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Barriers to belonging: the need for relatedness amongst people living with severe asthma

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ABSTRACT

Background: Severe asthma, that is, asthma that is relatively refractory to conventional therapy, affects 3–10% of the asthma population. It is associated with a significant burden affecting social and working life. Supporting the need for relatedness facilitates health behavior change and improves overall well-being. However, this has not been closely examined from the patients' perspective. This study examines relatedness in patients' narratives about their experiences of living with and managing severe asthma.

Methods: Rigorous and systematic qualitative research methods were used to conduct in-depth semi-structured interviews. Participants were included if they were ≥ 18 years old and diagnosed with severe asthma. Interviews were video and/or audio recorded, transcribed, and analyzed inductively and deductively informed by the self-determination theory construct of relatedness. Thirty-eight face-to-face interviews, lasting 1.5–4 hours, were conducted around Australia.

Results: Our findings show that living with a debilitating and unpredictable illness challenged participants' sense of relatedness. Two themes emerged: 1) *the desire to be understood: feeling isolated* and 2) *the desire to be accepted: 'I'm supposed to be like everybody else'*. For people living with severe asthma, feeling cared for, understood, connected to others and having a sense of belonging was valued. Their overall psychological well-being was dependent upon their sense of connection to others.

Conclusion: Future research should consider our findings of the challenges faced to preserve their sense of relatedness, when developing and implementing patient-driven self-management interventions for those living with severe asthma.

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Severe asthma; experiences; relatedness; qualitative

Introduction

Asthma is a long-term inflammatory condition that narrows the airways in the lungs (1). It is estimated that approximately 334 million individuals in the world have asthma and this will increase to more than 400 million by 2020 (1–3). Asthma severity can range from mild to severe. Severe asthma, that is, asthma that is relatively refractory to conventional inhaled therapy, affects 3–10% of the asthma population in all parts of the world (4,5). Whilst most people can effectively manage their asthma with treatment, people with severe asthma experience frequent or persistent symptoms and/or exacerbations despite taking high dose maintenance preventer medications (5). Severe asthma is also associated with a significant burden due to hospitalizations, and frequent attacks that may

be life-threatening and that affect social and working life (6).

In response to the growing global burden of chronic conditions, such as severe asthma, health policies have increasingly acknowledged the value of self-management to health. Self-management is a term widely used in the health care literature with no gold standard definition. It's been proposed that it is the work involved in the patient learning how to cope with system-related processes; the physical, psychological, social changes; and the spiritual and existential aspects of living with a chronic illness (7). Research has shown that successful self-management of a chronic condition can sustain physical and psychological well-being (8).

Research has shown that behavioral change is an effective method for improving self-management of chronic

illness and improving psychological well-being (9). Psychological theories of behavior change and motivation, such as self-determination theory (SDT), provide an understanding of the process and mechanisms of behavior change. Relatedness is defined as the need to feel connected, accepted and understood by others, to care for and be cared for by others, and to have a sense of belonging both with other individuals and with their community (10). According to SDT, patients who report a sense of relatedness are more likely to be self-directed to carry out and master tasks involved in making health behavior changes (10,11). However, this has not been closely examined from the personal perspective of a person.

The increasing importance and value of supporting a person's psychological well-being, combined with the lack of studies examining the patient's perspective of the impact of a chronic condition on their sense of relatedness, highlights the need for research in this area. Thus, the aim of this study is to examine the role of relatedness in patients' narratives about their experiences of living with and managing severe asthma.

Methods

A qualitative research approach was used to understand the experiential realm of people living with severe asthma (12). In-depth interviewing was used to elicit participant's views and interpretation of their experience (13).

Participants and recruitment

The research protocol was approved by the University of Sydney Human Ethics Committee (HREC 2015/934). Participants were recruited through their general practitioner (GP) or respiratory physician. They were provided with an information pack by their GP or respiratory physician and were asked to sign a consent form if they agreed to take part in the interview. To be included in this study, participants' had to be ≥ 18 years old, and diagnosed with severe asthma by a specialist respiratory physician according to the international severe asthma guidelines (5). Interviews were offered in English, French and Arabic, the interviewer being fluent in each. The aim was to include participants from different ethnicities, geographical locations and sociodemographic backgrounds.

Data collection and analysis

Interviews were conducted between October 2016 and March 2019. Participants attended a one-on-one interview

with the researcher in their own homes or elsewhere if preferred. Participants were encouraged to talk about all aspects of living with their condition, with minimum interruption from the interviewer. The interview guide was initially defined from a systematic review of the literature (14) (Appendix 1). Prompts included questions about how they managed their condition, the support they had received from friends, family and healthcare providers, and the impact it had had on their relationships. To ensure session uniformity, the same researcher conducted all the interviews. Interviews were audio and/or video recorded and transcribed verbatim. At the end of the interview, participants received AUD\$50 gift voucher as recompense for out-of-pocket expenses and a token of gratitude for their participation.

The transcripts were initially coded by the interviewer (DE) using NVivo software and were read by two authors of the research team (LS and KR). Data analysis was conducted both inductively and deductively, informed by the SDT construct of relatedness (10,15). The initial stage of coding involved constructing a coding framework with references to relatedness, feeling valued by others and a sense of belonging (DE). The codes were then grouped into patterns and labeled as categories. Analyses and comparison across and within the categories were conducted to develop themes. This required moving beyond describing the categories; it involved shifting to a higher level of interpretation (16). All authors were involved throughout the coding and analysis process. To protect the anonymity of the participants, pseudonyms are used.

Results

Participant characteristics

Thirty-eight participants aged between 19 and 74 years took part in the study. All participants spoke English fluently. The interviews were 81–235 (mean 146) minutes in length. Participants' sociodemographic characteristics are summarized in Table 1.

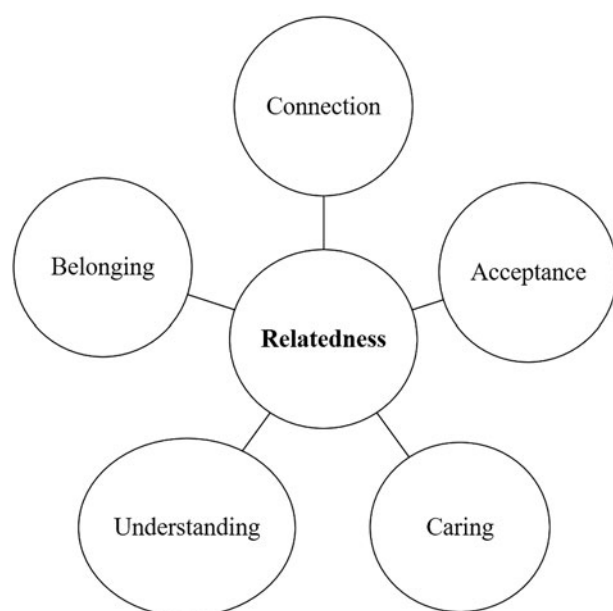
Findings

“...you're two feet tall, [it feels] like [people think] you're crying wolf for this disease that no one can tell you what's wrong with you and everybody's different... we're dying inside, all of us because no one understands.” (Teresa, 39-year-old female)

Our findings show that living with a debilitating and unpredictable illness challenged their ability to relate

Table 1. Characteristics of the participants ($n = 38$).

	N
Age range in years (mean)	19–74 (52.5)
Gender	
Female	21
Male	17
Time since diagnosis of severe asthma	
≤10 years	16
>10 years	22
Cultural identity	
Caucasian	35
Asian	2
Persian	1
Geographical location	
Metropolitan	21
Inner regional	9
Outer regional	8
Employment status	
Employed	14
Retired	13
Unemployed	11

**Figure 1.** Proposed conceptual diagram explaining the concept of relatedness.

to others. People's desire to feel a sense of relatedness was influenced by what they thought other people were thinking. Relatedness was represented as a holistic construct for people living with severe asthma. This included feeling connected, accepted, understood, cared for and a sense of belonging; if relatedness was threatened, individuals felt disconnected, unaccepted, misunderstood, uncared for, and with little sense of belonging (Figure 1).

Our analysis revealed two themes illustrating the perceived challenges in people's journey towards achieving a sense of relatedness. These were: 1) *the desire to be understood: feeling isolated* and 2) *the desire to be accepted: 'I'm supposed to be like*

everybody else'. It was apparent that participants wished to be accepted, and their overall perceived sense of relatedness, was strongly influenced by their desire to be understood (Figure 2).

The desire to be understood: feeling isolated

Participants' sense of relatedness was challenged when they felt judged by others. They expressed that, as a result of feeling misunderstood, they felt disconnected and judged from others and would further socially isolate themselves. This was a common experience amongst the participants. Participants reported mostly feeling misunderstood by those outside their immediate family and close friends. In these instances, they explained that they believed this was due to the condition 1) being invisible and 2) perceived by others as inferior to other chronic illnesses.

Feeling misunderstood: severe asthma as an invisible condition. Individuals described severe asthma as an *invisible condition*, where physically they may look well, and unless they had a potentially fatal asthma attack, no one would be able to understand that they live with a debilitating condition. For example, Ben reported:

I have to say I'm feeling crook [Australian term meaning ill], you know, with asthma, um, before they're— before they realise I— that I'm crook... It's an invisible— it's not a thing, unless I'm wheezy or something like that they can hear it, is one way, but that's not always the case. (Ben, 60-year-old male)

Participants reported feeling misunderstood due to the premium society places on physical attractiveness. Individuals described feeling torn between keeping up these expectations and having to take life-saving medications (oral corticosteroids, which are needed more often by people with severe asthma) which caused their weight gain. The pressure of having to keep up with these expectations challenged their emotional and mental well-being. Charlotte reported feeling embarrassed and isolated; she felt misunderstood, but was ambivalent about giving reasons to people for her weight gain:

...there's the embarrassment... because I'm a larger person and I think, "Oh they're just going to think... I'm fat and lazy." So, then I get torn between, between the privacy and-and telling them, and if I tell them then it sounds like an excuse...

(Charlotte, 52-year-old female)

Another common example of feeling misunderstood was parking in a disability spot when having to

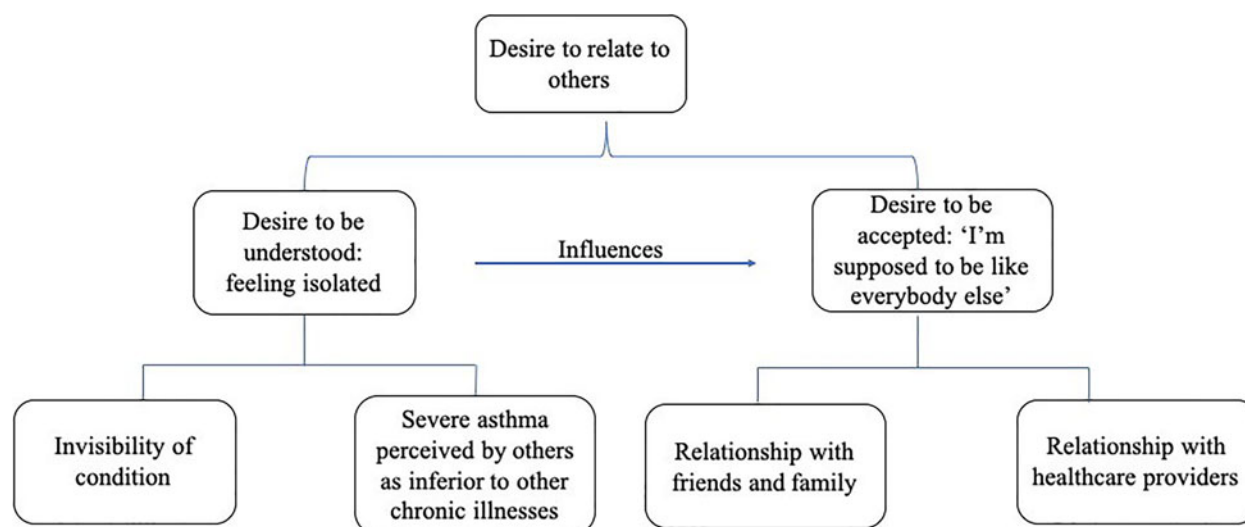


Figure 2. Conceptual diagram of the overarching theme and sub-themes discerned in this study.

go about their day-to-day activities, without facing judgements from the public. Donna reported that she had trouble walking a short distance without being out of breath. Yet in many public settings, she vividly recalled the hurtful comments that were said about her as people assumed that she was using her *grandmother's disability sticker*. She reported that people's lack of understanding might be due to the invisibility of her condition:

I got a disabled parking permit, because I couldn't [walk... you have to deal with people looking at you and going, why the hell are you parking in a disabled parking spot... One... guy [was] being so angry... and [he] was like, I could steal my grandmother's [disability permit] too, but I'm not that kind of human. (Donna, 39-year-old female)

Feeling misunderstood: severe asthma perceived by others as an inferior chronic illness. The experience of severe asthma for these participants was dominated by what they thought other people were thinking, that their condition is viewed and treated as inferior to others. Participants reported that they felt their condition was compared to other chronic conditions such as mild to moderate asthma and cancer. They described that the lack of understanding of the severity of their condition challenged their ability to relate to others. For example, Jane stated:

I don't think people understand what severe asthma is. People think of asthmatics as asthmatics, you take a little bit of [reliever medication], you know it relieves the wheeze and life just is normal. I don't think anyone

really comprehends this level of asthma. (Jane, 55-year-old female)

Bella further stated, that people showed less empathy for those who live with severe asthma as opposed to those living with cancer. This may be due to the meanings society places on cancer as a life-threatening illness:

But nobody takes any notice these days, you know, unless you've got cancer or something like that, people think, "Oh, poor person [towards the person living with cancer]" but you know you've got a bit of asthma, well so what? (Bella, 67-year-old female)

For Teresa, feeling misunderstood was a problem she had to face at the health system level. She reported that every six months she has had to seek financial support from Centrelink (a government service providing support to Australians who face financial hardship), and has had to face "the same lady" who seemed to believe that she would "get over" her asthma. This lack of understanding and empathy has made her feel helpless, powerless, judged and scared that she may lose these benefits:

Every time that I go in there... and it's that same lady and she just turns around and says she has asthma too and she knows what it's like, but you can only have six months and you'll be over it in six months, so [I'll] be fine., I don't know, it's scary for me because then I think to myself is Centrelink going to cut me off, and then if they do what am I going to do then? [cries]... (Teresa, 39-year-old female)

Efforts to be understood had an impact on participants' emotional and mental health. They expressed that, despite not wanting to feel different or judged,

they still wanted people to understand the severity of their condition. Yet for some, their attempts to explain this to others, resulted in their feeling “frustrated”. For example, Jessika stated that there were a few instances where her asthma was getting “bad”. In these moments she would ask for help from her friends and received comments that made her feel they didn’t understand the severity of her condition:

I think it can be really frustrating because they don’t understand, which I totally get...I was sick to a degree that my asthma was really bad...I know that if it is asthma, like, I’m not really going to mess with it...and -you can just, sort of, tell that like, they don’t really get it. They’ll be like, “Yeah, but, like, just drink anyway.” Sort of, stuff like that... (Jessika, 27-year-old female)

The desire to be accepted: ‘I’m supposed to be like everybody else’

Rich narratives described feeling accepted as the extent to which they felt heard, valued, cared for by the people that were closest to them. It was also apparent that participants’ desire to feel accepted was strongly influenced by their need to be understood. Individuals reported the importance of feeling accepted both medically (being able to understand their severity) and emotionally (receiving empathy and care). This was reflected firstly, through their interactions with healthcare providers and second, through their interactions with family and friends. Often, however, lack of acceptance by others was a common experience.

Feeling accepted by healthcare providers. Feeling accepted by their healthcare providers was important for those living with severe asthma. Participants reported having to search for healthcare providers whom they felt they could trust and who were aligned with their values. Feeling heard, understood, cared for and not judged strengthened their relationship and were features of acceptance. Jennifer reported feeling not heard and stated that she has had to change doctors over the years:

I think a couple of things turn them [general practitioners] off from me, I talk a lot and I try to explain what’s going on and... I’ve had different doctors over the years, you know. A lot of it is because I’ve got that belief coming in that they... won’t believe me just going and saying ‘I’ve got asthma’ ‘Oh, how do you know you’ve got asthma?’ . (Jennifer, 74-year-old female)

Jane reported that she used to feel judged by her general practitioner (GP) on the use of her reliever

medication. This made her feel uncared for, thus in her desire to feel accepted, she sought acceptance from another healthcare provider. She described her current healthcare provider as having provided exceptional support:

She [previous GP] just didn’t seem to care about her patients at all... so, I went down to the reception and I said can you make me another appointment right now to see another doctor. [The new GP has] gone out of her way to [help me] because [even though] she is quite busy... she tries everything to her ability to help me out as much as she can. (Jane, 51-year-old female)

Feeling accepted in a rural area was reported to be more challenging. For Teresa, living in a rural area proved to be difficult as she felt no-one understood her condition. However, she reported feeling accepted by her GP; she further stated that her GP played a crucial part in her life. This was illustrated by Teresa stating that she was able to open up to her GP about the psychological impact severe asthma had had on her life:

...my support’s in my doctor and if I wasn’t with her I don’t know where I would be because, like I said, in [country town], you’ve got to split here and everywhere [having to go to different general practitioners]. Whereas I know that I can go to her... she knows how much anxiety, how much depression... (Teresa, 39-year-old female)

Being in and out of hospital challenged their ability to keep friendships, jobs and their family life. Individuals reported the importance of developing relationships with the healthcare providers in hospital. Sarah reported that her specialist thought that she was being a *fake*. However, she valued being heard and accepted by the nurse who spoke up for her, and that this changed the specialist’s view:

...my specialist came in [hospital room], he said, ‘I don’t know why you’re so sick again’ and it was like, for me that felt like are you saying I shouldn’t be, I’m faking it? ... I told my nurse. The nurse friend I had [sic] ... spoke to him and told him how I was feeling and so the next time he came he said, ‘...there’s obviously something wrong with you that’s causing you these problems and we want to treat it.’ So, it was like total reversal... (Sarah, 59-year-old female)

Feeling accepted by family and friends. Due to the unpredictable nature of severe asthma, individuals described the changes in their relationships with partners and family members. They reported going from being carers to being cared for. Participants reported that they relied on their family to understand their

condition and recognize when to ring the ambulance. Despite feeling accepted by their family, the loss of independence and increasing demands for support left participants feeling guilty and a burden. For some, this changed the dynamic of their relationship. For example, Sarah described her partner becoming her full-time carer, which strained their relationship. She stated that she relied on her partner to become her medical voice when she [Sarah] was most vulnerable:

I think it's put a lot of strain on our relationship... it's not so much of a 50/50 relationship anymore. There are certain things I require of her and I can't help in lots of ways... I get molly coddled a lot and I don't like being molly coddled... My partner [is] getting more confident in making the decision without me [medical and household decisions] and even when I'm in hospital... (Sarah, 59-year-old female)

Joy's family had accepted her condition, however, she reported feeling guilty as her son had to support her. She reported how her condition had affected her family life:

I mean my family are my essential support and I have some great friends. I mean my son was in the States, he came home, he was on a scholarship playing soccer and doing a degree over there... So, he's taken on so much housework and helping out with his brother, and my husband has had to take, you know, on a lot of the things I used to do. (Joy, 55-year-old female)

Jennifer, however, felt she had to keep things to herself. She didn't feel that her husband was able to relate to her and accept the severity of her condition. She reported that her husband thought that her condition was mainly psychosomatic. This played a role in her decision to seek help. Feeling unable to share her worries, left her feeling guilty and embarrassed when having to telephone the ambulance service.

I don't get a lot of support really. I'm very, very silent when I get it. Like... my husband wouldn't have a clue how often I get asthma... [he] doesn't always believe in bringing them [ambulance], like he just... it doesn't register in his head that, you know, 'I'll take you in the car or call an ordinary doctor'... you just feel as though you're completely... it might be childish, it might be psycho schematic [sic], but I am terrified of making a fool of myself. I hate saying that, but it's true. (Jennifer, 74-year-old female)

Dylan didn't feel supported by his family. He described them as *unsympathetic*. He reported that, unless he was in hospital receiving oxygen, they were unable to accept his condition and show empathy:

... unsympathetic I would say, because they don't see it as a severe illness, they see you as "you're still living life, hey what are you worrying about" (laughs).

So yeah but I can understand where they're coming from because they don't see me as laid out, stretched out you know. Unless I'm in hospital in a tent receiving oxygen, you might get a bit of sympathy... (Dylan, 65-year-old male)

Discussion

The purpose of this study was to examine in depth the importance of relatedness to people living with severe asthma. Relatedness was represented as a holistic construct for people living with severe asthma. This included feeling connected, accepted, understood, cared for and a sense of belonging; if relatedness was threatened, individuals felt disconnected, unaccepted, misunderstood, uncared for, and with little sense of belonging. Our analysis revealed two themes illustrating the perceived challenges in people's journey towards achieving a sense of relatedness. These were: 1) *the desire to be understood: feeling isolated* and 2) *the desire to be accepted: 'I'm supposed to be like everybody else'*.

Our findings highlight the challenges people living with severe asthma face to preserve their sense of relatedness, through their desire to feel understood and accepted by others. For the participants in our study, feeling accepted and understood by their healthcare providers, close family members and/or friends nurtured their sense of belonging and connectedness. In their journey towards achieving a sense of acceptance and understanding, individuals reported the importance of receiving both medical and emotional support. In the context of relatedness, participants reported changing healthcare providers if they felt unaccepted, uncared for and misunderstood. However, the lack of acceptance and empathy from friends and/or immediate family, and people who occupy a position of power such as workers in social support, was out of their own personal control and emotionally challenging. The abuse of power from service providers and government agencies influenced their sense of connectedness and belonging. For some, feeling judged and misunderstood at an organizational level made them feel vulnerable and powerless. Studies have shown that daily social experiences are associated with daily well-being, particularly for individuals living with a chronic illness (17–19).

This study adds considerable depth to our knowledge about the impact of severe asthma highlighted in studies. Previous research has uncovered the negative impact severe asthma has on social relationships and overall quality of life (6,20–22), however these have been described in the absence of a

comprehensive theoretical model. Our study has provided a theoretical lens into explaining *how* and *why* the condition has impacted on their sense of belonging. Severe asthma has been found to be associated with poor social ties and relationships. A European survey reported that 27% of participants with severe asthma said their symptoms prevented them from seeing friends and family (23). Our study has reported one reason for feeling misunderstood is due to severe asthma being described as an ‘invisible’ condition not readily observable to others. However, asthma flare ups can be fatal, failing to respond to reliever inhalers. An article by Wenzel et al., coauthored by two patients with severe asthma suggested that severe asthma is like no “other medical disease” in which the patients are reluctant to admit having their disease (24). They suggested that this might be due to biases from healthcare providers who focus on the familiarity of asthma and on the assumption that conventional asthma treatment will be sufficient for all patients; the media and the general public perception of a mostly ‘invisible’ disease. Our findings have expanded this knowledge by suggesting that people’s sense of relatedness was continuously impacted by their social context. This may lead to feelings of vulnerability beyond the control of individuals. Looking at the narratives of people’s experiences of living with severe asthma, through the lens of relatedness, potentially furthers our understanding of the psychological efforts required to manage this condition and points to the need for health professional and public education about the serious nature of this condition.

Our findings have gone beyond the clinical perceptions of examining the impact severe asthma has had on quality of life. It has highlighted the psychological aspects of *why* people living with severe asthma might socially isolate themselves and *how* this has influenced their overall psychological well-being. Interviewees who reported diminished feelings of relatedness felt frustrated, angry and anxious. The biomedical model suggests that living with a chronic illness may be socially isolating. However, our findings have highlighted that their perceived connectedness to others also seems to influence their perceived ability to connect to themselves, hence enriching the current thinking of relatedness (25,26). According to ten Have et al., (27) the self is determined and constituted in relation with others. Thus, for those living with a debilitating condition such as severe asthma, the disconnect between body, self and feelings of connectedness can affect their overall psychological well-being.

Strengths of the study include its systematic qualitative methodology, and the use of a theoretical frame of reference. A limitation of this study is that participants did not encompass the ethnic diversity in the Australian population but had a similar Caucasian predominance as the Australian Severe Asthma Web-based Database (28).

Conclusion

This study has advanced our knowledge in understanding relatedness in patients’ narratives about their experiences of living with and managing severe asthma. Essentially our study has highlighted the psychosocial influences amongst people living with severe asthma, which do not fit the narrow framework of the biomedical model. Our findings show that threats to an individual’s sense of relatedness might produce vulnerability and impact on a person’s psychological well-being, which at times might be beyond their own personal control. In addition to symptom management and adherence to treatment, self-management also includes the ability to achieve a sense of relatedness with others. This can be instructive in furthering healthcare providers understanding of their patients’ perceived ability to manage living with their condition, and provide more holistic care for patients living with severe asthma.

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Ethical statement

The research protocol was approved by the University of Sydney Human Ethics Committee (HREC 2015/934).

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Appendices

Appendix 1. Semi-structured interview guide- sample questions

1. Can you take me back to your first memory of having breathing problems?
2. Do you remember the early days of living with severe asthma (SA)? Tell me about that.

3. What was your reaction to getting a diagnosis of SA? How did you feel about receiving his?
4. What your experiences been of telling family/friends/colleagues that you have SA? What was their reactions?
5. To what extent has living with SA impacted on your life? Tell me about a couple of instances of how this impact has affected your life.
6. Where or from whom do you find you get the most support from?
7. What does support mean to you?
8. Tell me what happens when you go to your Dr?
9. What does severe asthma mean to you?
10. How have things changed over the years for you in terms of living with your SA?