



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

Eleanor C. Majellano <sup>1,2</sup>, Vanessa L. Clark<sup>1,2</sup>, Juliet M. Foster<sup>3</sup>,  
Peter G. Gibson <sup>1,4</sup> and Vanessa M. McDonald <sup>1,2,4</sup>

**Affiliations:** <sup>1</sup>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, Australia. <sup>2</sup>School of Nursing and Midwifery, The University of Newcastle, Newcastle, NSW, Australia. <sup>3</sup>Woolcock Institute of Medical Research and The University of Sydney, Sydney, NSW, Australia. <sup>4</sup>Department of Respiratory and Sleep Medicine, John Hunter Hospital, Hunter Medical Research Institute, Newcastle, NSW, Australia.

**Correspondence:** Vanessa M. McDonald, Level 2 West Wing, Hunter Medical Research Institute, Locked Bag 1000, New Lambton, NSW 2305, Australia. E-mail: Vanessa.McDonald@newcastle.edu.au

## ABSTRACT

**Introduction:** Family carers and significant others play a fundamental role in the well-being of people with severe asthma. This study aimed to investigate the challenges faced by family carers/significant others of people with severe asthma, to understand if there is an unmet need and to explore coping strategies.

**Methods:** Carers of people with severe asthma were invited to participate in a face-to-face or telephone interview. Semi-structured interviews were conducted until reaching data saturation of themes. The 20 interviews were recorded and transcribed, and analysis of data followed an inductive thematic approach.

**Results:** We report three overarching emergent themes: 1) “Caring role impacts”, which centred around the negative and positive impacts of caring on carers’ well-being; 2) “Unmet needs”, which encapsulated the support needs participants desired and were categorised into unmet information, biopsychosocial needs and carers’ involvement in decision-making; and 3) “Coping strategies”, which were central to the range of tools and positive approaches in dealing with caring demands.

**Discussion:** Caring for someone with severe asthma can be burdensome and may negatively affect the physical and psychosocial health of the carer. Various coping strategies are used to manage the demands of these caring roles. Carers of people with severe asthma expressed a need for informational, biopsychosocial and involvement in care decision-making support. Tailored support services that are sensitive to their needs may improve their quality of life and encourage healthcare providers to value and acknowledge the important contribution that carers make.



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Caring for someone with severe asthma can be burdensome, affecting the physical and psychosocial health of the supportive person negatively. Tailored support services may improve their quality of life. <https://bit.ly/2KA9PWS>

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**Introduction**

Due to the complex nature of severe asthma, people with this disease experience physical and psychosocial burdens which negatively impact their quality of life [1–3]. Given the adverse impact of asthma on the daily lives of people with severe disease [3], it is likely that the burden of severe asthma also extends to families and significant others [3]. However, the burden that severe asthma has on carers is yet to be explored.

Informal carers, such as family members or significant others, are people who provide care and support to someone with a diminishing physical capacity or chronic life-limiting illness [4]. Whilst caring and supporting someone is regarded as rewarding for many carers [4], this dedication may also be at the expense of their own health, personal and financial needs [5].

Previous research investigating carers of people with chronic obstructive pulmonary disease (COPD) and interstitial lung disease have described the challenges of these caring roles [6–10]. Conversely, a number of comparative studies suggest that different chronic diseases present unique caring demands [11, 12]; therefore research needs to demarcate the type and extent of burden experienced by carers from the general aspect of caregiving [13]. Given the variable triggers and unpredictable nature of asthma, the caring role may impose different demands compared to diseases with an expected trajectory [14]. It is important to understand the impacts of severe asthma on family carers to inform an effective person-centred model of care, which includes not only the person with the disease but all family carers and all other relevant stakeholders. This qualitative study was therefore undertaken to explore the challenges faced by carers of people with severe asthma, particularly the emotional burden of caring, the unmet needs of carers and the strategies carers use to adapt to their caring role.

**Methods**

*Study design*

Participants were invited to take part in a qualitative study involving semi-structured interviews. Ethical approval was obtained from the Hunter New England Health Human Research Ethics Committee Approval No.2019/ETHO0143. The Consolidated Criteria for Reporting Qualitative Research (COREQ) was used to guide reporting (supplementary box S2) [15].

*Participants and procedure*

Inclusion/exclusion criteria are presented in table 1. People with severe asthma from the Australasian Severe Asthma Registry [16], the John Hunter Hospital Department of Respiratory and Sleep Medicine’s ambulatory care clinics and research database, or nationwide General Practice and Pharmacies provided the contact details of their nominated carer, after obtaining their carer’s permission. Purposive sampling was used to achieve participant diversity, caring duration and caring relationship. If a patient had more than one nominated carer, the carer with the longest caring duration was invited to be interviewed. Carers were approached by letter enclosing written study information and a consent form; the carer contacted the study coordinator to indicate their interest. Written or electronic consent was obtained prior to interview and was sent *via* mail or e-mail.

*Data collection*

Between September and December 2019, in-depth semi-structured interviews were conducted by EM (a female doctoral student and trained qualitative researcher) either face-to-face in a private room within the Hunter Medical Research Institute (HMRI) or by telephone. People with severe asthma were not present during interviews, and the confidential nature of the interview was reiterated to carers prior to

TABLE 1 Inclusion and exclusion criteria

	Inclusion	Exclusion
<b>Participants</b>	Able to speak English; identified as carer or support person by their family member, partner or friend with severe asthma; the carer or support person did not have to live with the care-recipient; providing unpaid care or support for someone with severe asthma	Carers aged <18 years; working as professional or formal carer
<b>Criteria for severe asthma</b>	High-dose inhaled corticosteroid and second controller; or frequent OCS or ACQ >1.5 or exacerbation requiring OCS in the past year	
<b>Caring experience</b>	≥6 months caring or supporting experience	

OCS: oral corticosteroids; ACQ: Asthma Control Questionnaire.

commencement. The interview guide was developed around the study aims and existing research literature, and explored carer roles, experiences, concerns and coping strategies (supplementary box S1) [6, 11, 14, 17–23]. Interviews were audio recorded. The face-to-face (n=4) interviews were 34–59 (mean 45, SD=9) minutes in length and telephone interviews (n=16) were 20–61 (mean 35, SD=13) minutes. Interviews continued until no new themes emerged. All interview quotations are labelled using caring relationship, participant number and age or decade to ensure confidentiality.

**Data analysis**

Digital interview recordings were deidentified and transcribed. Transcripts were verified against the original sound file by EM. NVivo Pro version 12.0 software was used to manage the data. Data analysis followed an inductive thematic approach [24] beginning with familiarising and re-reading of transcripts, then initial coding of 10 transcripts, and grouping of common codes into emergent themes. The interviewer kept a reflective journal to explore and identify recurring thoughts and ideas. Emergent themes and codes were discussed, and conflicting elements on the interpretation and analysis of the data were discussed until agreement was reached with co-authors EM, VM and VC. Thematic saturation was considered to be achieved when the identified themes were robust and no new information emerged from the data. Throughout the analysis, transcripts were frequently revisited to confirm the consistency of themes. Final sub-themes and themes were reviewed by all co-authors.

**Results**

Demographic details are presented in table 2. Participants were 34–80 years old (mean=59, SD=14), 11 (55%) of whom were females. Twelve (60%) identified as partners of their care-recipient, three (15%) as friends,

TABLE 2 Demographic characteristics of carers

Characteristic	Subjects n (%)
<b>Caring duration</b>	
<5 years	2 (10)
5–10 years	4 (20)
>10 years	14 (70)
<b>Sex</b>	
Female	11 (55)
Male	9 (45)
<b>Marital status</b>	
Married or <i>de facto</i> married	17 (85)
Widowed	3 (15)
<b>Education</b>	
Secondary education	9 (45)
Bachelor’s degree	9 (45)
Higher degree	2 (10)
<b>Employment status</b>	
Full-time employed	7 (35)
Part-time employed	1 (5)
Retired	10 (50)
Unemployed	2 (10)
<b>Caring relationship</b>	
Spouse/partner	12 (60)
Son/daughter	2 (10)
Father/mother	2 (10)
Brother/sister	1 (5)
Friend	3 (15)
<b>Ethnicity</b>	
Caucasian	16 (80)
Asian	4 (20)
<b>Location</b>	
New South Wales	16 (80)
Queensland	2 (10)
South Australia	1 (5)
Western Australia	1 (5)
Age range 34–80 years (mean±SD 59±14 years).	

two (10%) as parents, two (10%) as offspring and one (5%) as a sibling. The majority of participants were Caucasian (80%) and had been providing care for >10 years (table 2). From the interview data, three key and novel themes emerged, which are discussed with supporting representative statements. Within each theme there were interconnected sub-themes (figure 1). For context, box 1 contains a brief overview of tasks and support aspects carers discussed, additional descriptive quotes in supplementary table S1.

**Theme 1: “caring role impacts”**

This theme encompasses the inherent negative and positive impacts of caring on carers’ confidence and awareness, identity, physical and emotional health. Participants also spoke about the rewards of caring including reaffirmation of relationships and fulfilment of self-worth (table 3).

*Confidence and awareness*

Participants gained new skills and perceived confidence to recognise symptoms, taking appropriate action during acute attacks and maintaining such skills over time. Being a qualified first aider undoubtedly increased participants’ confidence in care:

Yes, I’m very confident. I also worked in schools and I was a first aid officer in primary schools, so dealt with young children with asthma.

Spouse, P10, 62

Others consciously blend their power of observation and heightened situational awareness:

Your powers – you have to develop powers of observation. A long time before you touch anybody you look and you see from their face, you see from their hands, you see from their skin, all of these things.

Friend, P13, 80

Having their own asthma diagnosis, although not severe, allowed one participant to understand what it was like to be breathless, giving her confidence to recognise her mother’s core symptoms.

I’m very confident about it because I’ve got it.

Daughter, P15, 55

Whilst some carers achieved confidence, others struggled to gain self-efficacy about their ability to provide the care required for the disease itself.

It’s the timing of that, recognising that things are becoming critical that I probably had the most difficulty with.

Spouse, P9, 66

*Caring identity*

Many participants perceived the caring role as inherent to their relationship with their care-recipients. Over time, some participants did identify as “carers”, yet others declined the term and viewed themselves as “partner” or “supportive person”; to them “carer” referred to health professionals. Others recognised themselves as on-call carers, and they discussed how the extent of their caring role increased as care-recipients’ symptoms increased or when there was a crisis, such as sudden severe attacks and/or a marked health deterioration.



FIGURE 1 Themes and subthemes from the thematic analysis.

**Box 1. Providing care and support**

Carers had wide-ranging “healthcare support” roles from medication management to attending healthcare appointments or dealing with sudden severe attacks.

**Healthcare support**

Participants described how they safeguard that care-recipient adheres to prescribed medications. They mainly spoke about the need to maintain ongoing awareness and monitoring on what medication their care-recipients were taking and ensuring prescriptions were filled.

“I have to know what he takes, when he takes it, what he needs when he’s having attack”. (Spouse, P10, 68)

“I’m sort of a nurse to her. So, I am the one to remind her to take this and that and don’t forget about, you know, basically I’m her secretary and nurse as well”. (Spouse, P1, 36)

**Emotional support** was also a key caring role. For example, during severe attacks interviewees described how they remained calm to “save” their loved ones or described giving comfort during attacks or encouragement by tailoring activities to the patient’s limitations.

“Sometimes I took her to places that she likes, going to the beach, just a therapeutic holiday. I call it a therapeutic holiday, just to feel her at peace, whatever”. (Spouse, P1, 36)

“When her asthma gets worse, she does. Like she always says oh take good care of my kids and I’m going to die soon, and then I say no, you’re not going to die, you just have to follow what your doctor told you and be strong for your kids”. (Friend, P17, 35)

*Accepting caring roles*

Most participants embraced their caring role willingly; however, others expressed feelings of anger and resentment. Participants felt valued when the care-recipients acknowledged their support. Participants shared that there was a strong desire amongst care-recipients not to become a burden in their own families and that they wanted to live with an improved quality of life.

She wants to change. She definitely wants to improve. That’s why we’re looking into things like bronchial thermoplasty and stuff, stuff like that. She wants to be able to help more, to do more and do some of the more normal things and be a bit more normal.

Spouse, P16, 47

Participants also described how their care-recipient’s condition was unfair, which led carers to feel bitter and angry. This was partly driven by frustration when none of the medications seemed to work.

It’s a pain in the neck when they’re sick. It’s awful when they’re sick. I’d rather do anything else. When they were really, really sick and wouldn’t listen, I just thought well just die, I don’t care really.

Spouse, P11, 7th decade

This particular quotation highlighted the severe burden on carers and the fluidity of their situation in the face of their significant other’s acuity.

*Caring impact on life*

The impact of caring on participant’s well-being was multifaceted, ranging from their health to their relationships and financial stability. Topics of interpersonal and extra-personal strains including reduction in sexual intimacy, disruption in social activities, lost income and career change caused by their caring roles were mentioned often.

Physical impacts included sleep disturbance and tiredness, particularly when the care-recipient also suffered from comorbid conditions, which made their role more challenging. Comorbidities complicated carers’ capacity to manage medication and created escalating care.

A bit difficult mainly because she doesn’t only have asthma. She’s got other medical things that just kind of stem from it, which means she’s a bit immobile these days. Yeah, it’s hard having to do everything.

Spouse, P16, 47

A participant reflected on how his caring role explicitly affected his lifestyle and level of sedentariness as his care-recipient became more physically sedentary.

The impact is that I am more sedentary than what I would normally be. So I’m more sedentary because she’s sedentary.

Spouse, P4, 66

TABLE 3 Theme 1: “caring role impacts”

Subtheme	Quotes
<b>Confidence and awareness</b>	<p>“So, I’m pretty confident about following our GP’s care plan and what to do in the time of an asthma attack”. (Spouse, P7, 46)</p> <p>“So things that I would be confident about is that it’s a severe respiratory condition and that it has hereditary origins and also can be environmental”. (Spouse, P4, 55)</p> <p>“Probably most confident is actually recognising when he is in trouble”. (Spouse, P2, 68)</p> <p>“What I’m confident about is helping my wife when she has an asthma attack. I have a fairly good idea of what I should be doing, how I can help and things like that”. (Spouse, P8, 68)</p>
<b>Caring identity</b>	<p>“I feel like I’m more a partner than a carer. I’m there to share with him, not so much do it for him”. (Spouse, P10, 68)</p> <p>“I do consider myself as a carer”. (Spouse, P1, 36)</p> <p>“When he was really ill I considered myself a carer”. (Spouse, P11, 7th decade)</p> <p>“I think, in a way, yes, because I can consider my role as an – as what I’ve said, as like an on-call carer”. (Friend, P20, 38)</p>
<b>Accepting caring roles</b>	<p>“I feel satisfied. I feel happy about it, that I was able to give my sister support that she needed”. (Sister, P19, 34)</p> <p>“You do anything, really, for the one that you love, but yeah, I don’t think that there’s much more positivity that you can get out of it, except that you’re doing the best that you can for the person that you love. As a carer, I don’t think anyone wants to be a long-term carer”. (Spouse, P7, 46)</p> <p>“You feel good, yeah. It doesn’t matter who they are, whether it’s – yeah, I just like helping people, that’s all. Rather me, I suppose”. (Spouse P5, 70)</p> <p>“I hate being a carer. I hate him being sick, but I think anybody that has a chronic disease like that hates being – it impacts on your quality of life. It impacts on both our quality of life”. (Spouse, P11, 7th decade)</p>
<b>Caring impact on life</b>	
Physical	<p>“So, it’s hard for me to try and go to bed early, because my brain doesn’t switch off. I have to use medication to help me sleep, otherwise I don’t go to sleep, or I sleep very lightly. Because L also – because of her size – she snores loudly, if she doesn’t use her sleep apnoea machine, that interrupts my sleep, but if she uses her machine it’s not so bad”. (Spouse, P7, 46)</p> <p>“When he’s unwell there’s lots of things and it’s tiring. You’re exhausted. You don’t sleep at night... when he’s really ill, it consumes your whole life; it’s an absolute daily, nightly consuming thing in that everything has to revolve around it”. (Spouse, P11, 7th decade)</p> <p>“... she has the diabetes as well, so it’s a constant thing for the whole day and into the night of pretty much medication. There’s more factors involved now. Like I said, there’s the diabetes and then there’s some other problems that she has prolapse and stuff. She has like a – we can’t go too far without having to go near a toilet and stuff”. (Spouse, P6, 63)</p>
Interpersonal	<p>“So a lot of the times the impact is that if we planned to go out for a picnic, for example, it would have to be reassessed on the day, even from one minute to the next”. (Spouse, P10, 68)</p> <p>“She doesn’t always want to have sex but she’s often, at times, can be rather breathless and it’s not possible”. (Spouse, P16, 47)</p> <p>“We might have missed out on either a family gathering, or we might have had to postpone an activity, like going to the movies or shopping because of her illness”. (Spouse, P7, 46)</p> <p>“A very long time ago I gave up smoking”. (Spouse, P9, 66)</p> <p>“It just teach (<i>sic</i>) me a lot of things, like you need to listen to your body, you need to get physically, you know get fit, and you just have to – if things doesn’t feel right, then you don’t ignore it, you seek help”. (Friend, P17, 35)</p> <p>“That she will come to me and listen to me. That’s important, for obvious reasons. I suppose it reconfirms that we have a close relationship because she will come to me in times of strife”. (Mother, P18, 72)</p>
Extrapersonal	<p>“I had to change roles and completely change my direction in my profession and there was a financial loss there in lost wages and benefits and stuff as well”. (Spouse, P11, 7th decade)</p> <p>“There wasn’t a place where we could live with the whole family that no one would be reacting to it”. (Spouse, P10, 68)</p> <p>“... had to leave at work, I have no carer’s leave anymore”. (Spouse, P1, 36)</p>
Emotional/psychological	<p>“I can get down, I actually suffer from depression myself, as part of being a carer. I actually had a nervous breakdown. I basically just hit the wall, as it were, and just couldn’t face caring for L for a while. I ended up being hospitalised”. (Spouse, P7, 46)</p> <p>“It gets to the point where I don’t want to have to put my hand over and see if she’s still breathing but that’s how it becomes sometimes ... you feel like you can’t do anything and then other times you just feel like you’re a bit helpless.” (Spouse, P6, 63)</p> <p>“Yes, a lot worries me. It worries me that S takes quite severe medications, as in the steroids that she has to take that at the moment basically enable her to breathe but eventually are going to destroy her organs”. (Spouse, P4, 55)</p> <p>“You never know every morning what the day brings and how he is going to wake up, in what condition he is going to be in. Normally you’ve got a sense throughout the night, it’s like having a baby, you’re on alert. You’re sort of asleep but you’re on alert, one ear is open. I think that’s about it”. (Spouse, P3, 68)</p>

Continued

TABLE 3 Continued

Subtheme	Quotes
	<p>"I had a nervous breakdown. It was a lot going on in my life and I had to come to terms with it". (Mother, P12, 66)</p> <p>"So, we have a daughter and she also suffers from anxiety because of L's asthma. If her asthma is really bad, our daughter almost switches into a mindset of almost panic. She wants to know if Mum's going to be okay and will she go to hospital. L's asthma is a trigger for our daughter's anxiety, so it does affect other members of our immediate family". (Spouse, P7, 46)</p> <p>"I'm afraid of losing her. So, it makes me feel helpless and hopeless". (Sister, P19, 34)</p>
<p>GP: general practitioner.</p>	

Living with someone with severe asthma negatively affected the psychological health of the carer. Whilst some participants were dominated by feelings of uncertainty, hopelessness, distress, fear, frustration, anger, guilt, anxiety and depression, some felt less troubled as care-recipients had not experienced life-threatening episodes.

Moreover, emotional strain was amplified by urgent visits to emergency departments for sudden severe attacks. Most participants found difficulties in adjusting to this. They talked about being trapped on a roller coaster of negative thoughts, emotions and actions. They felt that they were struck by a sudden tidal wave of emotions feeling helpless, worried, sad, frustrated, tired, alone, desperate, panicked, stressed, frightened and guilty. Although the intensity of the feelings declined after care-recipients recovered, these feelings stayed with them throughout their everyday lives. Some described how they suffered from depression which they related to their caring roles. The unpredictable nature of asthma awoke worries about the future, when the next asthma attack would occur and whether their care-recipient would survive. These mixed emotions extend to other family members.

But it's just like being in a roller coaster. You just go from one day to the next and what's happening next and you just don't think about this is your life.

Spouse, P11

I find myself that I'm almost on the roller coaster ride.

Spouse, P7, 46

For some, the threat of perceived adverse effects from asthma treatments also caused constant fear. The unwanted side-effects from long-term usage of oral corticosteroid brought particular worries.

Some participants spoke positively about how their caring roles motivated them to become more self-aware. Positive parental/marital/friendly relationships grew stronger over time despite the impact of severe asthma. Others reported finding clarity in their life priorities.

It would have brought us closer together if anything.

Mother, P12, 66

Further quotations for this theme are provided in table 3.

**Theme 2: "unmet needs"**

Carers have needs independent to those of the care-recipient and were categorised into sub-themes of adequate information, biopsychosocial needs and carers' involvement in decision-making. All participants were invited to suggest solutions or resources that they would like to see change. Table 4 summarises carers' proposed suggestions and their alignment to table 5.

*Adequate information*

Participants reported unmet needs regarding information about the disease, treatment, side-effects, symptom management, responding to urgent care and the ability to perform cardiopulmonary resuscitation:

I'm least confident about a severe asthma attack – what to do. Like, ringing an ambulance.

Spouse, P6, 63

Participants placed high value on receiving straightforward information explaining what severe asthma is and its treatment. When probed about how they wanted to receive such information, participants expressed the desire for online material, smart device applications or brochures.

TABLE 4 Suggested solutions of unmet needs identified

Care and support needs	Suggested solutions
<p><b>Adequate information</b></p> <p>Family carers and significant others of people with severe asthma need tailored information regarding:</p> <ul style="list-style-type: none"> <li>• Diagnosis, treatment and plan of care (example: when to ring an ambulance, symptom management)</li> <li>• Adverse effects of new treatments</li> <li>• Resuscitation techniques</li> </ul>	<p>Family carers and significant others of people with severe asthma recommended possible solutions including:</p> <ul style="list-style-type: none"> <li>• Tailored education and discussion with healthcare team regarding the diagnosis, treatment and responses</li> <li>• Simplified visual toolkits or leaflets regarding the nature, consequences and outcomes of severe asthma</li> <li>• Provision of information in multimedia format or training and symposiums</li> </ul>
<p><b>Biopsychosocial needs</b></p> <p>Family carers and significant others of people with severe asthma desire:</p> <ul style="list-style-type: none"> <li>• Access to needs assessment tools to assess capacity to provide care and support</li> <li>• Access to basic psychological and emotional support services</li> <li>• Access to local support groups or organisations</li> </ul> <p>Many family carers and significant others of people with severe asthma wanted for more:</p> <ul style="list-style-type: none"> <li>• Societal awareness and acceptance</li> <li>• Understanding of other people’s feelings</li> <li>• Consciousness of the difficulties and hardships of family carers or significant others of people with severe asthma</li> </ul>	<p>The suggested solutions apply to both support from a healthcare and a societal perspective:</p> <p><i>Support from a healthcare perspective:</i></p> <ul style="list-style-type: none"> <li>• Provision for an evidenced-based needs assessment tool to help identify and communicate with health professionals about their physical needs</li> <li>• Provision for technology-assisted counselling and psychological services</li> <li>• Organisation of supportive environments for carers of people with severe asthma</li> <li>• Promote support networks for new and long-term carers of people with severe asthma</li> <li>• Join online forums or organisations to connect and share experiences</li> <li>• Promote self-management</li> </ul> <p><i>Support from a societal perspective:</i></p> <ul style="list-style-type: none"> <li>• Listening and paying attention to the sensitive issues or problems associated with severe asthma</li> <li>• Advocacy toolkits</li> </ul>
<p><b>Carers’ involvement in decision-making</b></p> <p>Family carers and significant others of people with severe asthma desire to:</p> <ul style="list-style-type: none"> <li>• Participate and be involved in decision-making</li> <li>• Engage with competent and compassionate healthcare professionals</li> <li>• Access equitable outpatient specialist clinics in a timely manner</li> <li>• Equitable and efficient access to specialised clinical tests (example: pulmonary lung function testing)</li> </ul>	<p>Healthcare strategy should include:</p> <ul style="list-style-type: none"> <li>• Good communication skills especially when delivering critical information</li> <li>• Centralised and streamlined referral process to dedicated severe asthma clinics</li> <li>• Engagement and promotion of a patient-centred approach</li> <li>• Information links to other services that will help carers navigate the system</li> </ul>

*Biopsychosocial needs*

The time for self-care activities or pursuing their own interest were recognised as vital for maintaining physical wellness. Several participants had higher levels of unmet needs when care-recipients experienced an excessive symptom burden and were impacted by comorbid conditions. This added to their own health impact and they reported that they were less able to manage their own condition.

Demands for psychological wellness were frequently mentioned as important in managing difficult feelings associated with distressing situations. Participants considered the need for counselling, networking and support services both at the early and in the long-term stage of their caring roles. They were unaware that help may be available or did not know where to seek it. Although the majority desired access to support groups, many interviewees were also reluctant to seek support. Reasons for this included insufficient time, anxiety about leaving the care-recipient, the desire not to be social, finding repetitive information and the belief that finding and utilising support services is a matter of personal choice.

Participants frequently remarked on the need for the community to be aware and accepting that severe asthma exists. They desired activities that create awareness and knowledge to reduce the stigma of severe asthma.

*Carers’ involvement in decision-making*

Whilst some carers discussed the importance of their role as an expert partner in care, others felt inadequately involved in decision-making:

Well, I don’t really get too much feedback from them. In hospital, they do all their discussions with her.

Spouse, P6, 63

TABLE 5 Theme 2: “unmet needs of family carers and significant others of people with severe asthma”

Subtheme	Quotes
<b>Adequate information</b>	<p>“Probably the different medications that are coming out now, like with the new medications, the heavier ones that my Mum’s taking. It’s probably – I mean, I’d have to google them – it’s just that unknown factor”. (Daughter, P15, 55)</p> <p>“I’m least confident about a severe asthma attack – what to do. Like, ringing an ambulance”. (Spouse, P6, 63)</p> <p>“I had no idea severe asthma existed before meeting her”. (Spouse, P16, 47)</p> <p>“I knew nothing about severe asthma: I didn’t know how it affected her heart and general ability to move around. I’ve just seen her go physically downhill”. (Mother, P12, 66)</p> <p>“... something that provides tools to be able to cope with certain situations, or that provides information on medication that might be introduced into their asthma care plan for their partner or their child or their sibling”. (Spouse, P7, 46)</p>
<b>Biopsychosocial needs</b>	<p>“It gets a bit tiring having to make breakfast, lunch, dinner for everybody every day, put away all the washing whenever it needs to be put away. Just some help with the normal around the house stuff would be nice ... It would be nice to be able to do something occasionally ... Just basically tired and worn out”. (Spouse, P16, 47)</p> <p>“... if we come out of a stressful period where her asthma is really bad and she’s now recovering, then having to recover emotionally myself”. (Spouse, P7, 46)</p> <p>“I’m not aware of any specific help in relation to groups, support groups for carers or sufferers of severe asthma”. (Spouse, P4, 55)</p> <p>“No, not at all, I don’t have any support groups, none that I know of”. (Spouse, P1, 36)</p> <p>“But sometimes when people go, oh asthma, and I go, I always say, have you ever had an asthma attack? They go, no. I say when you have one then you will understand that you feel like you’re dying. It’s one of the worst things you could ever have – experience”. (Daughter, P15, 55)</p> <p>“It’s more his physical ability to do things. I find that I have to do more”. (Spouse, P2, 68)</p> <p>“I think the more information and the more emotional support you can get in the early stages, the better it is for the carer”. (Mother, P12, 66)</p> <p>“... just if someone can understand how bad she is, [I am] and how you feel and what you’re going through, just to explain that and have someone say, yeah, okay. Otherwise it just gets bottled up and you need to be able to let it out sometimes”. (Spouse, P6, 63)</p> <p>“I just comfort her whenever she feels helpless, but as a sister I sometimes also feel emotional too, but I don’t show it to her. I just make sure that I’m making her believe that everything will be fine, so it will give her strength to go on with her life with nothing worrying about asthma”. (Sister, P19, 34)</p>
<b>Carers’ involvement in decision-making</b>	
Carers’ involvement	<p>“I was always fully informed by the healthcare provider and felt that yes, I was recognised as being an important part of her management”. (Mother, P18, 72)</p> <p>“The doctor will let me stay with her, and the doctor will also explain it to me, her case, so I will understand more about her situation or her case about the asthma”. (Sister, P19, 34)</p> <p>“I think sometimes it would be helpful just for, say, some of the nurses or someone in the system to say it’s okay. It’s going to be all right. That sort of thing”. (Mother, P12, 66)</p>
Organisational deficiencies	<p>“If you want pulmonary function tests before the appointments like he has, it’s not made by the same team. The people across the way make that so to try to coordinate the appointments so that the pulmonary function appointments and P’s appointment all link in the same day so they work, it’s really difficult”. (Spouse, P11, 7th decade)</p> <p>“We’ve encountered a couple of GPs who don’t completely – who don’t come to grips with severe asthma ... who is not understanding ... and also not respectful. We just made sure that we didn’t go back to that GP... I think some – I’m thinking some GPs are not up to date with the fact that severe asthma exists”. (Spouse, P4, 55).</p>
Referral pathway	<p>“Yeah, and I suppose one of – a fear that I could have is that if the clinic wasn’t there at John Hunter and we never found out that S had severe asthma then I don’t know where we would be, or it could be that the severe attacks that she presents basically all the time might have just got too bad and might have lost her by now”. (Spouse, P4, 55)</p> <p>“Only that if she needs to come to a certain facility that somehow needs to go across to the ambulance service. That’d be my most pressing thing that I’d like to see acted on”. (Son, P14, 59)</p>

GP: general practitioner.

Conversely, when the carer role was recognised and supported, carer satisfaction was increased:

Completely satisfied with how I’m involved or how I’m accepted into discussions.

Spouse, P4, 55

As far as the health system is concerned, other carers highlight four sources of difficulties, which include organisational deficiencies (referral pathway), lack of resources (availability of lung function testing services, waiting times), communication between clinicians and carers or patients, and finding clinicians perceived as expert in diagnosing and treating severe asthma. The difficulties affirmed carers' challenges in navigating the system and advocating for caring recipients.

If she ever goes to hospital, just in emergency, for any reason, generally the doctors there are completely useless. All they do is shovel steroids into her and they won't listen that she's steroid resistant. It's in her chart and all her notes and everything.

They don't listen to her.

Spouse, P16, 47

Whilst some expressed doubts, others conveyed satisfaction with the quality of care and support received.

I think that is three-quarters of the battle if I'm being honest with you – knowing that you have that backup support. Knowing that you can speak to your doctor, speak to the professor.

Spouse, P2, 68

### *Theme 3: "coping strategies"*

Participants articulated several coping strategies to deal with the care burden. As challenges arose, they implemented a range of tools and skills for dealing with negative experiences. These included social and problem-solving strategies and emotional strategies (table 6).

#### *Social and problem-solving strategies*

Taking care of oneself and creating opportunities to take a break were regarded as critical for coping with their roles. Effective time management techniques made other carers take some time out:

Well I get up early and I walk the dog usually and then she stays in bed usually until I get back.

Spouse, P5, 70

Increased engagement in physical activities, hobbies or work was reported by carers when they received additional support from either a family member or friends. Whilst the majority of carers valued interaction with supportive relationships, some carers tended to distance themselves either physically or emotionally from stressful situations to rebuild themselves:

Sometimes I have to allow myself to have time away to be able to deal with that and get out of that carer role, to be able to make myself feel better as well, because that carer responsibility can be quite draining with regards to her asthma.

Spouse, P7, 46

#### *Emotional strategies*

Unconditional love appeared to make it possible for many of the participants to continue in their roles:

R's my best friend. I mean that was a fact prior to her being so unwell and that's not going to change.

Friend, P13, 80

Participants' ability to find a sense of meaning in their roles bolstered resilience and helped them go on with life:

You just do what you have to do.

Mother, P12, 66

## **Discussion**

We report the experience of supportive carers of people with severe asthma, an area not previously investigated. We found that carers experience increased levels of emotional distress during sudden severe attacks and have unmet needs relating to informational, biopsychosocial and carer involvement supports. This research adds important knowledge around family carers' roles and support needs, the impact of their role on well-being and coping strategies used. These data should be considered in the management of the person with severe asthma to ensure a holistic person-centred approach to care that includes family carers and all relevant stakeholders.

TABLE 6 Theme 3: “coping strategies”

Sub-themes	Ways of implementation	Quotes
<b>Social and problem-solving strategies</b>		
Self-care, social activities and hobbies	Physical activities (cycling, swimming, aquatic Zumba, boxing, Pilates, dog walking) Hobbies (creative crafts making, listening to music, electronic colouring, mindfulness meditation) Social activities (volunteering works, travelling)	<p>“So, I have to make time for myself to do some physical activity, whether it be walking or cycling or boxing or some form of gym work to try and take care of myself. So, I find physical activity helps to try and counteract the depressive feelings that I get. It’s an effort to do that physical activity because you’re in a particular mind state where you have to force yourself to get out of that particular mind state to make yourself feel good”. (Spouse, P7, 46)</p> <p>“I might take the dog for a walk generally every day and sometimes for only a few hundred metres”. (Spouse P4, 55)</p> <p>“I do like to go to aerobics, swimming ... I listen to music and just do some deep breathing and that’s about it”. (Spouse, P3, 68)</p> <p>“I do a Pilates. A very modified Pilates”. (Mother, P12, 66)</p> <p>“I do card making and make special box cards”. (Spouse, P10, 68)</p> <p>“I don’t play, I couldn’t run but I do the canteen and that, and I find that that is good therapy for me”. (Spouse, P2, 68)</p>
Informal social support	Engaging with family and friends Self-detachment	<p>“I would have been lost without my friend, D ... she was someone who understood, she was someone that would – I couldn’t have survived a few of those years without her”. (Spouse, P10, 68)</p> <p>“I honestly think as long as the family themselves know what’s going on, it can help a hell of a lot”. (Spouse, P8, 68)</p> <p>“I’m very lucky because I have a very supportive principal who if, I need to take time, she just goes, well family’s really important and your mum’s health is of course paramount, so I can take leave ... I’m able to take leave to do that, and my older brother’s the same”. (Daughter, P15, 55)</p> <p>“I’ve returned back to full-time work, so her sister does help out, I guess really more just assisting with transport, because L’s in a wheelchair anyway, so she really only serves more as transport up until the time if she does have a problem with her asthma. Because L’s carer is her sister it does provide a little bit of security in that I can come away from that situation knowing that there is someone with experience there who knows L. I would feel, if it was anyone else other than her sister, I would probably feel more stressed that they may not know what to do in the event that L has an asthma attack”. (Spouse, P7, 46)</p> <p>“Sometimes I have to allow myself to have time away to be able to deal with that and get out of that carer role, to be able to make myself feel better as well, because that carer responsibility can be quite draining with regards to her asthma”. (Spouse, P7, 46)</p>
<b>Emotional strategies</b>		
Acceptance and love	Self-acceptance Unconditional love	<p>“I love him to bits and be there for him always”. (Spouse, P3, 68)</p> <p>“I can find any work; I can’t find same wife as I have right now”. (Spouse, P1, 36)</p> <p>“You get to a stage where you just have to accept what’s going on in life”. (Spouse, P11, 7th decade)</p> <p>“No, because she’s always had asthma ever since we were – before we were married. It’s just part and parcel of day to day living with her. It’s just part of being her”. (Spouse, P9, 66)</p>
Resilience	Keeping things in perspective Positive sense of caring role	<p>“It’s just I know it’s part of life and everything, you’ve got to deal with the cards you’re dealt with and no matter what you got”. (Spouse, P5, 70)</p> <p>“It can be – it’s a life altering experience and it’s how you deal with it and support that either gets you through it or don’t”. (Spouse, P10, 68)</p> <p>“But on a positive note, I do like as a carer because I can take care of her”. (Spouse, P1, 36)</p> <p>“What I like about my role is that I can help my friend even though I’m not a doctor ... it’s kind of a big part of me”. (Friend, P17, 35)</p>

Participants reported that they are well placed to provide care and support to people with severe asthma but experience multifaceted impacts on well-being. Those caring for people with severe asthma with multiple comorbidities reported high burden, depressive symptoms and poor self-rated mental health. These data importantly reflect the impact of increasing disease burden on not only the person with the disease but also their significant others.

Whilst quantitative studies in other disease areas have found that caring is associated with poor quality of life [25, 26], this is the first to explore the emotional impact of caring on individuals supporting people with severe asthma. We report how the unpredictable nature of severe acute asthma attacks increases carers' emotional distress. These severe attacks differ distinctly from some other conditions that have a more chronic disease trajectory [14] and place psychological demands on carers, leading to anxiety, depression, stress, fear, helplessness and exhaustion. These findings are consistent with data from patients with severe asthma [3] and parents of children with asthma [22] who feel emotionally burdened due to the disease's unpredictable nature. The importance of including both the patient and carer in a person-centred model of care is essential to reduce the sizeable burden associated with respiratory disease, especially severe asthma [27]. A major difference between carers of adults and children however is that parent-carers are supported in their child's healthcare journey, whereas in the adult management support is usually and appropriately directed towards the patient. This highlights the importance of providing resources to carers dealing with highly stressful situations, which they have identified in this study as leading to worsening of carer biopsychosocial health [28].

Contrary to the findings of FOSTER *et al.* [3], where patients with severe asthma experienced disrupted identity, carer participants did not report concerns with identity. This suggests that becoming a source of support for loved ones may induce a natural human affective response [29]. Our data demonstrate that participants experience benefits from their caring including fulfilment of self-worth, personal growth and positive family functioning. Parallels can be drawn from other chronic diseases, where carers described positive experiences in their caring roles [30]. Our study suggests that caring for someone with severe disease is not purely associated with negative consequences, but one may find greater positivity if supported appropriately.

Another important finding from a support needs perspective is the lack of information accessible to carers about the disease, its course, treatment options/side-effects and when to call for emergency care. Information provided by health professionals about the disease is crucial to support carers in their caring roles. The lack of confidence in recognising when signs and symptoms require urgent attention may cause confusion in carers and increase frequent emergency presentations [31]. Importantly creating a clear referral or emergency pathways reduces waiting times and promotes timely care. Given the increased access to biological therapies [32] and management advances [33] that have occurred in severe asthma, it is not surprising that carers are in need of new knowledge and skills. Access to critical information could empower carers to maintain both their caring roles and well-being, which aligns with the needs of people with severe asthma [3].

Participants reported the need for clear information, timely access to care and positive relationships with health professionals, but some expressed dissatisfaction with these aspects. This is consistent with patient reports [34] and suggests that specialist clinics are often successful in providing competent and sensitive care for both care-recipients and carers, but other aspects of the severe asthma healthcare journey can cause significant difficulty for carers, such as access to services and information. A severe asthma carer support needs assessment tool may help identify sensitive support requirements [35]. A support programme and coping techniques should involve the carer and the patient. Previous research has demonstrated how inclusion of COPD family carers benefited in comprehensive pulmonary rehabilitation [36].

We identified how carers cope with their roles. Over time, carers had learned to accept the inherent consequences of caring, but still had to endure and cope with the unpredictable nature of asthma, obviously when encountering sudden severe attacks. Our findings that the majority of carers in this study use social and problem-solving strategies and emotional strategies to cope with caring demands concur with the previous studies [10, 28, 37]. These strategies enabled carers to achieve equilibrium between internal and external inputs that affect biopsychosocial demands [29] that result from their caring roles. This highlights the importance of carers engaging in self-care activities and hobbies, embracing extended support from families or support groups, and developing resilience.

Study strengths include purposeful sampled participants who had been carers for several decades providing rich data, rigorous methodology and extensive quotations to ensure the validity of the data. We acknowledge some limitations. Firstly, the majority of participants came from one geographical location, and despite efforts to include a diverse range of carers/support persons, they were largely Caucasian, not working full-time and mostly identified as spouses. Secondly, this study was not able to explore the

caregiving experience over the course of severe asthma. Lastly, the fact that most carers were caring for >10 years probably affected the results, as family carers involved more recently in caregiving roles may have other needs and experiences. Future research might include a greater mix of employment status, carer experience and cultural background, and include the views of carers living in rural areas. Carer burden and the roles of carers in supporting the self-management of people with COPD has been explored [8, 9]. Studies conducted show that carers reported health-related problems resulting from their caring role. An increase in caring burden is evident to family carers when patient's self-management declines over time, particularly during the advanced phase of COPD. There is a paucity of data showing the caring burden in severe asthma compared to that of COPD. This knowledge is critical to develop targeted resources and interventions aiming to support carers of people with severe asthma.

### Conclusion

Caring for someone with severe asthma can be burdensome and affect the physical and psychosocial health of the carer negatively. Carers discussed coping strategies to manage caring demands. They highlighted the need for adequate informational, biopsychosocial and involvement in care decision-making support. Tailored support services that are sensitive to carers' needs may improve their quality of life and encourage healthcare providers to value and acknowledge the important contribution that carers make.

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