

SUPPLEMENTARY INFORMATION

**“It’s like being on a roller coaster”:
The burden of caring for people with severe asthma**

ELEANOR C. MAJELLANO,^{1,2} VANESSA L. CLARK,^{1,2} JULIET FOSTER⁴, PETER G. GIBSON^{1,3},
AND
VANESSA M. MCDONALD^{1,2,3}

Author Affiliations

¹ National Health and Medical Research Council Centre for Research Excellence in Severe Asthma and The Priority Research Centre for Health Lungs, The University of Newcastle, Newcastle, NSW; ² School of Nursing and Midwifery, The University of Newcastle, Newcastle, NSW; ³ Department of Respiratory and Sleep Medicine, John Hunter Hospital, Hunter Medical Research Institute, Newcastle, NSW, Australia ; ⁴ Woolcock Institute of Medical Research and The University of Sydney

Correspondence: Vanessa M. McDonald, Level 2 West Wing, Hunter Medical Research Institute, Locked Bag 1000, New Lambton, NSW 2305, Australia.

Email: Vanessa.McDonald@newcastle.edu.au; Fax: +6140420046

Table S1: "Providing Care and Support"

Sub-themes	Quotes
Health care support	<p data-bbox="544 181 826 210">Managing Daily Medication</p> <p data-bbox="544 230 1264 304"><i>"I always try and make sure that she's had what medications she needs to have or if she hasn't had them or needs to have them, I'll encourage her to stop what she's doing and go and have them." (Spouse, P6,63)</i></p> <p data-bbox="544 329 1264 378"><i>"So, the main things I do is make sure that she takes her medication on time, and the right dosage of medication." (Spouse, P7,46)</i></p> <p data-bbox="544 416 810 445">Healthcare Appointments</p> <p data-bbox="544 459 1264 533"><i>"Well I'm just always with her all the time. I always write them down on the big whiteboard on the fridge so we never miss them or anything like that." (Spouse, P5,70)</i></p> <p data-bbox="544 557 1264 656"><i>" I always went into the room with her, even as she became older, so I was always there to help manage her care with the healthcare provider at the time, and I would ask questions and clarify the details of her care that we were about to undertake. (Mother, P18,72)</i></p> <p data-bbox="544 672 815 701">Assisting in Emergencies</p> <p data-bbox="544 714 1264 869"><i>"So I turned around and his face was pale, his lips were blue, he was not breathing. So I went and felt his pulse and he wasn't - his pulse was very, very weak. Then - so he wasn't breathing for about a minute, so I rang 000 and was about to pull him off the chair and start CPR and he did this horrendous cough. I think I just went into save this man's - just in automatically just do something." (Spouse, P3,68)</i></p> <p data-bbox="544 893 1264 1014"><i>"...it requires you as a carer to adapt and change very quickly with that, which has its own stressors. You have to be able to adapt quickly to be able to handle that situation and doing that is not always easy. Hence why I believe it's a real stress factor in that it's such an unknown, and that it's unpredictable." (Spouse, P7,72)</i></p>
Emotional Support	<p data-bbox="544 1061 660 1090">"My Rock"</p> <p data-bbox="544 1106 1241 1155"><i>"Just go up and have a cup of tea with her. Be a support person as best I can, you know, a good son." (Son, P14,59)</i></p> <p data-bbox="544 1205 1209 1258"><i>"Try and remain calm if they're having an asthma attack. Try and help them deal with it." (Spouse, P10,68)</i></p>

Box S1: Topic Interview Guide

- When it comes to your knowledge about severe asthma what would you say you are most confident about, and what you least confident about?
- What are the main things you do to support them?
- Can you tell me what it's like for you living with someone with severe asthma?
- Is your [partner/family member/friend] prescribed medications for their asthma? In what ways, if any, do you help with the medications?
- What role, if any, do you have in your [partner/family member/friend]'s health care appointments?
- In what ways are you satisfied or dissatisfied with how your partner involves you in discussions or decision-making?
- In what ways are you satisfied or dissatisfied with how the health care provider involves you in discussions or decision-making?
- Can you describe the role you think you have, if any, in providing your partner/family/friend with support/emotional support? How do you feel about providing this support?
- What impact would you say your [partner/family member/friend]'s severe asthma has on you?
- Do you consider you role as one of 'carer' for your [partner/family member/friend], and how would you describe your role?
Probes: What do you like about your role?
What don't you like about it?
- Can you tell me if anything worries you in relation to your [partner/family member/friend]'s severe asthma?
- I would also like to know what you feel comfortable about, or not worried about, regarding their severe asthma?
- To what extent does your [partner/family member/friend] understand your experience of being part of their severe asthma?
- Are there any things that make it difficult for you to take care of your own physical health? Tell me more about that.
- What kinds of things do you do to care for your own physical health? Are there things you don't get around to?
- Does the person you care for sometimes feel negative or down due to their experiences with severe asthma?
- What sort of emotional impact have bad attacks had on you or other family members?
Probe: Has your sense of well-being changed over time?
- How many hours of sleep do you normally get per night?
- Does your [partner/family member/friend]'s severe asthma have any impact on your sleep?
- Do you feel severe asthma impacts your relationship with your [partner/family member/friend]?
- Have there been times when you were unable to participate in something due to your [partner/family member/friend]'s severe asthma?
- Have you experienced barriers to physical intimacy because of severe asthma?
- To what extent are you aware of how your [partner/family member/friend] feels about these sorts of barriers or limitations?
Probe: How do you feel about it?
- To what extent do you find your [partner/family member/friend]'s severe asthma severe asthma unpredictable?
- Are there any activities, daily rituals, or habits that you use to cope with the unpredictable nature of asthma?
- Have you received any support from any carer's groups, friend or community groups to assist you as a [relative/friend] of someone with severe asthma?
Probe: What did you find helpful or unhelpful about it?
- Has your partner, family member or friend ever experienced a bad attack [that may have involved an urgent visit to a GP or to hospital]?
Probes:
How did this make you feel during and after the attack?
How did you respond to it?
What support, if any, was available for you during this period?
- Can you suggest any resources, or anything you would like to see change for partners, relatives or friends for people with severe asthma?
- Can you tell me if anything worries you in relation to your [partner/family member/friend]'s severe asthma?

Box S2: Consolidated criteria for Reporting Qualitative research (COREQ) Checklist

Domain and Items	Author Comment	Location in manuscript (page no)
Domain 1: Research team and reflexivity		
Personal characteristics		
1. Interviewer/facilitator Which author/s conducted the interview or focus group?	EM conducted the interview. However, all authors informed the designed of the interview schedule.	See page 4, Study design under Data collection.
2. Credentials What were the researcher's credentials? E.g. PhD, MD	<i>First Author-</i> MPH,BS Opto <i>Second Author -</i> PhD,B. Psychology, Hons1, <i>Third Author-</i> PhD Health Psychology, Bsc Psychology <i>Fourth Author-</i> MBBS, FRACP, PhD, FThorSoc <i>Fifth Author:</i> PhD, FThorSoc., BNurs, DipHthScien (Nurs)	-
3. Occupation What was their occupation at the time of the study?	<i>First Author:</i> PhD Candidate <i>Second Author:</i> Research Fellow <i>Third Author:</i> Research Psychologist <i>Fourth Author:</i> Senior Staff Specialist in Respiratory Medicine, NHMRC Practitioner Fellow, Co-Director NHMRC Centre of Research Excellence in Severe Asthma, Professor of Medicine <i>Fifth Author:</i> Professor of Nursing, Academic Clinician, Co-Director NHMRC Centre of Research Excellence in Severe Asthma, Co-Director Priority Research Centre for Health Lungs All author affiliations are listed in the title page	-
4. Gender Was the researcher male or female?	EM, VC, JF and VM - Female PG- Male	See page 4 under Data Collection (pertaining to the doctoral researcher).
5. Experience and training What experience or training did the researcher have?	EM completed a qualitative course and special training on Foundation of Qualitative Methodologies, Data Collection and Analysis.	Page 4 under Data Collection (pertaining to the doctoral researcher).
Relationship with participants		
6. Relationship established Was a relationship established prior to study commencement?	No	-
7. Participant knowledge of the interviewer What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Participants were informed on the purpose of the study and understood that it was a research study for EM.	-
8. Interviewer characteristics What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	EM declared her academic standpoint and participants were made aware that she was not from a medical background. This allowed EM to ask naïve questions and asks for clarifications where needed.	-
Domain 2: Study design		
Theoretical framework		
9. Methodological orientation and Theory What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	In the Data Analysis section, we explain how we used the thematic analysis by Braun and Clarke.	See page 5.
Participant selection		
10. Sampling How were participants selected? e.g. purposive, convenience, consecutive, snowball	Purposive sampling was used to select participants to capture maximum variation in views and experiences.	See page 4.
11. Method of approach How were participants approached? e.g. face-to-face, telephone, mail, email	Participants was approached via telephone, email and face-to -face.	See page 4 under participants and procedure for further details.

12. Sample size How many participants were in the study?	We recruited 20 participants.	See page 4.
13. Non-participation How many people refused to participate or dropped out? Reasons?	Not applicable as yet.	-
Setting		
14. Setting of data collection Where was the data collected? e.g. home, clinic, workplace	Data was collected via telephone interview or in person and took place in a private room at Hunter Medical Research Institute.	See page 4.
15. Presence of non-participants Was anyone else present besides the participants and researchers?	No	See page 4.
16. Description of sample What are the important characteristics of the sample? e.g. demographic data, date	Age range 34-80 years; mostly were female n=11, Caucasian n=16, providing care for >10 years. Please refer to Table 2 for further details. Data was collected between September 2019 and December 2019.	See page 5 See Table 2
Data collection		
17. Interview guide Were questions, prompts, guides provided by the authors? Was it pilot tested?	Interviews were semi-structured using a topic guide. (BoxS1) Probes were used to generate further explanation.	See page 4 and supplementary material Box S1.
18. Repeat interviews Were repeat interviews carried out? If yes, how many?	No	-
19. Audio/visual recording Did the research use audio or visual recording to collect the data?	Yes, audio recording was used throughout the data collection.	See page 4.
20. Field notes Were field notes made during and/or after the interview or focus group?	Additional field notes were made after the interviews.	See page 5.
21. Duration What was the duration of the interviews or focus group?	The interview ranged between 34-59 minutes (face to face); 20-61 minutes (telephone).	See page 4.
22. Data saturation Was data saturation discussed?	Yes, this was discussed in team meetings.	See page 5.
23. Transcripts returned Were transcripts returned to participants for comment and/or correction?	No. However, EM verified the transcript against the sound file for data accuracy.	See page 5.
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders How many data coders coded the data?	One	See page 5.
25. Description of the coding tree Did authors provide a description of the coding tree?	Coding described in Data Analysis section.	See page 5.
26. Derivation of themes Were themes identified in advance or derived from the data?	Themes were derived from the data.	See page 5.
27. Software What software, if applicable, was used to manage the data?	Yes, NVivo Pro version 12.0 were used to manage the data.	See page 5.
28. Participant checking Did participants provide feedback on the findings?	No	-
Reporting		
29. Quotations presented Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number	Yes, specific quotations to illustrate key themes are presented in Tables 3,4,6. All direct quotes are anonymised using a caring relationship and participant number.	See Tables 3,4,6.
30. Data and findings consistent Was there consistency between the data presented and the findings?	Yes	See page 6-12.
31. Clarity of major themes Were major themes clearly presented in the findings?	Yes	See page 6-12.
32. Clarity of minor themes Is there a description of diverse cases or discussion of minor themes?	Yes	See pages 6-12.