, 65 years, LC). There was a broad variety of characteristics in terms of onset, recovery and length, and no distinct pattern. However, a gradual increase and decrease of breathlessness severity was most common (Figure 2). The frequency of this type of episodic breathlessness was related to the patient's exercise capacity, and therefore varied. In terms of severity, patients described that although breathlessness could get really worse, they were still able to breathe and did not experience a sensation such as blocked airways (not able to breathe). Patients described several management strategies for exertional breathlessness such as avoiding exertion, pacing or using devices such as a stick or rollator:

It's all related to exertion. If I were to walk up the stairs now I know damn well that if I stop twice I'll be fine. (Male, 65 years, LC)

Well I remember when I was much fitter if you go out for a run or something. You come back and you're really fighting for breath. And it's like that only a lot more severe. And it doesn't take very much exertion. (Male, 70 years, MND)

Triggered episodes with unpredictable response (Type-3)

A few patients described a triggered type of episodic breathlessness with an unpredictable response, for example, getting out of the car caused severe breathlessness but not always, and at the same time, heavy exertion like climbing stairs was possible without severe breathlessness. There was no relationship between the level of exertion and the severity of episodic breathlessness as described in the other two types of triggered episodes. This type occurred with a quick onset and severe intensity (Figure 2). It was only described by 5 of 51 patients, suffering either from COPD or CHF (Table 2). Patients struggle to cope with this type of episodes due to the unpredictability of the episode. Keeping calm and not aggravating breathlessness by panic were mentioned repeatedly as coping mechanisms:

I walked a mile the other week without any problems. Then over the weekend I got out of my car and immediately I became breathless. (Male, 66 years, CHF)

Non-triggered, unpredictable attack-like episodes (Type-4)

Twenty-two of 51 patients (43%) described a type of episodic breathlessness which came like an attack out-of-the-blue without a warning signal or a trigger: 'It really hits me' (male, 79 years, COPD). Patients struggled with the unpredictability of these episodes, as they could not prepare for it or prevent it often causing anxiety and panic:

It's really out of the blue, all of a sudden, you never tell when it happens ... there are no warning signals. (Male, 77 years, COPD)

I mean I can control it to a degree but when it kicks in I can't control it. (Male, 69 years, COPD)

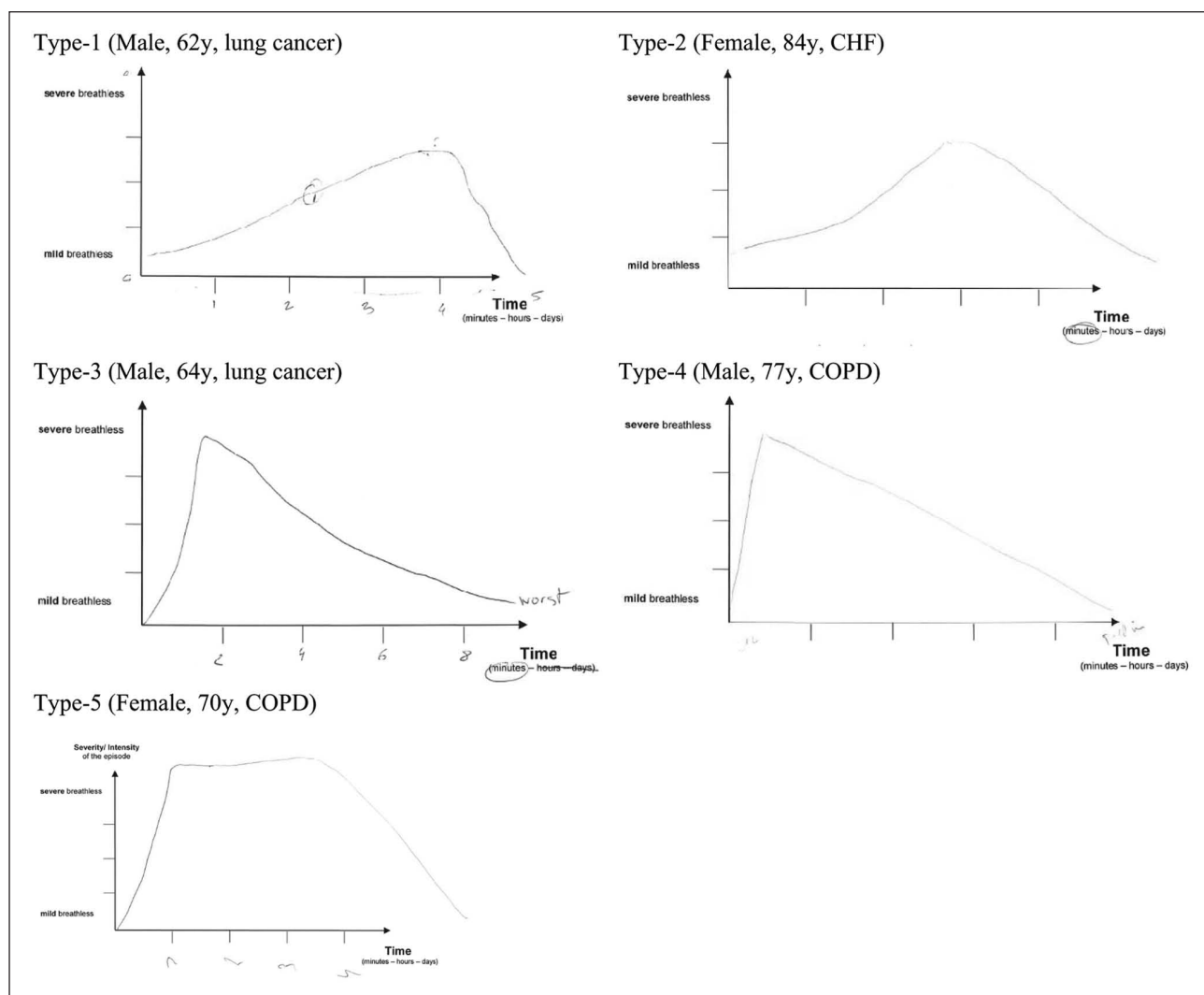


Figure 2. Patients' graphs illustrating the pattern of different types of episodic breathlessness. CHF: chronic heart failure; COPD: chronic obstructive pulmonary disease.

Table 2. Frequency of types of episodic breathlessness (% in relation to the disease group; sum does not add up to 100% because of multiple types per patient).

Diagnosis group	N total	Type-1 N (%)	Type-2 N (%)	Type-3 N (%)	Type-4 N (%)	Type-5 N (%)
CHF	15	1 (7)	14 (93)	2 (13)	9 (60)	1 ^a (7)
LC	13	2 (15)	11 (85)	0 (0)	5 (38)	1 ^b (8)
COPD	14	0 (0)	14 (100)	3 (21)	7 (50)	9 (64)
MND	9	2 (22)	7 (78)	0 (0)	1 (11)	0 (0)
Total	51	5 (10)	46 (90)	5 (10)	22 (43)	11 (22)

CHF: chronic heart failure; COPD: chronic obstructive pulmonary disease; LC: lung cancer; MND: motor neurone disease.

^aPatient with CHF and asthma.

^bPatient with lung cancer and COPD.

Patients experiencing these attack-like episodes more often described loss of control compared to other types, and also reported panic and fear of death. Patients described these

attack-like episodes as severe (intensity), with a quick onset and short duration (seconds or a few minutes), although longer durations occurred as well. The majority of patients

in this group suffered from more severe breathlessness and 18 of 22 (82%) patients experienced continuous breathlessness as well. Three patients described very short attacks, almost comparable to hiccups lasting only a few seconds: 'It's almost a yawn' (female, 66 years, COPD).

Triggered or non-triggered wave-like episodes in COPD (Type-5)

The majority of COPD patients described a type of episodic breathlessness that appeared similar to a wave; it gradually built to a maximum of severe breathlessness, then wearing off to normal breathing levels. Typically, patients felt warning signs such as chest tightness, painful breathing or coughing. This type of episodic breathlessness often lasts several minutes or sometimes even hours, with breathlessness intensity being much higher compared to normal fluctuations of existing breathlessness. However, patients had no means to interrupt this wave-like course. This was the only type that occurred triggered or non-triggered. Panic was the main worsening factor, which could potentially lead to emergency situations. Learning to control the panic was the most important management strategy of this type: staying calm, relaxing and letting the episodes pass by. Patients emphasized that the knowledge 'you will always be able to breathe' was extremely helpful to keep control of the episode. This wave-like episode was COPD-specific; although not all patients with COPD described this type (9 of 14), all patients who experienced it suffered from COPD:

And you know it's going to be happen. So you can't stop it. (Female, 70 years, COPD)

Impact of episodes of breathlessness on daily life (all types)

Patients mainly experienced panic when they were not able to breathe during episodes of breathlessness. Some patients reported a fear of death when they felt like drowning or suffocating, while some described a 'fear of the unknown' about the unpredictability or unknown pattern of episodic breathlessness:

And there is nothing worse than not being able to breathe. [...] It's terrible and I fear to die. (Male, 64 years, MND)

But, er, I do hate how vulnerable it's made me. [...] And, er, it's silly how much it affects you know, it's, er – I won't give in. (Female, 74 years, LC)

However, 8 of 51 patients stated that they did not experience panic during episodes of breathlessness. They had learnt effective management strategies by controlling the

panic, for example, staying calm by knowing that they will not die during the episode and that the breathing would come back:

I don't panic because I get used to it. (Female, 70 years, COPD)

Patients became frustrated about the limitations on activity and social life, often needing to rely on others. Some patients were concerned about the future, and some were well aware of the limited time. They feared episodes of breathlessness in the last moment of their life. However, these concerns were hard to distinguish from the general experience of breathlessness and did not seem to be specific to episodic breathlessness:

It's got to be ... my whole, er, life, the horizons have come in closer and closer and closer, geographically. Right? (Male, 65 years, LC)

I really feel like I'm not here for long, erm, I feel like my days are getting numbered now. [...] But I don't want to worry my husband. (Female, 69 years, COPD)

Other patients were able to manage their lives and also breathlessness much more stoically:

I don't get upset about talking about things, I know what's going to happen. Like everybody you're going to die but I'm going to die a bit earlier. (Male, 64 years, MND)

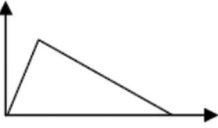
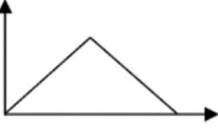
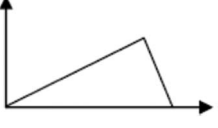
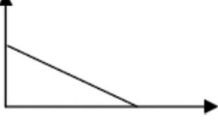
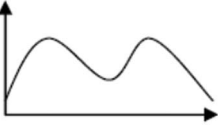
It doesn't worry me. (Male, 71 years, MND)

Patients' graphs illustrating the pattern of episodes of breathlessness

Thirty-nine graphs from 34 patients were analysed (18 patients were not able to draw a graph because they were unwilling, had eye problems or did not understand the concept). The graphs were grouped into four different categories (Table 3). The majority of graphs showed a quick onset and a slow recovery (group I) or similar time for onset and recovery (group II). Only four graphs described a slow onset and quick recovery (group III), and three graphs a recovery only (no onset, group IV). Only one graph could not be allocated to the four groups. This was a COPD patient (C-6) who drew two elevations ('waves'), occurring straight after each other after 30 min.

There was no strong relation between the four groups of graphs and the five types of episodic breathlessness, although typical patterns could be described and were representative for each type (Figure 2). There was a tendency that the attack-like episode (Type-4) was more often related to group I (quick onset) and the triggered

Table 3. Group analysis of patients' graphs with characteristics of the graph, number of graphs and the number of graphs with a plateau.

	Graph	Characteristics	Number of graphs	With plateau
I.		Quick onset Slow recovery	16	6
II.		Onset and recovery the same	15	3
III.		Slow onset Quick recovery	4	3
IV.		Recovery only	3	–
Special		Two waves	1	–

predictable episode (Type-2) to group II (onset and recovery the same).

Discussion

We explored patients' experiences of episodic breathlessness and were able to describe, for the first time, five different types of episodic breathlessness and different patterns. The two most important distinctions between the episodic breathlessness types are the relation to a trigger and whether the episode is predictable or not. The most common types are the triggered predictable episode (typical type for exertional breathlessness) and the non-triggered attack-like episode (unpredictable). The only disease-specific type is the wave-like episode, which is described by patients with COPD. Following advances in the area of breakthrough pain (regarding description and management strategies), a better understanding of episodic breathlessness and its pattern is essential for assessment and diagnoses of breathless patients in order to develop appropriate and effective management strategies.^{17,18} The results of this study will deepen the understanding and differentiation of episodes of breathlessness, and need further verification in clinical practice and larger surveys.

Aggravated breathlessness following exertion (Type-2) was the most frequent type of episodic breathlessness in our study. The high frequency is supported by other studies in non-malignant pulmonary diseases (67 of 68 patients reported exertional breathlessness) or cancer patients (85%).^{19,20} Type-2 was always triggered and related to the level of the trigger, which was one of the main reasons for the limitation of patients' activity, avoiding activity in order to reduce breathlessness.⁷ However, although breathlessness in this group could reach very severe levels, participants reported that they were always able to breathe. The knowledge that the episode will end and normal breathing will come back was an effective management strategy for this type of episodic breathlessness. The main characteristic of the attack-like type was the lack of a trigger (unpredictable) – this type came out-of-the-blue without any warning signal and was a real shock for the patient. Therefore, there was no chance for prevention. Not surprisingly, patients did panic and lost control over the situation more often compared to other types. Although more than 40% of patients in our study experienced this type of episodic breathlessness, it had rarely been described before. Two studies with 10 and 18 patients, respectively, described inexplicable episodic breathlessness occurring suddenly

without warning signs and wearing off again.^{7,21} In both studies, it was not clear whether these episodes were untriggered (Type-4) or triggered (Type-3).⁷ In contrast to the first study, where this type appeared only in cancer and not in COPD patients, we found this type also in COPD patients, which was in accordance with three other studies.^{21–23} Interestingly, patients with continuous breathlessness and higher severity experienced the attack-like type in particular. This needs further exploration in quantitative studies with more participants.

It could be hypothesized that patients with different diseases describe different patterns of episodic breathlessness. Our study does not support this theory as the majority of descriptions were similar across the four disease groups. The wave-like episode (Type-5) was the only disease-specific type related to COPD. Patients were not able to stop the occurrence and progress, but they could influence the pattern by controlling the panic, which was the key strategy to manage this type of episodic breathlessness. This type lasted mostly minutes or a few hours and was different from the experience of an exacerbation, which usually takes days or weeks to get back to normal life.^{24,25}

Of the MND patients, only one reported an attack-like episode and none reported Type-3 or Type-4. This MND patient was only slightly impaired by the disease, without any co-morbidities that could support the hypothesis that MND at early stages only led to the triggered predictable type of breathless episode. In addition, MND patients often reported less panic and fear and seemed to be less concerned about their situation and future expectations. This could be influenced by the fact that the clinic where MND patients were recruited was well known for their expertise and excellent support of MND patients. To our knowledge, only one study explored the experience of breathlessness in MND patients so far.²⁶ This study described – in accordance with our data – a coping strategy of MND patients ‘to live in the present’ and going on holidays when not affected too much by their illness.²⁶

The impact of episodic breathlessness was often related to episodes in general (instead of a specific type) or even breathlessness in general. The experience of limitations of activity or social life, anxiety, panic or fear of death is well known in the breathlessness literature, and often reported by other studies.²⁷

We had hoped that asking patients to draw the trajectory of their episodes would illustrate the different types of episodes more clearly. However, the analysis of the graphs did not support this as the patterns identified in the graphs did not show a strong relationship to the described types of episodic breathlessness, but typical patterns did appear. Nevertheless, we think that asking a patient to draw a graph of the experienced breathless episode is useful for better understanding of the individual pattern, rather than to characterize different types of episodic breathlessness across patients.

Strengths and limitations

This qualitative exploration revealed the description of episodes of breathlessness across different conditions, which allow comparison between groups.

This study used a qualitative, explorative study design, and therefore, proportions and frequencies have to be taken with caution. To determine prevalences of the different types of breathlessness episodes, a larger quantitative study is necessary. In addition, experiences of breathless episodes were collected retrospectively, and therefore, data could be influenced by recall bias. As this is an explorative study, the results need to be verified by a prospective study.

Implications for clinical care and research

In accordance with Lansing et al.,²⁸ a better understanding of the multidimensional character of breathlessness and its diversity and differences should improve therapeutic efficacy by better assessment, diagnosis and the development of effective treatment. The description of different types of episodes of breathlessness is a first step in this way. Clinicians’ assessment should include an accurate history of breathless episodes, in order to tailor individualized treatment and to find appropriate and type-specific management strategies. These strategies are likely to vary between the different types, for example, focused on the trigger for Type-2 and coping related for the attack-like type. The development of effective management strategies is the next important step and should be type-specific to address the diversity of episodic breathlessness. Management strategies should include non-pharmacological and pharmacological options. In addition, the presented types need to be confirmed in a larger survey across different diseases.

In conclusion, similar to advances in breakthrough pain over the last decades, much more effort in clinical care and research is necessary in the future to reduce the burden caused by episodes of breathlessness. The description of different types of episodes of breathlessness will inform this development.

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Conflict of interest

The authors declare that there is no conflict of interest.

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