



The experience of episodic breathlessness from the perspective of informal caregivers: a qualitative interview study

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Background: Episodic breathlessness is a common form of chronic breathlessness that is highly distressing for patients with diseases such as chronic obstructive pulmonary disease (COPD) and lung cancer in advanced stages. Little is known about the experiences of informal caregivers who care for patients with episodic breathlessness. The present study aims to explore and describe the experiences and coping strategies of informal caregivers who deal with this challenging condition.

Methods: This is a qualitative study based on semi-structured in-depth interviews with informal caregivers of patients suffering from episodic breathlessness. The interviews were recorded, transcribed verbatim, and analyzed using Mayring's qualitative content analysis.

Results: Thirteen informal caregivers were interviewed. The results suggest that the distress patients often experience during episodic breathlessness causes concern and anxiety among most informal caregivers. Particularly stressful for them is their own helplessness and uncertainty, especially when episodic breathlessness occurs for the first time. Over time, all informal caregivers interviewed had developed strategies to cope with the patients' episodic breathlessness. These strategies can be divided into two categories: (I) strategies directed at the patient to provide appropriate support during episodic breathlessness, and (II) strategies aimed at coping with the caregiver's own emotional burden. Despite these strategies, the need for professional support for informal caregivers often remains unmet, especially during the initial onset of episodic breathlessness.

Conclusions: Informal caregivers of patients with chronic breathlessness need support and advice on how to better cope with episodic breathlessness. Both patient and caregiver support need to be part of a comprehensive approach, e.g., as part of a breathlessness service.

Keywords: Episodic breathlessness; informal caregiver; palliative care; chronic obstructive pulmonary disease (COPD); lung cancer

Submitted Nov 16, 2021. Accepted for publication Jan 14, 2022.

doi: 10.21037/apm-21-3361

View this article at: <https://dx.doi.org/10.21037/apm-21-3361>

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Introduction

Chronic breathlessness is a common and burdensome symptom of advanced diseases with a prevalence of up to 98% among chronic obstructive pulmonary disease (COPD) patients. This prevalence increases towards the end of life (1,2) and has a substantial impact on the patient's functional status and quality of life (2,3). The American Thoracic Society defines chronic breathlessness as "a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity" (4).

Episodic breathlessness is "a form of breathlessness characterized by a severe worsening of breathlessness intensity or unpleasant sensation beyond usual fluctuations in the patient's perception" (5). There are several terms used in the literature which describe the same experience of a severe worsening of chronic breathlessness: acute breathlessness, dyspnea crisis, acute-on-chronic, and episodic breathlessness (6-8). While recognizing their slight differences, we use these here as equivalent terms. A patient might experience only episodic breathlessness, only continuous breathlessness, or both (3,4). In this paper, we use the term 'chronic breathlessness' as the overall experience of breathlessness including continuous and episodic breathlessness. Episodic breathlessness is thus one form of chronic breathlessness. Chronic breathlessness is a syndrome persisting despite optimal treatment of the underlying disease and requiring symptomatic management (9,10).

The sharp increase in breathlessness intensity and the limited duration are the main characteristics of episodic breathlessness (2,3,5). The prevalence of episodic breathlessness is up to 81% in advanced disease stages, even in spite of optimal treatment of the underlying disease (11,12). Because episodic breathlessness is typically short in duration (90% of episodes are less than 20 min), episodes are usually over before medication can take effect (11-13); therefore, managing the episodes is challenging. Affected patients report anxiety and panic during episodic breathlessness (14), which can propel breathlessness into a vicious circle, or a "Dyspnea-Anxiety-Dyspnea Cycle" as Bailey describes (15).

To our knowledge, no scientific research has been conducted on the question of how informal caregivers experience patients' episodic breathlessness specifically. While a few studies (3,8,16-18) describe the informal caregiver's burden due to patients' chronic breathlessness, there is a lack of research on informal caregivers' experiences with patients' episodic breathlessness. The studies that do exist affirm the burdensome impact of

chronic breathlessness on informal caregivers (17,19). Informal caregivers report experiencing anxiety and panic due to their patient's chronic breathlessness (16). Some describe the need to learn more about chronic breathlessness to better support the patient and to manage their own fears about the patient's chronic breathlessness (16). Informal caregivers can benefit from professional support to help them better cope with their patients' chronic breathlessness (19). Dyadic interventions are recommended, which take into account both the patient's and the informal caregiver's needs, as well as the influence of the relationship between patient and informal caregiver on the patient's chronic breathlessness (16,20).

The present qualitative study aims to explore informal caregivers' experiences and perspectives on the episodic breathlessness of their patients and how they cope with caring for someone with episodic breathlessness. We present the following article in accordance with the COREQ reporting checklist (available at <https://apm.amegroups.com/article/view/10.21037/apm-21-3361/rc>) (21).

Methods

Study design

We used a qualitative study design based on semi-structured, face-to-face in-depth interviews. The qualitative study is part of a larger interventional feasibility study entitled "Cognitive and Behavioral Intervention for the Management of Episodic Breathlessness in Patients with Advanced Disease: A Single-arm Therapeutic Exploratory Trial (Phase II)" (CoBeMEB). The CoBeMEB study was conducted following the Declaration of Helsinki (as revised in 2013). The study was approved by the Ethics Committee of the Medical Faculty of the University of Cologne (reference number: 18-209) and written informed consent was provided from all participants.

The CoBeMEB study evaluates the feasibility and potential effects of a brief cognitive and behavioral intervention to enhance the management of episodic breathlessness in patients with a life-limiting and progressive disease, like cancer (stage III-IV), COPD (stage III-IV), interstitial lung disease, or chronic heart failure (stage III-IV).

Participants and recruitment

Participants with recurrent episodic breathlessness despite

Table 1 Main topics

Episodic breathlessness: patient's experience from informal caregiver's perspective
Informal caregivers' own burdens and challenges with the patient's episodic breathlessness
Strategies developed by the informal caregivers to better cope with the burdens and challenges

optimal treatment of the underlying condition, as well as with a life expectancy of more than 8 weeks according to the attending physicians, were included. Eligible patients of the CoBeMEB study were asked to name a close and trusted person who is most involved in their care (informal caregiver) who agreed to be contacted by the study team for the qualitative study. The informal caregiver was contacted by the study team via telephone or directly and informed about the study aims and procedure. Informal caregivers who were at least 18 years of age and who had sufficient German language skills were invited to participate in the study. These caregivers provided written and informed consent.

Recruitment took place between April 2019 and February 2020 at the Bethanien Hospital in Solingen, Germany (Department of Respiratory Medicine) and at three sites of the University Hospital of Cologne in Germany: the Department of Palliative Medicine, the Center for Integrated Oncology (CIO), and the Department of Cardiology and Respiratory Medicine. To reach full data saturation, we additionally recruited informal caregivers through five support groups for patients with lung diseases and their informal caregivers. The inclusion criteria were the same as for the CoBeMEB recruitment (see above).

Data collection

Demographic data was obtained before participants were interviewed. Additionally, the seven-item short form (ZBI-7) of the Zarit Burden Interview, a self-assessment tool of the physical, psychological, social, and financial burden of informal caregivers was completed (22). Burden was assessed on a 5-point Likert scale (item 1–6: never =0, nearly always =4; item 7: not at all =0, extremely =4) with a range of 0 to 28, calculated by adding the scores for all items. Higher scores indicate a greater burden. The interviews were completed by

three interviewers (TR, AB, YE) at the informal caregivers' home or the clinic. A topic guide was used to ensure that all relevant aspects were discussed by all interviewers. The topic guide was developed by two researchers (TR, AB) based on the research questions and the already existing literature on informal caregivers and how they cope with their patient's chronic breathlessness (16). With an exploratory approach, informal caregivers were asked to describe their experiences and strategies concerning their patients' breathlessness episodes and how episodic breathlessness affects their everyday life. Field notes were made after each interview.

Table 1 describes the main topics of the interviews.

Data analysis

The interviews were tape-recorded, transcribed verbatim, and pseudonymized for analysis. The interviews were analyzed using content analysis according to Mayring (23), using MAXQDA18[®]. After reading the transcripts several times to become familiarized with the content, we selected one interview transcript to analyze first in order to develop a preliminary categorisation system. This step was carried out separately by two researchers (TR, AB). The main categories were created deductively based on the topic guide, while the subcategories were created inductively. Subsequently, all further interviews were analyzed and the main categories were adapted. The individual analysis was performed by one researcher (TR) and revised by a second researcher to ensure reliability. This included the encoding, paraphrasing, and summarizing of all interviews to accordingly get the interviews reduced to the essential core of the respective statement. The contents of the respective subcategories were again assigned to groupings of suitable keywords in order to sort the volume of data and to outline specific aspects that informal caregivers emphasize concerning episodic breathlessness. The categories of these groupings were then formed inductively. The coding was repeatedly revised for all interviews. The final step focused on the identification and summary of the most relevant and remarkable content regarding the research questions.

Statistical analysis

The results of the ZBI-7 questionnaire were analyzed with SPSS (IBM Corp., Armonk, NY, USA) and presented as median and range (see *Table 2*).

Table 2 Informal caregivers' sociodemographic characteristics

Informal caregivers, n=13	Value
Age	
Median [range], years	63 [50–78]
Gender	
Female	7
Male	6
Diverse	–
Patient's primary disease	
COPD	11
Lung cancer	2
Relationship to patient	
Wife/husband	10
Life partner	3
Living situation	
With patient	11
Living separated from patient's home	2
Employment	
Working	5
Not employed	2
Currently on sick leave	1
Retired	5
ZBI-7 score	
Median [range] (n=12)	10.5 [0–17]

Numbers are presented unless otherwise stated. COPD, chronic obstructive pulmonary disease; ZBI-7, Zarit Burden Interview.

Results

Participants

For this study, 13 informal caregivers were interviewed (seven women, with an average age of 63.23 years; SD =9.06). Seven informal caregivers were recruited through the CoBeMEB study, in which 49 patients participated, and six through the support groups. In total, 15 informal caregivers were asked to take part and two informal caregivers declined (reasons: lack of interest in interview). Participating informal caregivers' sociodemographic characteristics were summarized in *Table 2*. Eleven interviews were conducted at home and two interviews at the University Hospital of Cologne. The mean duration of the interviews was 36 min (range, 17–60 min). In four

interviews, the affiliated patient was also present. Twelve informal caregivers reported their burden on the ZBI-7. The median score was 10.5, indicating a medium-high burden (22).

How informal caregivers describe the patient during their episodic breathlessness

Physical exertion, emotional stress, and infections were reported to be the main triggers for episodic breathlessness. All informal caregivers were able to clearly distinguish episodic breathlessness from continuous breathlessness. The majority of informal caregivers described that episodic breathlessness causes an emergency; subsequently, the patient was no longer able to do anything else except endure the breathlessness episode: *“Well, they express themselves in great distress. I can't say it any other way. A very great need, is then, nothing more goes at the moment. He must stand still.”* (informal caregiver 126, wife of patient with COPD).

Patients' emotional reactions to breathlessness episodes were also discussed by the informal caregivers. They described restlessness, fear, and even panic: *“His eyes were protruding and he was totally panicked and he was shaking all over.”* (informal caregiver 218, life partner of patient with COPD).

In contrast, some patients appeared to be able to maintain control over their emotional response to episodic breathlessness. For example, one informal caregiver reported she did not have the impression that her husband experienced panic during episodic breathlessness: *“He has never panicked.”* (informal caregiver 624, wife of patient with COPD).

How informal caregivers experience the patients' episodes of breathlessness

Informal caregivers described their experiences with episodic breathlessness predominantly in negative impressions and feelings. The overriding feeling of most informal caregivers during episodic breathlessness is their own helplessness, since they were unable to relieve patients' breathlessness.

The uncertainty of whether episodic breathlessness would last for a short time or whether it would worsen over a longer period causes concern, fear, and even panic for informal caregivers. Some informal caregivers found it difficult to decide whether and when the patient needs professional acute medical care. Fear of the patient's suffocation was often present for informal caregivers: *“And that's when I got so*

Table 3 Informal caregivers' strategies for dealing with episodic breathlessness

Coping strategies directed to the patient	Coping strategies for caregivers' own benefit
<ul style="list-style-type: none"> • Staying calm (not showing own feelings) • Supporting the patient (waiting together, offering help, speaking words of assurance, breathing together, stroking back, proposing known measures) • Not caring excessively/not challenging the patient (having little/no conversation with patient, keeping a distance or leaving patient alone but staying close by) • Bringing auxiliary means (medicine oxygen device, hot water bottle, hot roll), measuring O₂-saturation • Foreseeing complications: making decisions for the patients (packing bag for hospital, calling an emergency doctor in time, driving the patient to the hospital) 	<ul style="list-style-type: none"> • Staying calm, encouraging oneself • Reassuring oneself by comforting the patient • Recalling that COPD patients do not choke • Accepting patient's needs during episodic breathlessness (e.g., patient does not want help from the informal caregiver) • Concentrating on the patient • Handing over responsibility when rescue services arrive, trusting in competent health care professionals • Setting limits for the patient that establish timelines to contact professional support, even if he or she does not want it • Having emergency contacts in mind
Caring role	Self-affected role

COPD, chronic obstructive pulmonary disease.

panicked, if you don't do anything now, somehow, he's right here, he's going to die next to you, you're standing next to him and you can't do anything." (informal caregiver 427, wife of patient with COPD); *"But then when that doesn't work anymore, so he needs help and then I feel it's sometimes difficult to gauge, how serious is this? Is it now so that I may have to call the doctor or is that a thing that he can then overcome?"* (informal caregiver 440, wife of patient with COPD).

In contrast to the reports associated with fear, three informal caregivers did not experience any anxiety during episodic breathlessness and felt they could handle the situation well. One of them reported being rather annoyed when episodic breathlessness occurred, but not experienced fear or panic.

Supportive factors for informal caregivers

Two factors gave informal caregivers security and helped them to better cope with the patient's episodic breathlessness: first, the patient's ability to undertake coping strategies during his or her episodic breathlessness and thus to gain control over the situation had a relieving effect on informal caregivers. The second factor, which assured safety for the informal caregivers, was knowing that health care professionals could be called for help if necessary.

Coping strategies of informal caregivers for dealing with patient's episodic breathlessness

In addition to these two factors, informal caregivers developed strategies to better cope with the patient's

episodic breathlessness. These strategies could be divided into two categories: (I) coping strategies directed to the patient to help him or her, and (II) strategies used to better cope with one's own emotional distress. *Table 3* lists the identified strategies.

Some strategies could be found in both categories; for instance, the effort of informal caregivers to stay calm during episodic breathlessness helped both the patients and the informal caregivers themselves. In addition, a synergy effect was described: informal caregivers found it much easier to stay calm if the patient also remained calm during episodic breathlessness.

Other strategies conflicted with each other. For example, several informal caregivers found it challenging to comply with the patient's request to be left alone during a breathlessness episode. Many informal caregivers learned from past experiences that being left alone was often the best support for patients; however, patients were more likely than informal caregivers to wait too long before calling an ambulance. Informal caregivers perceived this as stressful, as they felt that calling for professional help sooner rather than later could de-escalate the situation faster. The strategy of refraining oneself from action in order to respect a patient's wishes could thus conflict with the strategy of relying on professional support when needed.

Learning over time: years of experience help in coping with patient's episodic breathlessness

Informal caregivers reported the lack of background information they had about episodic breathlessness and

chronic breathlessness was burdensome, especially at the onset of the disease. Self-gained knowledge about episodic breathlessness, including management strategies, helped informal caregivers to better and more confidently cope with their patients' episodic breathlessness: *"I now know what's happening, I wasn't informed at all about these things, what's going on now, why is it like this now, why are the lungs closing up, why is there no more air coming in and you're just faced with a bunch of questions without answers. That was the worst and most stressful part of the story."* (informal caregiver 120, husband of patient with COPD).

Informal caregivers expressed that receiving professional support immediately at the onset of their patients' episodic breathlessness would have been helpful, as their uncertainty in coping with breathlessness episodes was most severe during that time. Informal caregivers adapted their communication with their patients in order to better cope with them during episodic breathlessness. This involved accepting and trusting in the patient's statements concerning his or her condition and expecting that the patient openly communicated when his or her condition deteriorated: *"I had to get signals from him that I could trust."* (informal caregiver 427, wife of patient with COPD).

Changes in everyday life due to episodic breathlessness

Informal caregivers of patients with episodic breathlessness must be changed their daily routine to avoid the above-mentioned potential triggers for the patient. The fear of episodic breathlessness severely restricted patients and informal caregivers in planning and carrying out activities, especially those outside the home: *"You can't plan a lot of things, if we want to do something, it's always like this, then you actually have to wait until shortly beforehand, how is the condition, can you actually do it, no, because then it doesn't work."* (informal caregiver 440, wife of patient with COPD).

Discussion

To the best of our knowledge, this qualitative study is the first one to explore the experiences and coping strategies of informal caregivers who accompany patients with episodic breathlessness. Informal caregivers want to support patients during episodic breathlessness and help them to regain normal breathing as quickly as possible. Since they are often only partially successful, especially when episodic breathlessness first occurs, informal caregivers feel helpless and thus experience a strong emotional burden. The main

elements of this distress are a feeling of helplessness in the face of the acute event and uncertainty about the outcome of the breathlessness episode, including fear of the patient's death. The lack of knowledge about episodic breathlessness and the best ways to deal with the episodes is stressful for informal caregivers, particularly during the initial occurrences of episodic breathlessness. This stress tends to be very high at the beginning and to decrease with time and with the development of coping strategies. The list of coping strategies described and used by informal caregivers adds new insights to the existing literature. The interviewed informal caregivers in our study emphasized that the need for professional support around the issue of episodic breathlessness is mainly associated with the initial onset of episodic breathlessness.

Informal caregivers' emotional experiences with patients' episodic breathlessness closely resemble the patients' experiences described in the literature. Patients predominantly describe anxiety and panic during episodic breathlessness, which can further increase breathlessness (5,6,19). This was also expressed by the informal caregivers in our study. In addition, our interviews confirm and complement findings from studies on chronic breathlessness from the perspective of informal caregivers. Informal caregivers perceive acute situations of breathlessness as stressful experiences (18,19) in which they experience fear and panic (9,18,19) and feel helpless (18). Especially challenging is assessing in which cases and at what point emergency medical services should be called (18). These experiences are similar to the experiences of the informal caregivers from our study. In addition, similar to our study, dealing with acute situations of breathlessness is described as a learning process for patients and informal caregivers, which they learn to better manage over time (18) with the support of health care professionals (16). The consistency of our findings with the established literature is not surprising, considering episodic breathlessness is generally included in studies on chronic breathlessness.

Concerning the coping strategies of informal caregivers, some of the strategies described in our study can also be found in studies on chronic breathlessness. For instance, the strategy of accepting the patient's needs is addressed by Gysels *et al.* (16,18): informal caregivers notice that trying to support the patient with suggestions of strategies is not always helpful for the patient. Malik *et al.* (17) report acceptance as a coping strategy of informal caregivers in dealing with breathlessness in palliative care patients. In addition, the strategy of setting limits with the patient (see

Table 3) is also described as a coping strategy of informal caregivers of patients with chronic breathlessness in Farquhar's and Ferreira's studies (16,19).

Finally, our study highlights the need for support for informal caregivers, because of the relevant burden caused by episodic breathlessness. The results of the ZBI-7 indicate a high burden on informal caregivers of patients with episodic breathlessness, with a higher score even than that of informal caregivers of patients with advanced cancer, as reported by Higginson *et al.* (22) [mean 7.4 (SD =5.6), median 7 (min 0, max 21)]. Furthermore, informal caregivers of patients with episodic breathlessness require support in both in their roles as a caregiver and an affected person. The importance to consider the various informal caregivers' roles for appropriate care has been suggested in earlier studies on caregivers in the more general context of palliative care (24). In addition to professional help, the exchange with other affected informal caregivers, for example in the context of a self-help group, can be a further source of support (18,25). Finally, our data suggests that informal caregivers need more professional help and support particularly in the early days of their patients' diagnosis, because the burden is especially high at the initial occurrences of episodic breathlessness, before adaption takes place. Malik *et al.* (17) also describe that it takes time to be able to adapt to the care situation and expectations that accompany chronic breathlessness.

Two experiences are typical for informal caregivers of patients with episodic breathlessness: first, the experience of panic by both patients and informal caregivers, and second, the struggle of informal caregivers with their desire to help the patient, which often opposes the patient's need to be left alone. This is also shown by the few studies on informal caregivers of patients with chronic breathlessness when episodic breathlessness is described as "acute breathlessness" or "exacerbation" (5,16,18). This highlights a central discussion about the relationship between episodic breathlessness (or acute/severe/attack/dyspnea-crisis/acute-on-chronic) and chronic breathlessness (4-7,9,26). In our understanding, episodic breathlessness is one form of chronic breathlessness, and cannot be discussed separately from chronic breathlessness. However, it is a specific form of chronic breathlessness that is often experienced with high burdens, panic, and a need for help and strategies to cope with it. To better manage chronic breathlessness, it is useful to assess whether a patient experiences episodic breathlessness and if so, to teach his or her informal caregiver strategies to cope with these episodes.

Implications for clinical practice and research

Our study presents initial findings on the experiences and coping strategies of informal caregivers facing patients' episodic breathlessness. These findings form an important research basis for designing and implementing new supportive interventions for informal caregivers, as strategies developed in the past are rarely directed at informal caregivers of patients with episodic breathlessness (27-29). Informal caregivers are often not adequately considered by health care professionals in their role as affected persons and caregivers of patients with chronic breathlessness (20,30-32). Informal caregivers often feel ill-prepared to deal with their patient's chronic breathlessness (16,33). Plus, the patient's chronic breathlessness causes changes which can affect the informal caregiver as well, creating the need for support for informal caregivers as well as patients (24). By attending breathlessness services, informal caregivers can increase self-efficacy and reduce anxiety (34). Previous studies that focus on the needs and burdens of informal caregivers of patients with chronic breathlessness emphasize the importance of addressing informal caregivers in their roles as both caregivers and affected persons (8,18,31,33). To identify the needs of informal caregivers of palliative patients the "Carer Support Needs Assessment Tool (CSNAT)" (31) can be considered. This tool is also already validated for caregivers of patients with COPD (35). Thus, it could be useful for professionals to support informal caregivers with regard to episodic breathlessness. With this regard, professionals are asked to perceive informal caregivers in their two roles as caregivers and affected persons timely after initial episodic breathlessness occurs to support them to identify their own needs and to find solutions together. In summary, breathlessness services should consider the needs of patients and informal caregivers in a comprehensive approach. Existing interventions for patients and informal caregivers can be taken into account (16,28,36-38).

Limitations and strength of the study

The reliability of this study was strengthened by having two researchers independently review and analyze the data.

Four informal caregivers were interviewed in the presence of their respective patients, which may have resulted in informal caregivers feeling inhibited towards talking about their burdens. Nevertheless, we obtained detailed descriptions of informal caregivers' experiences regarding patients' episodic breathlessness for the first

time. The aforementioned needs and strategies provide opportunities to tailor future intervention studies not only to patients with episodic breathlessness but also to their informal caregivers.

Only two informal caregivers of lung cancer patients could be interviewed, so their experiences are underrepresented. The extent to which there are similarities or differences in the informal caregivers' experience of the two patient groups cannot be answered by this study and requires future comparative evaluation.

Conclusions

Episodic breathlessness is a stressful event not only for patients but also for their informal caregivers, especially at the time of its onset. Informal caregivers learn over time, through their experiences with the patient, to develop and apply strategies to help the patient during episodic breathlessness. At the same time, these strategies help to support the informal caregivers themselves in their distress and feelings of helplessness. The need for professional support is high at the beginning of the disease when informal caregivers have little experience with episodic breathlessness. Health care professionals are encouraged to educate and train informal caregivers alongside patients about triggers, courses of action, and coping strategies of episodic breathlessness.

Acknowledgments

The authors thank all participants of the study for their willingness to participate and give insights into their experiences. We thank the staff at participating centers for their support in recruitment. We would also like to thank Hannah Spencer for her support in proofreading as a native speaker.

Funding: The work was supported by the Federal Ministry of Education and Research (funding code: 01GY1716). The funding source had no impact on the study design, data collection, analysis, or interpretation of the data.

Footnote

Reporting Checklist: The authors have completed the COREQ reporting checklist. Available at <https://apm.amegroups.com/article/view/10.21037/apm-21-3361/rc>

Data Sharing Statement: Available at <https://apm.amegroups.com/article/view/10.21037/apm-21-3361/dss>

[com/article/view/10.21037/apm-21-3361/dss](https://apm.amegroups.com/article/view/10.21037/apm-21-3361/dss)

Peer Review File: Available at <https://apm.amegroups.com/article/view/10.21037/apm-21-3361/prf>

Conflicts of Interest: All authors have completed the ICMJE uniform disclosure form (available at <https://apm.amegroups.com/article/view/10.21037/apm-21-3361/coif>). STS reports the funding from the Federal Ministry of Education and Research (funding code: 01GY1716) and from the University Hospital of Cologne. The other authors have no conflicts of interest to declare.

Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). The study was approved by the Ethics Committee of the Medical Faculty of the University of Cologne (reference number: 18-209) and informed consent was taken from all individual participants.

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Cite this article as: Reitzel T, Bergmann A, Schloesser K, Pauli B, Eisenmann Y, Randerath W, Tuchscherer A, Frank K, Simon ST, Pralong A. The experience of episodic breathlessness from the perspective of informal caregivers: a qualitative interview study. *Ann Palliat Med* 2022;11(7):2225-2234. doi: 10.21037/apm-21-3361