

Response to Reviewer A

We appreciate the reviewer's constructive and valuable comments. We have addressed each of the concerns and questions in the following response letter and have revised the manuscript carefully and think that the manuscript has benefitted greatly from the subsequent changes. More detailed responses to each comment are given below.

Informal carers of patients with breathlessness are a relatively under-researched and unsupported group, so studies that increase our understanding of informal carers experiences and that can inform intervention design are welcome. I enjoyed reading the paper but would recommend the following:
ABSTRACT:

Comment 1: BACKGROUND: not all COPD or cancer patients have advance disease – suggest re-word this sentence.

Reply 1: Thank very much you for your comment. Indeed, our study focusses on patients with advanced stages of diseases such as COPD or lung cancer, this is an important precision.

Changes in the text: We modified the text as advised (see page 2, line 33).

INTRODUCTION:

Comment 2: Final paragraph: suggest add “specifically” to end of first sentence starting “To our knowledge...”

Reply 2: Thank you for the suggestion.

Changes in the text: We added “specifically” as advised (see Page 4, Line 84).

Comment 3: Final paragraph: suggest add references 3,17,18 and 23 to “While a few studies (8, 16)...”

Reply 3: Thank you for the advice.

Changes in the text: We added the references 3, 17, 18 and 23. (see Page 4, Line 85)

METHODS:

Comment 4: Participants and Recruitment: it is important for the reader to know how you identified the carers - what was the wording of the question asked of the patients? This is important as not all patients (or carers) recognised the term carer/caregiver. This will help the reader judge how representative your sample is of everyone in a caring role.

Reply 4: Thank you for your comment. This is important to consider. The patients were asked: Can you name a trusted/close person who is most involved in your care? The wording of this question is not ambivalent in German and matches well with the English term "informal carers/caregivers". We used it already in earlier studies.

Changes in the text: We modified the text as advised and inserted the exact wording of the question about having an informal caregiver (see page 5, line 123).

Comment 5: Participants and Recruitment – second paragraph: do you mean data saturation,

thematic saturation, theoretical saturation or what type?

Reply 5: Thank you for your question, this is an important precision. We mean data saturation.
Changes in the text: We added the word “data” (see page 5, line 133)

Comment 6: Data collection: suggest change “conducted” to “completed”

Reply 6: Thank you for your suggestion.

Changes in the text: We changed the wording as advised (see Page 6, line 140 and 143)

Comment 7: Data collection: suggest edit start of next sentence to start “Burden is assessed on a...”

Reply 7: Thank you for your comment.

Changes in the text: We modified the text as advised. (see Page 6, line 141)

Comment 8: Data collection: Three interviewers seems a lot for only 13 interviews – why was this? What impact could it have had on the data?

Reply 8: Thank you for your questions. Most of the interviews were conducted by two interviewers. However, we had to involve a third interviewer for one interview because of staff shortages. We acknowledge that this might have diminished the reliability of the results. However, the third interviewer was the PI and project lead of the study who was very well familiarized with the topic guide through the other two interviewers in order to minimize this risk of bias in advance. The results of the interviews show high agreement independently of the person who completed the interviews. This suggests that the risk for bias could be kept to a minimum.

Changes in the text: -

Comment 9: Data collection: suggest change “considering the research questions” to “based on the research questions”

Reply 9: Thank you for your suggestion.

Changes in the text: We have modified our text as advised (see page 6, line 146).

Comment 10: Data collection: suggest change “Table 1 describes...” to “Table 1 describes the main topics of the interviews”

Reply 10: Thank you for your advice.

Changes in the text: We changed the sentence as advised (see page 6, line 151).

Comment 11: Data analysis: do you mean “preliminary categorisation system”?

Reply 11: Thank you for your question and this precision. Yes, this is exactly what we mean.

Changes in the text: We adjusted the wording as questioned (see page 7, line 162)

Comment 12: Data analysis: unclear what you mean by “Further analysis was performed by...” – what further analysis?

Reply 12: Thank you for your question. With further analysis we mean all the individual analysis (including encoding, paraphrasing, summarize) after implementing the main and subcategories .

Changes in the text: We deleted the original sentence (see page 7, line 173) and modified the text to clarify what further analysis means (see page 7, line 165-167).

Comment 13: Data analysis: also unclear what “All results of the individual analysis were revised by...” involved and why it was done and the impact of this

Reply 13: Thank you for your comment. Two researchers did the implementing of the main and subcategories by analyzing all of the interviews. After that, just one researcher did the encoding, paraphrasing and summarizing of all interviews. To ensure reliability, one researcher revised these steps.

Changes in the text: We deleted the original sentence (see page 7, line 173-174) and modified the text to clarify this part (see page 7, line 165-167).

RESULTS

Comment 14: Any data on the ethnicity of the carers?

Reply 14: Thank you for your question. We did not ask about ethnicity explicitly.

Changes in the text: -

Comment 15: Throughout this section the findings are reported in the present tense – they should be past tense e.g. “experiences” should be “experienced”, “can handle” should be “felt they could handle”, “find” should be “found” etc. The whole results section needs reviewing for this.

Reply 15: Thank you very much for this language correction.

Changes in the text: We modified the whole result section as advised in past tense (see page 8-13).

Comment 16: All quotes need an identifier so that the reader can judge the spread of sources of quotes (or they could mainly be from the same couple of carers)

Reply 16: Thank you for your suggestion. We will attach the number of the carer to the quote.

Changes in the text: We inserted the number for each informal caregiver from the study to every quote (see page 9,10,12,13).

Comment 17: Line 246 – suggest change “in the process of” to “during”

Reply 17: Thank you for your comment.

Changes in the text: We changed the wording as advised (page 10, line 237).

Comment 18: Table 2 – what are “divers” (Gender)?

Reply 18: Thank you for your question. There was an “e” missing in divers. Of course, you spell it “diverse”. Even if nobody stated to be diverse in our study, we did not want someone to feel left out. With diverse we mean people, who do not identify themselves as female or male.

Changes in the text: We corrected the spelling to “diverse” (see table 2).

Comment 19: I liked Table 3!

Reply 19: Thank you!

DISCUSSION

Comment 20: Think there is a word missing in first paragrah, line 322 “This stress tends to...”

Reply 20: Thank you for your comment. You are right and we are sorry about that. We inserted the

missing words.

Changes in the text: We inserted “to be very high at the beginning” to the sentence as commented (see page 14, line 316)

Comment 21: I found it difficult to identify what this paper adds – much of the discussion is focused on how it supports/is supported by existing literature. There needs to be some clarity on the unique contribution of this paper.

Reply 21: Thank you for your comment. We agree that we need to be more specific. What is unique in this paper is that we focused explicitly on the perspective of **informal caregivers on episodic breathlessness**. This specific perspective has never been investigated before. Furthermore the strategies (see table 3), which informal caregivers use, adds new insights to the existing research and literature.

Changes in the text: We adapted and modified the discussion section (see page 14, line 317-319).

Comment 22: The statement that self-help groups are a great source of help to carers need a reference.

Reply 22: Thanks for your comment. We agree that references are necessary.

Changes in the text: We inserted references (see page 15, line 354)

Comment 23: The paragraph starting “Finally...” discusses the dual needs of carers as clients in their own right and co-workers – the work of Stajduhar et al 2008 should be referenced here: <https://pubmed.ncbi.nlm.nih.gov/18922609/>

Reply 23: Thank you for the suggestion.

Changes in the text: We inserted the suggested reference as advised (see page 15, line 352)

Comment 24: I don’t think you have the evidence to say that the greatest need for professional help is at the initial occurrence of episodic breathlessness – professional help is acutely needed at the end of life too.

Reply 24: Thank you for your comment. We deleted the sentence and reformulated the paragraph, in order to better address your comments 22-24.

Changes in the text: see changes in the discussion section (see page 15 and 16, line 344-363)

Comment 25: Last two paragraphs of the discussion section (starting “Two experiences...” and “This highlights...”) before the first subheading should be one paragraph.

Reply 25: Thank you for your comment. We linked these two paragraphs together.

Changes in the text: We modified the text as advised (see page 16, line 369)

Comment 26: Line 380: suggest change “needs” to “experiences” - they are conceptually different.

Reply 26: Thank you for your comment. We agree that “experiences” is more suitable.

Changes in the text: We changed “needs” to “experiences” as advised (see page 16, line 380)

Comment 27: Line 383-384: I disagree that past strategies for episodic breathlessness were only directed at patients, the Cambridge Breathlessness Intervention Service was (and is) for carers as well. See: <https://pubmed.ncbi.nlm.nih.gov/25358424/> and

<https://pubmed.ncbi.nlm.nih.gov/27044249/>

Reply 27: Thank you for your comment. We absolutely agree and we know the CBIS/BIS very well. Most existing interventions for a better coping of episodic breathlessness are addressed to the patients and very rarely to their carers.

Changes in the text: We modified the text and inserted the references as advised (see page 16, line 383-384)

Comment 28: Line 395: not sure why the word “immediately” is included here – professionals are unlikely to be present when these episodes occur

Reply 28: Thank you for your comment. We meant by “immediately” to support in a timely manner after the appearance of the initial occurrence of episodic breathlessness. So probably we should use another wording.

Changes in the text: We changed the word “immediately” to “timely after initial episodic breathlessness occurs” (see page 17, line 398)

Comment 29: Line 395-396: asking professionals to “offer support” is a bit vague – their first priority should be identifying carers in the first place, then working with the carer to identify their needs, then identifying solutions together. Given that you reference a CSNAT paper (ref 27: Ewing et al, 2013), I was surprised that you hadn’t considered its potential utility as an intervention to identify and address carers’ support needs in an individually tailored person-centred way within the breathlessness service: <https://csnat.org/>. The intervention comprises the CSNAT (the tool itself) and an approach to carer need identification and support. The CSNAT (the tool itself) has now been validated for carers of patients with COPD and the utility of the broader intervention explored in this carer group: <https://pubmed.ncbi.nlm.nih.gov/33761766/>. This is an evidence-based intervention with international uptake which could be delivered within a breathlessness service.

Reply 29: Thank you for your comment, these aspects are really important. Unfortunately we missed to mention this tool in the first place.

Changes in the text: We modified the text as advised and inserted the suggested reference (see page 17, line 393-396).

Comment 30: In the abstract you refer to how both patient and carer support need should be part of a comprehensive approach. There is a patient “version” of CSNAT which was actually first developed for patients with COPD that you might like to consider: the Support Needs Approach for Patients (SNAP) <https://thesnap.org.uk/>. SNAP’s evidence base in COPD:

<https://pubmed.ncbi.nlm.nih.gov/34677104/>, <https://pubmed.ncbi.nlm.nih.gov/31748307/>, <https://pubmed.ncbi.nlm.nih.gov/30834813/>

Reply 30: Thank you for the interesting references. We definitely should insert them.

Changes in the text: We modified the implication section and inserted the suggested references (see page 17, line 398-401).

Comment 31: A further intervention dedicated to carers of patients with breathlessness may also have utility: <https://supporting-breathlessness.org.uk/> (which is based on refs 16 and 28: Farquhar et al 2017 and 2015)

Reply 31: Thank you for your comment.

Changes in the text: We inserted these references as well (see page 17, line 401).

Comment 32: Line 399: thought there were three interviewers? Says two here

Reply 32: Thank you for your comment. Indeed, this sentence lacks accuracy. There were three interviewers collecting the data, i.e. completing the interviews. But two researchers reviewed and analyzed the data. To precise this sentence, we will only mention that the two researchers reviewed and analyzed the data.

Changes in the text: We deleted the word “collect” (see page 17, line 405)

Comment 33: Suggest delete the sentence “We conducted a qualitative descriptive study...” as it doesn’t add anything to the discussion of strengths and limitations.

Reply 33: Thank you for your suggestion.

Changes in the text: We deleted the sentence as advised (see page 17, line 405-406)

Comment 34: Good to see consideration of the impact of patients being present in four interviews.

Reply 34: Thank you for your comment.

Comment 35: Good to see consideration of the possible impact of different patient diagnoses on the carer experience

Reply 35: Thank you for your comment.

Response to Reviewer B

We appreciate the reviewer’s time to read and comment on our manuscript.

Breathlessness is one of the major distressing symptoms in palliative care setting not only for patients but also their families.

Thus, this manuscript provides important insight about the needs or burden of informal caregivers related to episodic breathlessness.

Overall, this manuscript are well-written.

I have only one point to suggest.

This study included only 7 informal caregivers from the mother study which included 49 patients. Thus, I think there is some frailty in generalizability of the result. So, please consider the risk of selection bias.

Reply to Reviewer B: Thank you for your comment. Generalizability by a qualitative study with 13 participants is challenging. However, we used a broader approach than the CoBeMEB (Mother) study in order to reduce selection bias.

Changes in the text: -