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# Living with Severe Asthma: A Self-Determination Theory Perspective

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Daniela Eassey  
B. Pharm (Hons 1)

A thesis submitted in fulfilment of the requirements for the degree of  
Doctor of Philosophy

School of Pharmacy  
Faculty of Medicine and Health  
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# Statement of originality

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This thesis describes research carried out at the University of Sydney School of Pharmacy under the supervision of Professors Lorraine Smith, Helen Reddel and Kath Ryan.

This is to certify that to the best of my knowledge the content of this thesis is my own work. This thesis has not been submitted for any degree or other purposes.

I certify that the intellectual content of this thesis is the product of my own work and that all the assistance received in preparing this thesis and sources have been acknowledged.

Daniela Eassey

BPharm (Hons I)

11 October 2019

# Acknowledgements

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# Table of contents

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<b>Statement of originality .....</b>	<b>ii</b>
<b>Acknowledgements.....</b>	<b>iii</b>
<b>Table of contents .....</b>	<b>v</b>
<b>List of Figures .....</b>	<b>xi</b>
<b>List of Tables .....</b>	<b>xii</b>
<b>Dissemination of research and awards.....</b>	<b>xiii</b>
<b>Scholarships .....</b>	<b>xix</b>
<b>Glossary of acronyms.....</b>	<b>xx</b>
<b>Abstract.....</b>	<b>xxi</b>
<b>Thesis overview.....</b>	<b>xxviii</b>
<b>Part A – Background .....</b>	<b>30</b>
Overview of Part A .....	31
<b>Chapter 1: Severe asthma- the Biomedical Model.....</b>	<b>32</b>
1.1 The global burden of chronic conditions .....	32
1.2 Current understanding of asthma .....	33
1.2.1 Managing asthma .....	36
1.3 Severe asthma.....	38
1.3.1 Managing severe asthma .....	41
1.4 The push for effective self-management.....	42
1.4.1 Disentangling the concept of self-management .....	43
1.4.1.1 Definition of self-management .....	43
1.4.1.1.1 Self-care and self-management .....	46
1.4.1.1.2 Self-management and goal setting .....	46
1.4.2 Asthma guidelines: self-management- what’s in policy? .....	47
1.5 Self-management gap.....	49
1.6 Summary .....	51

<b>Chapter 2: Theoretical framework.....</b>	<b>53</b>
2.1 Health and well-being .....	53
2.2 Well-being and theory .....	54
2.3 Self-determination theory .....	55
2.3.1 Basic psychological needs .....	58
2.3.1.1 Autonomy .....	58
2.3.1.2 Competence .....	59
2.3.1.2.1 Distinguishing the terms self-efficacy and competence.....	59
2.3.1.3 Relatedness .....	60
2.4 Summary .....	60
<b>Research aims .....</b>	<b>62</b>
<b>References .....</b>	<b>63</b>
<b>Part B – Methods .....</b>	<b>84</b>
Overview of Part B.....	85
<b>Chapter 3: Methods .....</b>	<b>86</b>
3.1 Introduction .....	86
3.2 Research methods .....	89
3.2.1 Database for Individual Patient Experiences method .....	90
3.2.2 Data collection .....	91
3.2.2.1 Preparation and recruitment .....	91
3.2.2.2 Sampling .....	93
3.2.2.3 Study setting .....	93
3.2.2.4 Interviews.....	94
3.2.2.5 Ethical consideration.....	96
3.2.2.6 Safety protocol for the researcher .....	97
3.2.3 Reflexivity.....	97
3.2.3.1 Reflection as the researcher .....	98
3.2.4 Data analysis .....	100
3.3 Summary .....	103
<b>References .....</b>	<b>104</b>

<b>Part C – Findings .....</b>	<b>110</b>
Overview of Part C.....	111
<b>Chapter 4: Systematic review of people’s experiences of living with severe asthma</b>	
<b>.....</b>	<b>112</b>
Preface.....	112
Authorship statement .....	113
Abstract .....	115
Introduction .....	115
Methods .....	116
Results .....	116
Discussion .....	121
Strengths and limitations .....	122
Implications for clinical practice .....	122
References .....	123
Supplementary material .....	124
Postscript to Chapter 4: An update to the systematic review .....	127
<b>References .....</b>	<b>130</b>
<b>Chapter 5: A systematic review of people’s experiences of living with a chronic illness</b>	
<b>using a self-determination theory perspective</b>	
<b>.....</b>	<b>131</b>
Preface.....	131
Authorship statement .....	132
Abstract .....	134
Introduction .....	135
Methods .....	138
Results .....	140
Discussion .....	153
Strengths and limitations .....	156
Implications for clinical practice .....	157
<b>References .....</b>	<b>158</b>

<b>Chapter 6: The impact of severe asthma on patients' autonomy: A qualitative study</b>	<b>165</b>
.....	
Preface.....	166
Authorship statement .....	167
Abstract.....	168
Introduction .....	168
Methods.....	169
Results .....	170
Discussion .....	173
Strengths and limitations.....	175
Conclusion.....	175
References .....	175
<b>Chapter 7: Living with severe asthma: the role of perceived competence and goal achievement</b>	<b>177</b>
.....	
Preface.....	177
Authorship statement .....	178
Abstract .....	180
Introduction .....	181
Methods .....	183
Results .....	185
Discussion .....	195
Strengths and limitations.....	197
Implications for clinical practice.....	197
Conclusion.....	198
References .....	200
<b>Chapter 8: Barriers to belonging: the need for relatedness amongst people living with severe asthma</b>	<b>208</b>
.....	
Preface.....	208
Authorship statement .....	209
Abstract .....	211
Introduction .....	211
Methods .....	212



Results .....	212
Discussion .....	216
Strengths and limitations .....	217
Conclusion .....	217
References .....	217
Supplementary material .....	218
<b>Part D – Synthesis of the Findings: Discussion and Conclusion .....</b>	<b>220</b>
Overview of Part D .....	221
<b>Chapter 9: Discussion, implications and concluding remarks.....</b>	<b>224</b>
9.1 Advances in theoretical understanding .....	224
9.1.1 Enriching our understanding of autonomy, competence and relatedness .....	225
9.1.1.1 Autonomy: beyond supporting health-related behaviours .....	227
9.1.1.2 Supporting competence: beyond holding individuals responsible.....	230
9.1.1.3 Relatedness: beyond feeling connected to others .....	233
9.2 Emotions as a mediator to wellness .....	235
9.3 Summary: combing the constructs.....	237
9.4 Applying the constructs to the principles of chronic care .....	238
9.5 Practice implications .....	239
9.5.1 Microsystem recommendations .....	243
9.5.1.1 Supporting psychological needs in clinical practice .....	243
9.5.1.2 Incorporating the use of narratives in an evidence-based world .....	244
9.5.2 Macrosystem recommendations.....	248
9.5.2.1 Re-framing the concept of self-management and patient-centred care .....	248
9.6 Strengths and Limitations .....	250
9.7 Concluding remarks .....	251
<b>References .....</b>	<b>253</b>
<b>Appendices .....</b>	<b>264</b>
Appendix 1- Additional publication.....	265
Appendix 2- Ethics approval letter and trial registration .....	285
2.1 Institutional ethics approval letter .....	286
2.2 Australian New Zealand Clinical trials registration .....	288
Appendix 3- Data collection documents .....	293
3.1 Australian College of Rural and Remote Medicine – advertisement.....	294

3.2 One-page study summary for Physicians .....	295
3.3 Participant information packs .....	296
3.3.1 Summary information leaflets .....	296
3.3.2 Participant information sheet .....	297
3.3.3 Consent form.....	302
3.3.4 Consent to withdraw form .....	304
3.3.5 Copyright form.....	305
3.3.6 Reply form .....	307
3.4 Sociodemographic questionnaire.....	308
3.5 Interview guide.....	310
3.6 Patient agreement to video/audio recording and transcript amendments .....	312
Appendix 4- Distance travelled.....	313
Appendix 5- Supplementary material for second systematic review (Chapter 5) .....	316
5.1 Critical Appraisal Skills Programme (CASP) checklist .....	317
5.2 Summary of included tables .....	318
Appendix 6- Supplementary material for competence manuscript (Chapter 7) .....	320
6.1 Confirmation of acceptance for publication in Chronic Illness.....	321
6.2 Additional quotes for Theme 1: Self-care is important .....	322
6.3 Additional quotes for Theme 2: Being at one with the illness .....	324
Appendix 7- Overall aims of project and translation to practice .....	326

# List of Figures

---

Figure 1 - Thesis overview including relevant publications .....	xxix
Figure 2 - Worldwide prevalence of asthma .....	34
Figure 3 - Lung airways .....	35
Figure 4 - Asthma stepwise management .....	38
Figure 5 - Prevalence of severe asthma.....	40
Figure 6 - Self-determination theory micro-theories .....	56
Figure 7 - Summary of methodology and methods.....	103
Figure 8 - Flowchart of the participant recruitment process .....	165
Figure 9 - Conceptual diagram summarising the findings .....	226
Figure 10 - Conceptual diagram of the role of autonomy .....	230
Figure 11 - Conceptual diagram of the role of competence.....	233
Figure 12 - Conceptual diagram of the role of relatedness .....	235
Figure 13 - Conceptual diagram combining the constructs .....	237
Figure 14 - Conceptual diagram summarising practice implications.....	242

# List of Tables

---

Table 1 - Biologics available in Australia.....	42
Table 2 - Phases of thematic analysis .....	102
Table 3 - Details of included studies: update from second systematic review .....	129

# Dissemination of Research and Awards

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The theoretical and empirical work presented in this thesis have been published and/or presented in the following journals, and international and national conferences:

## Peer reviewed papers

### Chapter 4

- **Eassey D**, Reddel HK, Foster JM, Kirkpatrick S, Locoock L, Ryan K, Smith L. “... I’ve said I wish I was dead, you’d be better off without me”: a systematic review of people’s experiences of living with severe asthma. *Journal of Asthma* 2018: 1-12.

### Chapter 5

- **Eassey D**, Reddel HK, Ryan K, Smith L. “It is like learning how to live all over again” A systematic review of people's experiences of living with a chronic illness from a self-determination theory perspective." *Health Psychology and Behavioral Medicine* (under review).

### Chapter 6

- **Eassey D**, Reddel HK, Ryan K, Smith L. “The impact of severe asthma on patients’ autonomy: a qualitative study". *Health Expectations* 2019; 00: 1– 9.

### Chapter 7

- **Eassey D**, Reddel HK, Ryan K, Smith L. “My asthma has made me doubt my ability to do things” The impact of living with severe asthma on perceived competence and setting goals. *Chronic illness* (accepted for publication 19<sup>th</sup> September 2019).

## Chapter 8

- **Eassey, D.**, Reddel, H. K., Ryan, K., & Smith, L. (2019). Barriers to belonging: the need for relatedness amongst people living with severe asthma. *Journal of Asthma*, pp. 1-9. doi:10.1080/02770903.2019.1656230.

### **Additional publications**

(See Appendix 1)

- Pickles K., **Eassey D.**, Reddel HK., Locock L., Kirkpatrick S., Smith L. (2018). "This illness diminishes me. What it does is like theft": A qualitative meta-synthesis of people's experiences of living with asthma." *Health Expectations*, 21(1), 23-40.

### **Published abstracts**

- The Thoracic Society of Australia and New Zealand (TSANZ) Conference, TSANZ Oral Presentations. *Respirology* 2017, 22: 18-100. doi: 10.1111/resp.13009.
- The Thoracic Society of Australia and New Zealand (TSANZ) Conference, TSANZ Poster Presentations. *Respirology* 2018, 23: 104-215. doi:10.1111/resp.13268.
- The Thoracic Society of Australia and New Zealand (TSANZ) Conference, TSANZ Poster Presentations, *Respirology* 2019, 24: 103-206. doi:10.1111/resp.13492.
- American Thoracic Society (ATS) Conference, ATS Poster Presentations, *Am J Respir Crit Care Med* 2019: A4077-A.

## **Conference presentations (in reverse chronological order): podium**

### International

- **Eassey D**, Reddel HK, Ryan K, Smith L. The Impact of Severe Asthma on Patient Autonomy. Self-Determination Theory (SDT) Conference, 21-24 May 2019. The Netherlands.
- **Eassey D**, Reddel HK, Ryan K, Smith L. Understanding the self-management strategies of people living with severe asthma: a qualitative study. European Society for Health and Medical Sociology (ESHMS) Conference, 6-8 June 2018. Lisbon, Portugal.
- **Eassey D**, Reddel HK, Ryan K, Smith L. It is so hard communicating... [healthcare providers] really need to listen to what the person is saying, not what [they] think they're saying."': A qualitative study of people's experiences of living with severe asthma. The International Conference on Communication in Healthcare & Health Literacy Conference, 8-11 October 2017, Baltimore, USA.

### National

- **Eassey D**, Reddel HK, Ryan K, Smith L. "[Severe asthma] is a constant thing that is very debilitating... every day is a bit of a struggle": People's experiences of living with severe asthma". Woolcock Institute, 27 April 2018. Sydney, Australia.
- **Eassey D**, Reddel HK, Ryan K, Smith L. People's experiences of living with Severe Asthma. Postgraduate Conference, School of Pharmacy, 25-28 September 2018. Sydney, Australia.
  - Prize for Best Presentation (1st)

- **Eassey D**, Reddel HK, Ryan K, Smith L. People's experiences of living with Severe Asthma, Centre of Excellence in Severe Asthma Meeting, 24 October 2018, Newcastle, Australia.
- **Eassey D**, Reddel HK, Ryan K, Smith L. Understanding the self-management strategies of people living with severe asthma: a qualitative study. American Association of Pharmaceutical Scientists (AAPS) University of Sydney Student Chapter Annual Symposium, 17 November 2017, Sydney, Australia.
  - Prize for Best Presentation (2<sup>nd</sup>)
- **Eassey D**, Reddel HK, Ryan K, Smith L. A Qualitative Study of People's Experiences of Living with Severe Asthma, School of Pharmacy Respiratory Theme meeting, 23 October 2017, The University of Sydney, Sydney, Australia.
- **Eassey D**, Reddel HK, Ryan K, Smith L. People's experiences of living with Severe Asthma, Centre of Excellence in Severe Asthma Meeting, 25 October 2017, Newcastle, Australia.
- **Eassey D**, Reddel HK, Ryan K, Smith L. People's experiences of living with Severe Asthma, Centre of Excellence in Severe Asthma Meeting, 26 October 2016, Newcastle, Australia.

### **Conference presentations: oral poster and presentations**

#### International

- **Eassey D**, Reddel HK, Ryan K, Smith L. The Impact of Severe Asthma on Patient Autonomy: A Qualitative Study. American Thoracic Society (ATS) Conference, 17-22 May 2019. Dallas. USA.



## National

- **Eassey D**, Reddel HK, Ryan K, Smith L. “How do people with severe asthma experience autonomy? An exploratory study. The Thoracic Society of Australia and New Zealand (TSANZ) Conference, 29 March-1 April 2019. Gold Coast, Australia.
- **Eassey D**, Reddel HK, Ryan K, Smith L. “[Severe Asthma] Is Constantly with Me... Every Day Is a Bit of a Struggle” A Qualitative Study of People’s Experiences of Living with Severe Asthma. The Thoracic Society of Australia and New Zealand (TSANZ) Conference, 24-27 March 2018. Adelaide, Australia.

## **Conference presentations: poster**

## International

- **Eassey D**, Reddel HK, Ryan K, Smith L. “I lived quite an active life, I used to go for walks and ride my bike, and then all of a sudden... I just gave it all up”. The role of competence in people’s experiences of living with severe asthma. Self-Determination Theory (SDT) Conference, May 2019. The Netherlands.
- **Eassey D**, Pickles K, Reddel HK, Foster F, Smith L. “I like to know and make my own choices”. Personal Experiences of Severe Asthma: A Review, video presentation, International Conference on Narrative of Health and Illness, November 2016, Tenerife, The Canary Islands.
  - Awarded first prize for best video presentation:  
(<https://www.youtube.com/watch?v=Efh5XUP08ew&feature=youtu.be>)

## **Invited talks**

- **Eassey D**, Reddel HK, Ryan K, Smith L. Understanding the self-management strategies of people living with severe asthma: a qualitative study. Royal Prince Alfred Hospital Pharmacy meeting, 23 October 2018, Sydney, Australia.

## **Translation into practice**

- Contributed to the development of a severe asthma toolkit which was launched during the TSANZ 2018 conference (<https://toolkit.severeasthma.org.au/>)
- HealthTalk website (<https://healthtalkaustralia.org/>) – severe asthma module (launching October - November 2019)

# Scholarships

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## Research Scholarships

- National Health and Medical Research Council Centre of Excellence in Severe Asthma  
PhD Scholarship awarded February 2016 - June 2016
- Australian Government, Australian Postgraduate Award/Research Training Program  
Stipend; awarded June 2016 - August 2019
- National Health and Medical Research Council Centre of Excellence in Severe Asthma  
Top Up Scholarship awarded June 2016 - August 2019

## Travel Scholarships

- National Health and Medical Research Council Centre of Excellence in Severe Asthma  
Travel Grant
  - 2017
  - 2018
  - 2019
- Postgraduate Research Support Scheme Travel Grants
  - 2017
  - 2018
  - 2019

# Glossary of acronyms

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AIHW	Australian Institute of Health and Welfare
BPNs	Basic Psychological Needs
BNT	Basic Needs Theory
CET	Cognitive Evaluation Theory
COT	Causality Orientation Theory
SDT	Self-Determination Theory
GINA	Global Initiative for Asthma
GCT	Goal Contents Theory
HCPs	Healthcare providers/ Healthcare professionals
ICS	Inhaled Corticosteroids
LABA	Long acting beta <sub>2</sub> agonist
NHMRC	National Health and Medical Research Council
OCS	Oral Corticosteroids
OIT	Organismic Integration Theory
RMT	Relationship Motivation Theory
SABA	Short acting beta <sub>2</sub> agonist
WHO	World Health Organisation

# Abstract

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## Background

Asthma is a heterogenous condition, usually characterised by chronic airway inflammation that affects people of all ages. It is estimated that 300 million individuals in the world have asthma. Asthma severity which can range from mild to severe, is based on the level of treatment required to control symptoms and prevent exacerbations. Severe asthma affects 3-10% of the asthma population. Severe asthma is defined as asthma that requires high-dose treatment to remain controlled or remains uncontrolled despite high dose therapy. Whilst most severe asthma research has been devoted to understanding pathophysiology, biomarkers and testing novel treatments, there is a dearth of research focusing on patients' experiences of self-management of severe asthma.

To improve health outcomes for patients with severe asthma, treatment guidelines emphasise the importance of patient-centredness, shared decision making and self-management. Research has demonstrated that understanding people's attitudes, beliefs and values can impact behaviours and health outcomes. Greater attention is needed to understand the patients' experiences and perspective to improve understanding of the emotional, psychosocial and physical impact of living with this condition, which may shape opportunities for directing patient-centred health interventions.

Self-determination theory represents a broad framework to explain health related behaviours and motivation on an individual level. According to this theory, people have three basic psychological needs: autonomy, competence and relatedness. The need for autonomy refers to the experience of behaviour as volitional and self-endorsed. Competence, in turn, refers to feeling a sense of mastery and efficacy in one's activities. Relatedness reflects the extent to

which a person feels accepted, understood, cared for and connected to others. Fulfilment of these three needs has been shown to contribute to enhanced motivation and improved health outcomes.

Drawing on the self-determination theory constructs of autonomy, competence and relatedness, a qualitative research design was used to investigate lived experiences and behaviours from the perspective of people living with severe asthma. More specifically, the aims of this doctoral work were to examine, from the patients' perspective, the impact of severe asthma on 1) their sense of autonomy 2) perceived competence to set and achieve goals, and 3) their sense of relatedness.

## **Methods**

### *Systematic reviews*

Two systematic reviews were conducted. The first systematic review of the qualitative literature was conducted to examine the experiences of people living with and managing severe asthma. Electronic databases and reference lists were searched to identify studies exploring the patients' experiences and perception of living with and managing severe asthma. Analysis and synthesis of the data were conducted by drawing on elements of the meta-ethnographic method and using a comparative thematic analysis approach.

The second systematic review examined the views and experiences of people living with a chronic illness from the available qualitative literature that drew on self-determination theory. Electronic databases and reference lists were searched to identify articles that used qualitative methods and explored the lived experiences of people living with and managing a chronic illness, and the analysis underpinned with self-determination theory. Using a framework synthesis approach, categories were informed by self-determination theory's constructs of autonomy, competence and relatedness. These were then thematically analysed to identify

patterns of data within and between categories. A systematic and iterative process was used to derive the final synthesis of the overarching theme and associated categories.

### *The impact of living with severe asthma on autonomy, competence and relatedness*

Potential participants were invited to take part in the study through their general practitioners or respiratory physicians. The interviews were conducted in Australia between 2016 and 2019. The aim was to include participants from different ethnicities, geographical locations and sociodemographic backgrounds. A total of thirty-eight participants were recruited. The researcher (PhD Candidate) conducted the interviews in the respondents' homes, or elsewhere if preferred. Participants were asked to tell their own story from the point when they first noticed they had breathing problems. They were encouraged to talk about their experiences of living with this condition, with little interruption from the interviewer. Interview topics were initially defined from the first systematic review but later modified as new themes emerged. Follow-up, open-ended questions and prompts were used to further explore the self-determination theory concepts of autonomy, competence and relatedness. Data was categorised using a hybrid approach to analysis incorporating both inductive and deductive methods, informed by the self-determination constructs of autonomy, competence or relatedness. Analysis and comparison across and within categories were conducted to develop final themes.

## **Findings**

### *Systematic reviews*

The findings of the first systematic review revealed a paucity of studies reporting on people's experiences of living with severe asthma and there was a focus on clinical rather than personal issues. The key theme emerging from the analysis was that individuals with severe asthma strive for autonomy in their efforts to reclaim 'power' over their asthma. The synthesis

revealed that severe asthma was disempowering and a threat to identity and life roles. This review revealed that more attention needed to be paid to understanding the self-management strategies and personal goals of those living with this condition.

The findings of the second systematic review revealed that patients living with a chronic illness endeavoured to be 'free from disease'. Living with a chronic illness was perceived as a disease if it challenged a person's sense of autonomy, competence and relatedness. The review also revealed the current emphasis on fixing 'issues' that are perceived to hinder people from managing their condition. Thus, fails to explore what matters to patients in terms of their desire to manage (or live well with) their chronic illness. The findings suggest the need to move beyond the narrow approach underpinned by medical paternalism and pre-determined medical goals, towards taking a broader approach to understanding what it means to live well with a long-term condition.

#### *The impact of living with severe asthma on autonomy, competence and relatedness*

The findings from this doctoral work examined, from the patients' perspective, 1) the impact of severe asthma on their sense of autonomy, 2) perceived competence to set and achieve goals, and 3) their sense of relatedness. These findings are divided into three sections.

#### *The impact of severe asthma on participants' autonomy*

Participants' autonomy was enacted or challenged in a range of situations, such as interacting with health-care providers, maintaining employment, managing symptoms, and dealing with threats to self-identity. Two main themes were discerned from the analysis: (a) the desire to live an "unconstrained" life: this was influenced by participants' interactions with healthcare providers and desire to maintain employment; and (b) preservation of self-identity: participants sought to maintain their valued role and strived for "normality". This study has



highlighted important clinical implications for healthcare providers in identifying and understanding the day-to-day psychological and physical challenges patients face to support self-management and maximise quality of life. Overall, this study has advanced knowledge in understanding the complex dynamics of patient autonomy in contemporary medical practice, using the narratives of people living with severe asthma. Using self-determination theory as a framework allowed us to question assumptions made within the biomedical model about people's experiences of living with severe asthma and their associated behaviours.

*The impact of living with severe asthma on perceived competence and achieving goals*

The analysis revealed that perceptions of goal-setting and perceived competence to manage severe asthma were inextricably linked. It was apparent that the success of achieving broad life goals depended on meeting asthma goals. Participants' desire to achieve their broader goals was strongly driven by their perceived ability to master managing their condition, which at times required more than medical strategies. Two main themes were discerned from the analysis: 1) "learning how to look after yourself": self-care is important and 2) "reaching an agreement with severe asthma": being at one with the illness. These findings provide support for the need for deep reflection on the current approach to caring for patients with severe asthma. Identifying patient perceived competence for achieving asthma goals has the potential to unravel unmet psychological and emotional needs and bring healthcare professionals closer to the patient-lived experience.

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

The findings show that living with a debilitating and unpredictable illness challenged their ability to relate to others. 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. The 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. Overall, the findings show that threats to an individual's sense of relatedness produce vulnerability and impact psychological well-being, which at times might be beyond one's personal control. These findings can be instructive in furthering healthcare providers' understanding of their patients' perceived ability to manage living with their condition and provide more holistic patient-centred care for those living with severe asthma.

### **Conclusion**

Collectively, the findings of this thesis provide new understandings of the lived experience of severe asthma and show the current biomedical approach to supporting patients is disconnected from the experiences narrated by participants. This thesis adds to the current literature examining people's illness experiences, however, rather than offering descriptions, which are equally important, it offers explanations of *how* people live with severe asthma and manage their condition, *what* helps them flourish psychologically and *how* this influences their overall well-being. Using self-determination theory as a theoretical lens provided a philosophical framework, allowing assumptions made within the biomedical model about managing severe asthma to be questioned.

The findings suggest there is an urgent need to reflect on current clinical practices and to follow the aims of policy and theory that emphasise closing the "power" gap between patients and healthcare providers, by supporting patient autonomy, understanding patient values,

capabilities and beliefs, and to more broadly supporting people to live with their condition. The research reported in this thesis provides empirical evidence of how healthcare providers could aim to enable patients to live well with severe asthma. This thesis has important implications for policy and practice. The current health system does not meet all of the needs of people living with severe asthma. They were not solely focused on acute problems (for example, flare-ups); but also, focus on the ongoing sequelae of the psychological work involved in living well with the condition. It is clear that drawing on our findings on autonomy, competence and relatedness, new approaches could provide a framework for thinking more broadly about the current perspective of severe asthma management. The outcomes of this research should impel healthcare stakeholders such as asthma educators, policy makers and healthcare providers, to reflect on and consider the implications of these perspectives for practice and policy.

**Keywords:** severe asthma, self-determination theory, autonomy, competence, relatedness, qualitative study, patient experience, lived experience, health behaviours, motivation, self-management, living well, patient-centred care

# Thesis overview

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This thesis is presented in 4 parts (A-D) consisting of 9 chapters as outlined below and in Figure 1.

Part A of this thesis details the background literature relating to the biomedical understanding of severe asthma and current approaches to self-management (Chapter 1) and provides justification for using self-determination theory as a theoretical lens (Chapter 2). This part identifies significant research gaps in the literature leading to the research aims and objectives of this thesis.

Part B details the research methods used in this thesis (Chapter 3).

Part C includes a systematic literature review examining the qualitative literature exploring people's experiences of living with severe asthma (Chapter 4). This part also includes a second systematic review of the qualitative literature drawing on self-determination theory to explain people's experiences of living with a chronic illness (Chapter 5). Following the two systematic reviews this part provides the findings of our study exploring people's experiences of living with and managing severe asthma drawing on self-determination theory constructs autonomy, competence and relatedness. This is divided into Chapters 6, 7 and 8 respectively.

Part D provides a discussion of the findings of the studies described in this thesis and concluding remarks (Chapter 9).

NB: Tables, figures and references throughout this thesis are numbered sequentially within each chapter, rather than throughout the thesis as a whole. This style was chosen as Chapters 4, 5, 6, 7 and 8 are manuscripts that are either published or under review in peer-reviewed journals.

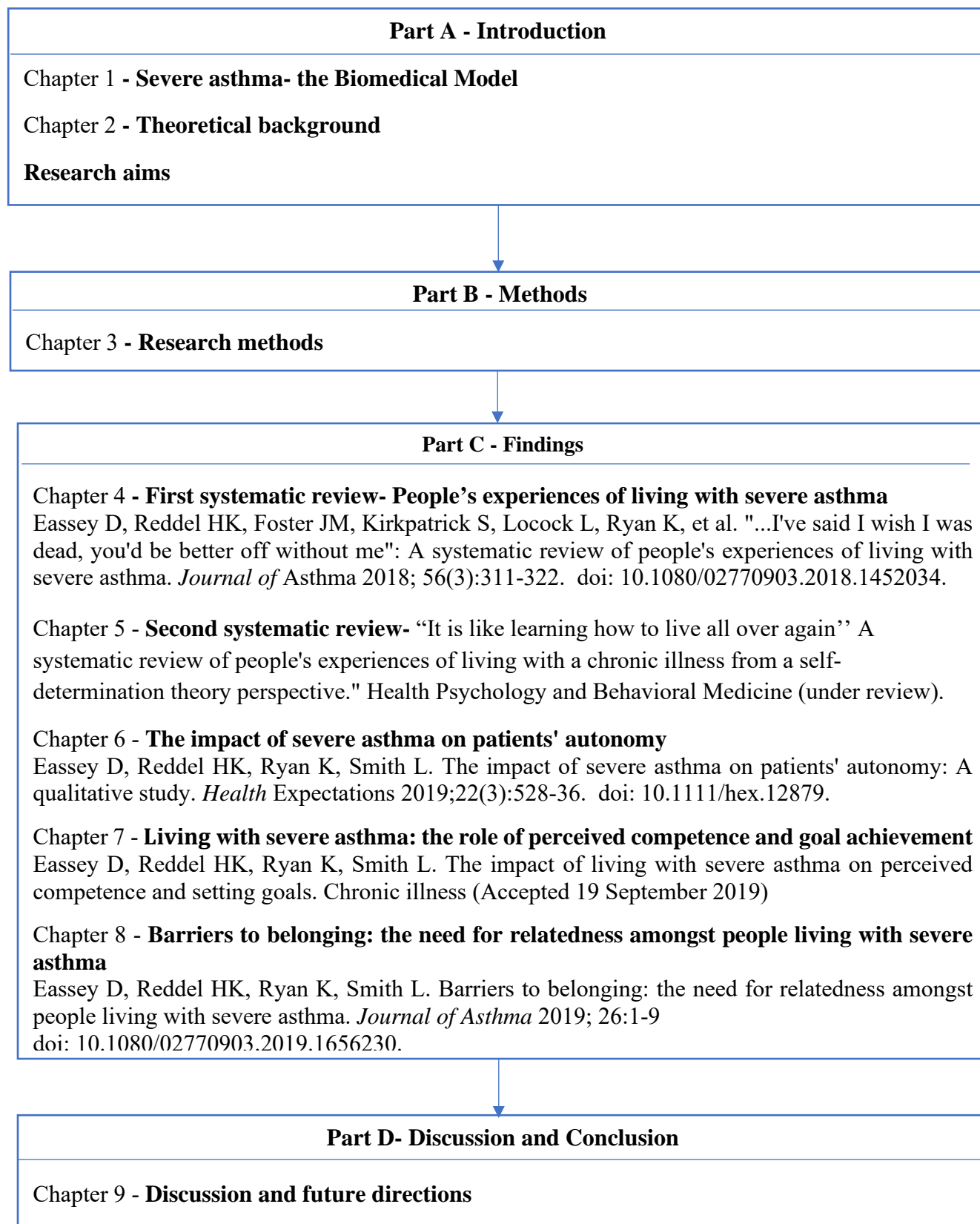


Figure 1. Thesis overview, including relevant publications

# **Part A: Background**

# Overview of Part A

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Part A provides an introduction to this thesis. This part begins with a review of severe asthma as a condition that requires medical management. It will describe the biomedical understanding of severe asthma, the management of this condition, and how this affects people living with it from a medical perspective (Chapter 1).

The next chapter (Chapter 2) introduces a theory that will be used to explain the findings of the analysis of the interviews collected for this study. First, a justification is provided for using self-determination theory as a framework. This macro theory consists of six micro theories. For the purpose of this doctoral study, the self-determination theory fourth micro theory on people's basic psychological needs is used as a framework to understand people's behaviours. Following this, details of the overall research aims and objectives of this doctoral work are described.

# Chapter 1: Severe Asthma – the Biomedical Model

## 1.1 The global burden of chronic conditions

The prevalence of chronic diseases is rapidly increasing and has become a global concern (1). The personal and economic impacts of chronic diseases are a serious challenge for national governments and international organisations (1). The term ‘chronic diseases’ refers to a broad range of long-term and persistent health conditions which may lead to other health complications and may be associated with functional impairment or disability (2). ‘Chronic diseases’ are often also described as ‘long-term conditions’, ‘chronic illnesses’, ‘chronic conditions’ or ‘noncommunicable diseases’. Examples include heart disease, arthritis, asthma, high blood pressure and diabetes. Many chronic conditions are complex and are often associated with lifestyle risk factors such as poor diet, physical inactivity and smoking (2) .

According to the World Health Organisation (WHO), by 2020, chronic diseases are expected to account for almost three-quarters of all deaths worldwide (3). In Australia, chronic diseases are responsible for nine out of ten deaths (4). It is estimated that just under half of the Australian population (47.3%) lives with one or more chronic conditions (5). Chronic conditions are the major driver of health system utilisation and costs (4). For example, in Australia they account for 70% of the total healthcare expenditure. In 2017, The Australian Institute of Health and Welfare (AIHW) estimated that \$180.7 billion was spent on health (6).

In addition to the direct healthcare costs, there are significant and numerous burdens to the individual, their carers and families. Living with a chronic condition is associated with emotional, psychological and physical effects. Effects may include absenteeism from work, social isolation, stigma, stress and reduced independence (7-9). Many individuals living with a



chronic condition perceive their health and quality of life to be poorer than those without chronic conditions, across a range of emotional and social aspects (8).

Given the global burden of chronic illnesses on both the patient and society, addressing these has become a priority for healthcare systems around the world. In 2002, the WHO released a report entitled “Innovation Care for Chronic Conditions: Building Blocks for action” (1) and reported the urgent need for action to care for people with chronic conditions (10). As a result, a significant effort has been made to direct national and international policies towards improving the prevention, treatment and ongoing management of chronic illnesses (10). As part of improving the management of chronic conditions, health professionals are encouraged to shift from practising using a disease-oriented approach towards a more person-centred approach. This includes practising using a collaborative manner and responding to patients’ needs and empowering them (11). Patient-centred care is constructed around reducing paternalism and the hierarchal gap between patients and healthcare providers, promoting goals, and ensuring the patient’s preferences, values and beliefs guide all clinical recommendations (12).

## **1.2 Current understanding of asthma**

Respiratory diseases impose an immense worldwide health burden and are the leading cause of mortality and morbidity (13). Of all chronic respiratory conditions, asthma and chronic obstructive pulmonary disease (COPD) are the most common. In 2015, these diseases ranked among the top 20 conditions causing disability globally (14). It is estimated that more than 300 million people worldwide have asthma, with approximately 250,000 annual deaths (15-17). If the current trends continue, it is estimated prevalence will increase by more than 100 million

asthma patients by 2025 (18, 19). According to the 2018 Global Asthma report, Northern and Western Europe, Brazil and Australia have the highest prevalence of asthma in the world (17) (Figure 2). Asthma places a significant economic burden on society (20, 21). The economic costs associated with asthma are estimated to rank as one of the highest among chronic diseases due to the significant healthcare utilisation associated with this condition (22).

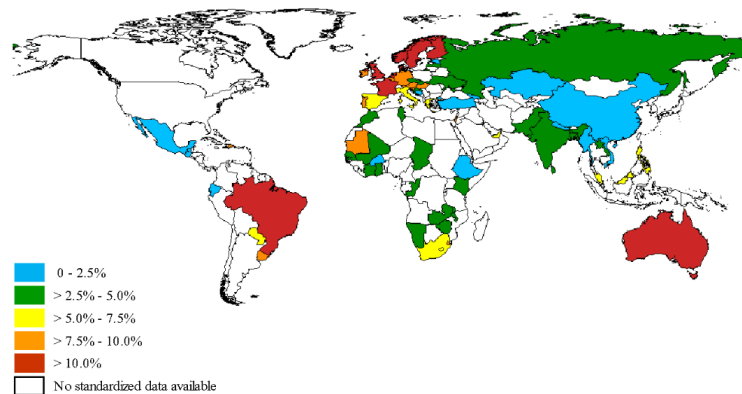


Figure 2. Worldwide prevalence of asthma (23).

Described since Hippocrates, asthma affects people from all age groups. The word "asthma" originates from the Greek meaning short of breath, meaning that any patient with breathlessness had asthma (24). As medical technology developed, asthma was defined as a “heterogenous disease, usually characterised by chronic airway inflammation in which many cells play a role, including mast cells and eosinophils. It is defined by the history of respiratory symptoms such as wheeze, shortness of breath, chest tightness and cough that vary over time and in intensity, together with variable expiratory airflow limitation” (Figure 3) (25, p.2). The aetiology of asthma is still not very well understood, but it involves a complex interplay between underlying genotype and environmental triggers that may increase the risk of developing asthma or may lead to differences in natural history of response to treatment. Because of differences in the influence of genes and environment, there is a wide range of disease heterogeneity and severity

in asthma (26). Triggers for individual episodes of symptoms vary between individuals and they may be allergenic or non-allergenic. Allergenic triggers include allergens such as dust mites, pets and mould. Non-allergenic triggers include viral respiratory infections, exercise, active and passive smoking, meteorological changes, medicines such as non-steroidal anti-inflammatory drugs (NSAIDs) and aspirin; and food chemicals/additives (27). In susceptible patients, this condition is characterised by recurrent attacks of breathlessness and wheezing particularly at night or early in the morning, and chest tightness (28). These symptoms are usually associated with variable expiratory airflow obstruction that is often reversible either with or without treatment (29).

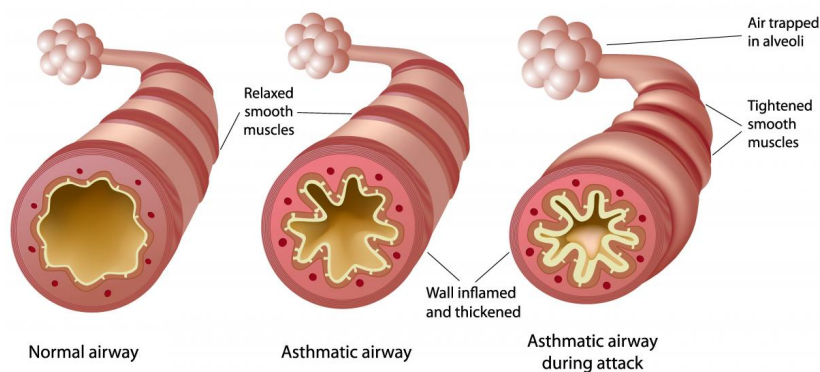


Figure 3. Diagram comparing lung airways without asthma, with asthma and during a flare up, illustrating differences in inflammation, muscle tightness and mucus production (30).

Whilst most research has been devoted to understanding the pathophysiology of asthma and treatment options, much less is known about patients' experiences of living with and managing this condition and its impact on their quality of life. A review by Pickles et al., (31) reported on the personal experiences of living with mild to moderate asthma. The authors reported that asthma affects the quality of life of the individual and their friends and family. They further highlighted the “work” associated with living with this condition (see Appendix 1). Findings

showed that individuals tailored their behaviours in response to their immediate social and physical context, including interactions with their healthcare providers (31). The “work” of living with asthma was at times an intensely emotional experience (31). Similarly, a review by Andrews et al., identified that many self-management interventions focused predominantly on medical management and overlooked the psychosocial aspects of the asthma experience (32).

### *1.2.1 Managing asthma*

According to the Global Initiative for Asthma (GINA), the long-term goals of asthma management are to achieve good symptom control, and to minimise future risks of asthma-related mortality, flare ups, persistent airflow limitation and side-effects of treatment (29). Asthma care involves using pharmacological and non-pharmacological treatments. Non-pharmacological treatments include smoking cessation, physical activity, and in some patients, avoidance of triggers and allergens including, but not limited to, food allergies, mould, dust mites and pollen.

Asthma treatment steps are based on a comprehensive assessment including the level of asthma control together with modifiable risk factors, comorbidities, lung function and patient preference (29). Asthma control is defined as the extent to which the manifestation of asthma is controlled, with or without treatment (33, 34). GINA recommends a therapeutic stepwise approach (step-up if necessary and step-down when possible) to pharmacological management of asthma (29). In practice, a common response to uncontrolled asthma is to step up treatment. These guidelines suggest that prior to considering any treatment step up, healthcare providers are urged to check patient inhaler technique and adherence.

Most people with asthma need two kinds of pharmacological treatment: quick relief medicines (also known as ‘relievers’) and controller medicines (also known as ‘long-term control medicines’ or ‘preventers’). Asthma treatment initially depends on the presenting symptoms, lung function and modifiable risk factors, whereas ongoing treatment decisions are based on an individualised cycle of assessment, adjustment of treatment and review of the response (29).

Reliever medications containing a short acting inhaled beta<sub>2</sub> agonist are used as needed to relieve symptoms of breathlessness. Regular preventer medications, such as inhaled corticosteroids (ICS) or a combination of ICS and a long-acting beta<sub>2</sub> agonist (LABA), are prescribed according to the severity of symptoms and appropriate inhaler device. These are used every day and long-term, to reduce the risk of exacerbations. For some patients, a combination of ICS-LABA (such as formoterol) inhaler is used as both the daily maintenance treatment and as the patient’s reliever medication. Other add on therapies such as long acting muscarinic antagonists and biologics may be considered if patients have persistent symptoms and/or exacerbations despite high doses of ICS and a LABA (Figure 4).

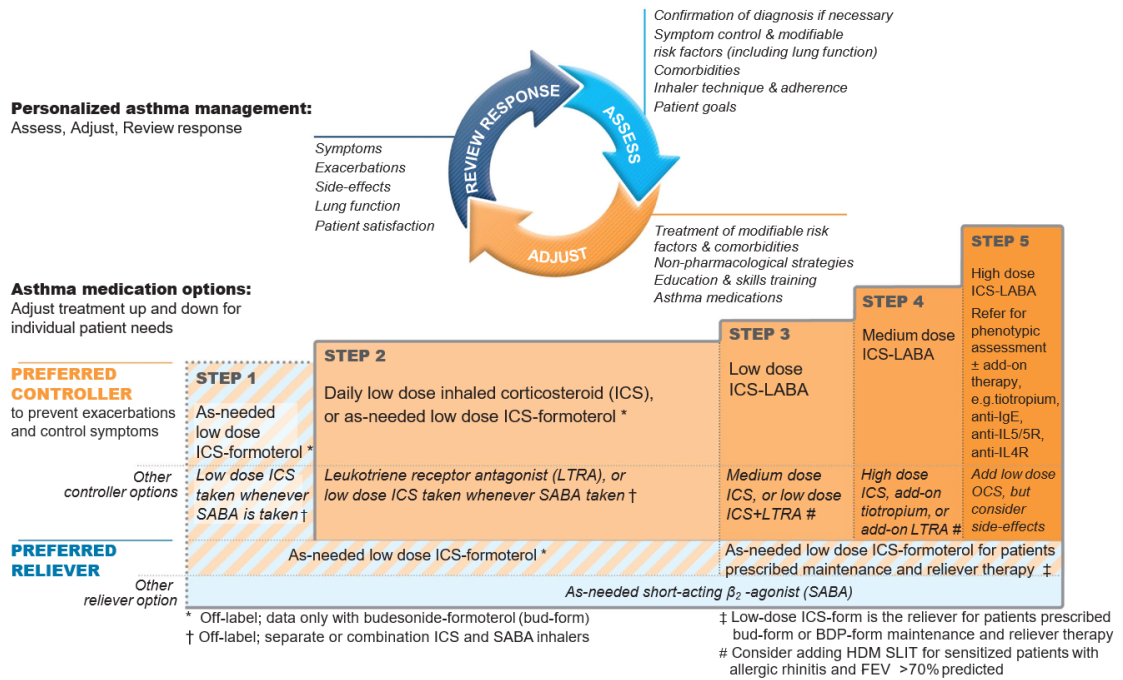


Figure 4. GINA stepwise management (29). Written permission to use this figure was obtained from GINA.

### 1.3 Severe asthma

In Australia, nearly 12% of the population (approximately 2.4 million) has asthma and the healthcare costs of asthma to the Australian economy is estimated at \$28 billion per annum (35). Overall costs of asthma, which include the individual direct costs and indirect costs are related to the severity of the condition (36). GINA classifies asthma on the basis of clinical phenotype, severity and pattern of airflow limitation (29). Asthma severity is assessed retrospectively from the level of treatment required to control symptoms and exacerbations (29). The level of severity can be categorised into mild, moderate and severe (29). In a few people with asthma, the disease is severe and may be life-threatening.

Until the 1970s, doctors were reluctant to give a diagnosis of ‘asthma’ because the long-term outlook was poor (37). In a textbook published in 1981, asthma management was described as “largely palliative” (37). Since then, the majority of patients living with asthma have been successfully treated with standard therapy of ICS with or without LABAs. As a result, hospitalisations of asthma patients and deaths due to asthma have markedly decreased (38). However, deaths remain high and there are misperceptions that asthma is no longer a problem in Australia. In 2017, there were 441 deaths due to asthma (39). This is largely related to the health gains made in mild and moderate asthma. However, these gains have not translated to severe asthma (38). The mortality rate due to asthma in Australia remains high on an international scale (38).

In 2014, a consensus definition of severe asthma was published that drew a distinction between difficult-to-treat asthma and severe asthma (40, 41) (Figure 5). Difficult-to-treat asthma is asthma that remains uncontrolled despite high dose treatment, or that requires such treatment to remain well controlled (40, 41). It is estimated that 17% of people with asthma have difficult-to-treat asthma. These patients may have uncontrolled asthma because of poor management skills (incorrect inhaler technique, non-adherence) or due to other comorbidities (42).

‘Severe refractory asthma’ or ‘severe asthma’, however, is a subset of difficult-to-treat asthma. ‘Refractory’ means that it does not respond as well to normal inhaled preventer treatment as it does for most people with asthma. Severe asthma affects 3-10% of the asthma population (43). Specialist assessment is required to exclude modifiable problems such as misdiagnosis, poor inhaler technique and non-adherence (41).

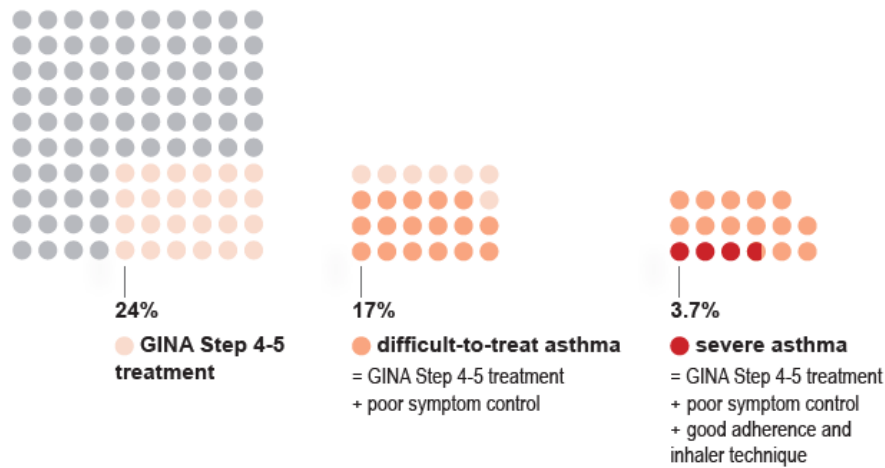


Figure 5. Prevalence of severe asthma. Data were collected from a Dutch population survey of people with asthma (44). Written permission to use this figure was obtained from GINA (45).

Severe asthma has a great impact on the quality of life of patients and their families (46, 47). A study in the United Kingdom reported that due to the frequent hospitalisations and debilitating symptoms, two in three patients with severe asthma were unable to hold full-time employment (48). Severe asthma accounts for high morbidity and is estimated to contribute to half the healthcare cost of all asthma (49, 50). A Canadian report identified the annual cost per patient with severe asthma to be 10 times more than those with mild to moderate asthma (51).



### *1.3.1 Managing severe asthma*

The medical goals of severe asthma are to reduce the burden of symptoms, exacerbations and medication side effects (52). The keystone of asthma management is to achieve and maintain asthma control (29, 33, 34). To date there is no gold standard measure of asthma control, but it includes both symptom control and reduction in future risk of adverse outcomes (29, 33, 34).

The current tools used in clinical practice can be categorised as subjective (patient-reported) and objective (physiological and inflammatory measures) (33). Subjective measures include patient-reported questionnaires such as the Asthma Control Test or the Asthma Control Questionnaire (53). Objective measures include, but are not limited to, spirometry and the fractional exhaled nitric oxide test (FeNO). Spirometry is used to detect and measure airway obstruction in children over 5 years old and adults (54). It also has some utility for predicting future attacks. FeNO measurements correlate modestly with eosinophilic airway inflammation. In some asthma phenotypes, rising FeNO measurements are associated with future adverse asthma outcomes (54). This test, however, is not routinely recommended in all patients due to incomplete evidence of benefits in asthma management but may be useful in people with some severe asthma phenotypes whose symptoms respond poorly to inhaled corticosteroids (54).

There is an emphasis in guidelines that severe asthma management must be individualised and tailored to the phenotypic characteristics of the patient (29, 45, 55). Severe asthma differs between individuals due to different underlying disease mechanisms. Identifying asthma phenotype can assist in prediction of response to targeted therapy (52). Asthma phenotypes are defined as recognisable clusters of demographics, clinical and/or pathological features (56). In the severe asthma population, it is recommended to characterise the features of asthma in

individual patients, in order to identify potential treatment options (56). Some well-recognised severe asthma phenotypes include: severe allergic asthma, eosinophilic asthma and non-eosinophilic asthma (56).

Some patients may benefit from low dose oral corticosteroids but long-term side effects can be common and burdensome (29). Other treatments for severe asthma include add-on therapies such as tiotropium, anti-fungal agents, montelukast, low dose macrolide antibiotics and biologics (Figure 4 - GINA Step 5). Biologics (also known as ‘monoclonal antibodies’) are made from the cells of living organisms such as bacteria or mice, that are modified to target specific receptors in humans (57). For severe asthma, these biologics target antibodies, inflammatory ligands or cell receptors to block specific pathways that lead to inflammation that cause asthma symptoms. In Australia, three monoclonal antibodies are currently available and approved for severe refractory asthma (Table 1).

Table 1. Biologics currently available in Australia for severe refractory asthma (58).

<b>Drug name</b>	<b>Target</b>	<b>Asthma phenotype</b>
Omalizumab	IgE	Allergic asthma
Mepolizumab	IL-5	Eosinophilic asthma
Benralizumab	IL-5 Receptor	Eosinophilic asthma

#### **1.4 The push for effective self-management**

Self-management is described as a crucial component of chronic illness care (59, 60). People with a chronic disease, such as severe asthma, are encouraged by their healthcare providers to learn how to manage their condition (59). Self-management involves healthcare providers equipping patients with the skills and knowledge to manage their condition (59). For people living with severe asthma, this includes learning how to monitor their asthma control, adhering

to their treatment, avoiding triggers, planning a regular review with their healthcare provider, being able to recognise and respond to worsening symptoms and having an up to date asthma action plan (29). A written asthma action plan is a set of instructions given by the doctor to help a patient with asthma or their carer to recognise and respond to worsening symptoms of their condition (29, 52, 61).

Self-management and self-care are concepts that are an integral part of chronic illness care. Yet, more recently a body of work has highlighted that these concepts are inconsistent in practice, highlighting the tensions inherent in supporting patients (62, 63). The broader ideals of self-management acknowledge the complexity of living with a chronic illness and include a myriad of medical, psychological, social and cultural domains (64). Yet, enacting these ideals is inconsistent in practice and how patient self-management should be supported by healthcare providers is open to interpretation. It has been argued that supporting self-management has become over medicalised (65).

#### *1.4.1 Disentangling the concept of self-management*

##### *1.4.1.1 Definition of self-management*

Over the past two decades policy makers have developed an interest in promoting and supporting better self-management, particularly amongst people living with a chronic illness, as a way of improving health outcomes and containing spiralling healthcare costs (1, 66, 67). People living with a chronic illness are expected to take a more active role in their own healthcare.

There is no ‘gold standard’ definition of self-management. Self-management was originally based on the self-efficacy theory of Albert Bandura (68). Creer and colleagues felt that the term

also inferred that the patient was an active participant in their health (69). Corbin and Strauss later categorised self-management as the work required to manage the chronic illness at home, which they identified involved three tasks (70). The first task involved medical management which included adherence to appropriate medication. The second set of tasks included creating, changing or maintaining meaningful behaviour such as lifestyle behaviours. The final task required dealing with emotions such as learning how to cope with feelings of anger, fear and depression (70). In 2002, a review by Barlow et al., (71) further defined self-management as:

“The individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition. Efficacious self-management encompasses ability monitor one’s condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. Thus, a dynamic and continuous process of self-regulation is established” (71, p 178)

These different theoretical approaches to defining self-management reflect the same general idea that chronic care requires patient responsibility. Critics have argued that the emphasis on individuals masks social and structural factors which may contribute to the management of chronic conditions (65, 72, 73). These perspectives have also given little consideration to how the power dynamics across and within the systems levels and social relations (for example through patient-healthcare professional encounters) may influence patient self-management.

Lorig and Holman (2003) similarly defined self-management as the day to day management of a chronic illness (74). They, however, proposed other self-management tasks including shared decision-making, improving self-efficacy and developing a partnership with healthcare

providers. While these self-management tasks are regularly stated in healthcare literature across chronic illnesses, a shortcoming of this definition is that it lacks attention to the emotional and psychosocial aspects of living with an illness. Ryan and Sawin argue that self-management involves knowledge and beliefs (for example self-efficacy, outcome expectancy and goal congruence); self-regulation skills and abilities (for example goal setting, self-monitoring, reflective thinking, decision making, planning and action, self-evaluation and emotional control); and social facilitation (such as influence, support and negotiated collaboration) (75). However, this theoretical stance fails to address the psychological or existential challenges of adapting to and living with a chronic condition, such as deriving meaning from the illness experience, integrating it into one's life and reconciling emotions (64, 76-78).

Self-management is conceptualised as comprising two different processes: motivational and self-regulatory (79, 80). The motivational process involves a personal driving force to engage in a behaviour in order to achieve an outcome (for example goals) (79, 81). The self-regulatory process involves evaluating and controlling feelings, desires and actions in the perspective of attaining their goals (79, 82). The theoretical underpinnings of self-management suggest support for 'effective' self-management should involve interventions targeting both the motivational as well as the volitional phases of health behaviour (81). Arguably, the notion of targeting patient behaviours is problematic in that it can contribute to increased feelings of failure, disappointment, stigmatisation and guilt among people with chronic conditions (83, 84). Other theorists have suggested shifting the notion that patients need to be 'effective self-managers' to understanding the individuals' everyday practices, illness experience and social context (85-87).

#### *1.4.1.1.1 Self-care and self-management*

The terms ‘self-care’ and ‘self-management’ are often used interchangeably in the healthcare literature (88), although they are defined differently (32). Self-care refers to both the ability to care for oneself and the performance of activities necessary to achieve, maintain or promote optimal health (89, 90). Self-management involves all aspects of a person’s life that may have been affected by living with a chronic condition (91, 92); it is also the ability and process that individuals use in conscious attempts to gain control of their disease, rather than being controlled by it (90, 93).

#### *1.4.1.1.2 Self-management and goal setting*

In the past few years there has been a great deal of research about the importance of patients participating in their health care, and the necessity for self-management of chronic conditions. Healthcare providers can help patients engage with their own care by identifying the goals (valued outcomes) that are important to them as well as support them to achieve those goals (81).

Goal-setting reflects one of a range of processes involved in self-management (81), and is an important aspect of managing a chronic illness. Goal-setting is frequently applied in self-management support programs and interventions, as it is found to enhance patients’ self-efficacy, and help them change their health behaviours and improve health outcomes (74, 94-96).

Early theorists of goal-setting theory were Locke and Latham, who initially used goal-setting to understand achievement behaviours in the workforce (97). It is one of the most effective

psychological strategies incorporated into the health literature for improving performance and motivation in patients to self-management (95, 98, 99). There is now a broad literature demonstrating the beneficial effects of goal-setting in other research domains such as academic achievement (100), health behaviours (101), and organisational management (102). It has been suggested that goals motivate people to develop strategies that will improve performance. According to Locke et al., (97, 102) accomplishing goals can lead to satisfaction and further motivation, which in turn has shown to improve performance.

Self-management should begin with exploring patients' beliefs and values (11). Depending on what is important to the patient, goals for the patient's self-management can be set and actions can be planned with the support of their healthcare providers (79, 95, 99, 103, 104). In the clinical context, however, goal setting tends to be associated with symptom management and treatment adherence over patient goals. From a psychosocial perspective, the current ways in which goal setting is understood within the clinical context is problematic. Clinical goals often overlook the broader set of emotional, psychological and social issues people face with living with an illness (105, 106).

#### *1.4.2 Asthma guidelines: self-management– what is in policy?*

In asthma management guidelines, there is an increasing emphasis on supporting 'effective' or 'optimal' self-management for people living with asthma (66). The term 'asthma self-management education' was coined by Gibson et al. in 2002, to comprise asthma education, self-monitoring of peak expiratory flow of symptoms, regular medical review and a written asthma action plan (107). The Australian Asthma Handbook (AAH) suggests that supporting self-management should be seen as an inherent part of 'good' medical care and should also

include the patient in decisions regarding their management program (32, 108). According to the AAH 'effective self-management' includes five main components 1) having an up to date written asthma action plan 2) actively monitoring asthma symptoms 3) correct use of inhaler devices 4) adherence to agreed treatment plan and 5) patient education and regular review with healthcare providers (108). These components were also evident in guidelines from other countries such as the National Asthma Education and Prevention Program in the US (109), and the British Guideline on the Management of Asthma in the United Kingdom (110).

What is clear from these guidelines, is that people living with asthma are responsible for managing their condition. Tellingly, this has emphasised that the current method of supporting patient self-management, which focuses on disease control, education and motivation, remains a dominant method of practice. For those living with severe asthma, arguably, the current disease-focused method seems to be insufficient. Despite 'good management practices', patients living with severe asthma still have uncontrolled symptoms. This highlights that although medical management is important, managing a debilitating condition is complex.

The identification of goals is central to the individualisation of self-management plans (68, 79, 111). Goal setting in asthma management guidelines includes finding out what the person understands about their asthma and discussing their goals for treatment (108). These guidelines are informed by growing evidence that individualised asthma action plans, negotiated in the light of patient goals, have the potential to improve a range of health outcomes and quality of life (79, 112, 113). Research has shown, however, that healthcare professionals providing self-management support have tended to prioritise goals focused on the medical management and clinical outcomes over goal preferences of patients living with a chronic illness (114-117). This



suggests that there may be a disconnect between the goals that matter to individuals and those focused on by health professionals and health care systems.

Recommendations for self-management support are based on evidence-based practice (118). Despite the push in policy to implement patient-centred self-management support, there is still a lack of clarity on how to put these recommendations into practice. Current practice takes an objective approach to chronic care, while self-management support theoretically, considers the social, psychological, emotional impact of living with a condition. The various dimensions of self-management are rarely considered or addressed in practice. There seems to be another disconnect between policy and practice. According to Dunn (119), this may be due to the time constraints, motivation and lack of training healthcare providers receive.

These disconnects can be heightened for those living with severe asthma. It is clear that supporting self-management for those living with this condition requires moving away from narrow medical parameters to a broader approach which focuses on helping people to live well with their condition. Careful attention needs to be given to the person, their illness experiences and life circumstances.

### **1.5 Self-management gap**

Research has shown several frameworks of self-management which have enhanced our understanding of self-management of chronic illness (11, 70). There is growing recognition of supporting self-management for those living with a chronic illness. With respect to severe asthma, there is an emphasis in guidelines to promote self-management and improve asthma control through supporting self-care practices such as taking medication regularly, awareness of symptoms and in some cases, avoidance of triggers (120). The majority of studies report that

interventions targeting asthma self-management improve asthma control (120-125). These focus on targeting patient behaviour and motivation through providing feedback on inhaler technique, education, brief motivational interviewing and goal setting (120, 121, 123, 126-129). Despite this, the translation of effective self-management in practice remains poor, with research indicating that there are unmet patient needs, and that current biomedical strategies fail to execute a meaningful partnership between the patient and their health-care provider (32).

The current biomedical way of practising has been described as focusing on taking control, labelling the patient and treating them according to their presenting symptoms and other features. Whilst this approach undoubtedly provides a model of best practice medical care, it does not take into account the complexity of living with and managing a debilitating and unpredictable chronic illness such as severe asthma. Karnilowicz further argues that chronic illnesses “are objectified and often hidden behind the doors and within the walls of the clinician's office” (130, p. 278). The patient’s illness experience and the social, psychological, emotional impact of living with the condition are rarely considered or addressed. Yorke et al., (131) conducted a systematic review on the efficacy of psychological interventions in asthma. Although quality of life was increased following cognitive behavioural therapy, no recommendations for clinical practice could be made, confirming the need for further well-designed research.

For people living with severe asthma, the current model of asthma management is often ineffective. There is evidence for the need for self-management approaches to move away from the narrow biomedical focus on supporting patient to manage their long-term conditions, and towards a broader approach which encompasses not only medical, but also the social, emotional

and psychological aspects of living with a chronic illness. A key part of changing this focus is understanding patients' values, beliefs, and goals, and their overall experiences of living with their condition.

## **1.6 Summary**

Severe asthma is a complex and heterogeneous disease that affects 3-10% of individuals with an asthma diagnosis. It accounts for high morbidity and is estimated to contribute to half the healthcare cost of all asthma. For people living with severe asthma, the current model of asthma management is often ineffective. Severe asthma guidelines encourage healthcare providers to support patient self-management and acknowledge their goals and beliefs when deciding on treatment plans. It has been shown, however, that in practice healthcare providers remain focused on the medical aspects of managing a chronic illness. Research has shown that conditions under which clinical practices function (for example, time constraints, motivation and lack of training for healthcare providers) pose barriers for healthcare professionals to provide more holistic patient-centred care (119). Clinical circumstances have been shown to be increasingly challenging, making it easy for practitioners to solely consider evidence-based guidelines and to perceive patients in formulaic ways (132).

This narrow biomedical approach to treating the problem overlooks broader challenges of living with a chronic illness. The goal of many clinicians and patients is to enhance quality of life. Current approaches, however, struggle to achieve this for people living with severe asthma. Unsurprisingly, research suggests that there are unmet patient needs and there is a disconnect between what is suggested in policy, how it is translated into clinical practice and what people need in order to live well with their condition. To achieve truly patient-centered care, there is a

need to shift from the narrow focus of supporting patients to be ‘effective self-managers’ towards a broader and more holistic approach to support. This would incorporate the medical, emotional and psychosocial aspects of living with a chronic illness. Before recommendations can be made and interventions tested, there is a recognised need to understand the lived experiences of people living with a chronic illness, their perceived capabilities to self-manage and their wider social context.

## **Chapter 2: Theoretical Framework**

The previous chapter described the biomedical understanding of severe asthma, the management of this condition, and how this affects people living with it from a medical perspective. This chapter provides an understanding of key concepts such as health and well-being, couched in the theoretical world of behaviour and motivation. To throw a light on the lived experience in more depth, this chapter makes a philosophical shift towards examining the subjective experiences of health, illness and well-being and seeks to account for phenomena that are overlooked by the 'medical gaze'.

### **2.1 Health and well-being**

Health is "grounded in the experiences and concerns of everyday life...[and it] provides a means for personal and social evaluation" (133, p.60). The concept of health can be understood as a subjective as well as an objective experience. In other words, it has several dimensions and may be applied to different areas of life (134, 135). Health is not a condition that one feels in oneself, rather it is a condition of being present, involved, and engaged with people and everyday tasks (136). In the process of explaining health, people have dichotomised the term and defined it negatively or positively. When defined negatively, health tends to be described as an illness. Defined positively, health is the feeling of 'well-being' (137, 138). The idea of experiencing 'well-being' has been characterised as a common human goal that is valued and should be achieved. In the medical domain, 'well-being' has been proposed to be a common goal between healthcare providers and their patients, where healthcare aims to support patients for 'well-being' and patients aim to experience 'well-being'. Within the positivist paradigm, researchers have argued that for patients to experience 'well-being' in the face of living with an

illness they need to be motivated, engaged and self-disciplined (64, 133, 139). This builds on the medicalised idea that people living with an illness (such as a chronic condition) need to have a healthy lifestyle and learn how to self-manage, in order to experience ‘well-being’. Policy makers such as the WHO, have defined experiencing well-being and being healthy as a subjective concept - “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity” (140). Seligman, on the other hand, offered a philosophical description of the concept of well-being and suggested that people have ‘building blocks’ that need to ‘flourish’ to build well-being (141, 142). These building blocks consist of positive emotions, engagement, relationships, meaning and accomplishment (PERMA) (141).

## **2.2 Well-being and Theory**

Theories such as self-determination theory, self-efficacy theory and self-regulation theory (143), include the notion that perceived motivation and behaviours influence well-being. These theories share the same goal of understanding behavioural change. They differ, however, in their underpinnings of factors considered as driving forces to motivation and behavioural change (for example, perceived confidence, autonomy, competence and relatedness).

The term ‘motivation’ refers to what drives an individual to action or behaviour. Theories of motivation focus on what drives and sustain this drive to behavioural change for improved psychological well-being (68, 143, 144). Previous theories have generally treated the concept of motivation as a unitary entity. For example, in Bandura’s theory, the concept of self-efficacy is the central mechanism underlying motivated behaviours and being unmotivated is what results from a lack of self-efficacy (68). Self-determination theory (SDT) is different from the other approaches to motivation. Ryan and Deci suggested that “there are different types and

sources of motivation that impact on the quality of dynamics of behaviour” (145, p.14). Rather than seeing motivation as a unitary phenomenon, SDT suggests that motivation is reflected upon one’s own values, beliefs and goals. SDT posits that motivation is driven by achieving satisfaction of three basic psychological needs. SDT proposes that people’s values, beliefs and goals affect their needs, and ultimately their well-being.

### **2.3 Self-determination theory**

This section provides an overview of the six micro theories couched within the macro theory of SDT, but emphasis will be made of its micro theory (basic needs theory) as it underpins the data analysis conducted for this thesis.

Self-determination theory is a research-based psychological theory of motivation, personality and well-being (146). This theory was developed in the 1970s and 1980s by Professors Edward L. Deci and Richard M. Ryan’s work on intrinsic motivation (145, 147). From the perspective of SDT, people are optimally motivated and experience well-being when they satisfy the need for autonomy, competence and relatedness (145).

Over the past 20 years, a growing body of work has applied SDT in studies such as workplace motivation (148-150), healthcare (151, 152), physical activity (153), education (154) and leadership (155). Such work has examined and tested the efficacy of SDT framed interventions for diverse issues related to behavioural change, motivation and supporting autonomy. SDT consists of six inter-related micro theories (Figure 6): cognitive evaluation theory, organismic integration theory, causality orientation theory, basic needs theory, goal contents theory and relationship motivation theory.

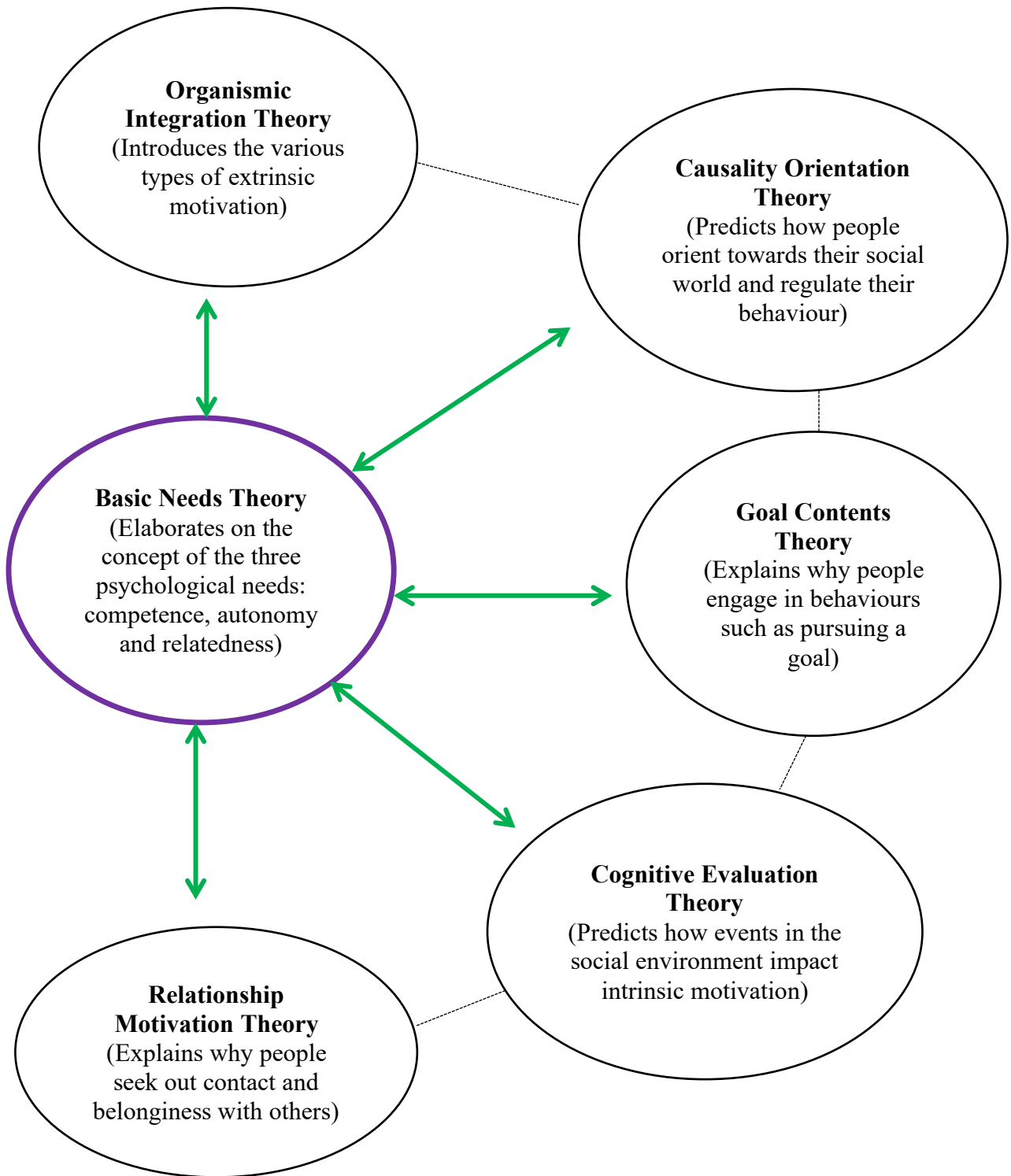


Figure 6. Conceptual diagram highlighting the six micro theories of self-determination theory and illustrating that central to this theory are people’s basic psychological needs (145, 147).



Taken as a whole, these micro theories examine the types of motivation and predict performance and well-being outcomes (147). Cognitive evaluation theory addresses the social and environmental factors that facilitate and undermine intrinsic motivation. Organismic integration theory focuses on the internalisation process of completing behaviours. In other words, people become more self-determined in engaging in behaviour if they start to internalise ownership and value the activity. Causality orientation theory addresses individual differences in people's tendencies toward self-determined behaviour. Goal contents theory differentiates between basic needs for well-being in terms of extrinsic (for example fame and fortune) and intrinsic (for example pursuit for well-being) goals. Relationship motivation theory proposes that people seek out contact and belongingness with others. Finally, at the heart of SDT is the postulate that people have three basic needs. Basic needs theory (BNT) describes these three psychological needs that Deci and Ryan (145, 147) argue are universal and vital for well-being.

The current literature utilising SDT in the health domain includes concepts of each of these micro theories and their use to design interventions to target patient self-management behaviour (151, 156). Research has shown that understanding patients' motivation may be associated with improved health outcomes (151, 156, 157). For example, a number of studies have focused on understanding how patients can be motivated to self-manage their diabetes more effectively (156, 158-160). Although these studies have shown positive features for understanding and influencing patient's motivation for health-related behaviours, no studies have sought to interrogate SDT in the context of people's personal experiences of living with a long-term condition. In other words, there is limited understanding of the relationship between living with a long-term debilitating and unpredictable condition and people's capacity to achieve basic

needs of autonomy, competence and relatedness, and how this influences their overall well-being.

### *2.3.1 Basic Psychological Needs (BPNs)*

Basic needs theory (BNT), argues that psychological and physical well-being are grounded on three basic psychological needs: competence, autonomy and relatedness. According to Deci and Ryan (143), when one or more of these needs is thwarted, there is a distinct cost to an individual's well-being.

#### *2.3.1.1 The need for autonomy*

Among the three basic needs postulated by SDT, the primary construct concerns the need for autonomy. According to Ng et al., (151) SDT is the only theory of motivation that identifies autonomy as a human need. Research has shown that most people value their autonomy rather than feeling controlled by someone (161), however, upon acquiring a chronic condition, one's personal autonomy may be challenged. In common usage and in some theories, the concept of autonomy overlaps with independence (162, 163). In contrast, SDT explicitly differentiates these concepts both theoretically and empirically (162, 164-166). According to Vansteenkiste et al., (154, 167) autonomy within SDT does not mean acting independently. Ryan and Deci define dependence as reliance on others for goods or guidance (145). Given this definition, people can choose to rely on others and thus be autonomously dependent or autonomously independent (145).

Autonomy is viewed as an intrinsic source of motivation to have control over one's life and behaviour. It refers to acting with a sense of volition, as opposed to being influenced by external

forces (168) and aligns with one's sense of identity (147, 169). Importantly, this refers to acting in accord with one's beliefs and values (169). The motivational effects of supporting an individuals' autonomy have been well documented, especially with regard to supporting self-management of a person living with a chronic illness (158).

### 2.3.1.2 The need for competence

Of the three basic needs postulated by SDT, the construct of competence is argued to be an important characteristic in motivational drive. Competence is defined as the need to master personally challenging tasks, or perceived capabilities to accomplish tasks or activities. White argues (170) it is also an individual's capacity to interact effectively with their environment. An important characteristic of the need for competence is personal effectance, or the need to effect change on the environment and attain valued outcomes or goals, which include the personal importance of the task. Research has shown that strengthening a patient's sense of competence improves self-management (171), satisfaction with patient-clinician goal setting, achievement and well-being (172, 173).

#### *2.3.1.2.1 Distinguishing the terms self-efficacy and competence*

Self-determination theory (145) and self-efficacy theory (68, 174) both include the concept of 'perceived capabilities' at a core level. The terms 'competence' and 'self-efficacy' are used interchangeably in the literature, however there are distinguishable characteristics which may give a better understanding of their roles in motivation and human behaviour. Self-efficacy is a key construct in social-cognitive theory. It does not address the outcome of successfully completing a behaviour or its impact on one's sense of self, only whether an individual can execute a behaviour given the circumstance (175). Ryan and Deci describe self-efficacy as a

“rather simplistic conceptualisation of agency” (169, p.257). They argue that psychological and physical well-being is grounded in the combined forces of competence, autonomy and relatedness (169).

#### 2.3.1.3 The need for relatedness

The third basic need is relatedness. SDT recognises the importance of relatedness in the human experience and provides an understanding of how interpersonal experiences and their dynamics can influence individuals’ thoughts, feelings, and behaviours (143, 147). Relatedness refers to people’s inherent 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 (147). Patients who report a sense of relatedness are more likely to be self-directed to carry out and master tasks involved in making health behaviour changes (143, 147). Ryan and Deci suggested that if the need for belongingness and connectedness with others is met, it promotes internalisation of the value of effective self-care (143). People experience relatedness most typically when they feel cared for, have a sense of belonging and significance among others. Deci and Ryan suggested that it is equally important that people experience themselves as giving or contributing to others (176).

## 2.4 Summary

There is evidence that taking a philosophical stance towards examining the subjective experiences of people living with severe asthma, could account for the experiences of living with and managing this condition that are overlooked by the ‘medical gaze’. In the clinical context, patient-centred approaches to supporting self-management tend to focus on narrow medical goals such as improving adherence. From a psychosocial perspective, current

approaches to supporting self-management are understood within the clinical context. This is problematic as it overlooks the broader set of emotional, psychological and social issues people face when living with a chronic illness. Clearly, a person's perceptions and experiences of living with a chronic illness are extremely important. Research has shown that personal, environmental and social factors, goals and values play a role in the way people with chronic illnesses manage and live with their condition.

Self-determination theory (SDT) argues that psychological and physical well-being are grounded in three basic psychological needs: competence, autonomy and relatedness. The current literature utilising SDT in the health domain has focused on designing interventions to target people's basic needs to enhance health behaviours (151). Although these studies show positive features for understanding and influencing patients' motivation for health-related behaviours, there is a lack of understanding about the highly nuanced and personal experiences of living with a long-term condition.

Health professionals tend to 'support self-management' in a clinical manner by focusing on setting medical regimens (177), such as changing self-care health behaviours and setting medical goals but as a result overlook patients' personal needs on an individual level. One explanation could be a lack of research evidence and focus on the patient's experience of living with a chronic illness. One way of examining closely these current gaps in our understanding of the lived experience of severe asthma is to apply SDT concepts of autonomy, competence and relatedness. In doing so, progress can be made towards understanding the psychological and social phenomena of severe asthma.

Drawing on the literature presented in Chapters 1 and 2, the following section provides an overview of the research aims and objectives to address the gaps described above.

## **Research aims and objectives**

The overall aim of this thesis is to investigate people's experiences of living with and managing severe asthma using a self-determination theory perspective. The outcomes of this research will be used to propose new understanding and interpretations of SDT and offer broader practice recommendations that enable people to manage and live well with their chronic condition.

To address this overall aim, five specific research objectives were established, as outlined below:

1. To conduct a systematic review examining the qualitative literature on people's experiences of living with and managing severe asthma. (Chapter 4)
2. To conduct a systematic review examining the qualitative literature on people's experiences of living with and managing a chronic illness using self-determination theory. (Chapter 5)
3. To explore the impact of living with and managing severe asthma on patients' autonomy. (Chapter 6)
4. To examine, among people living with severe asthma, the role of perceived competence in achieving their goals. (Chapter 7)
5. To examine the role of relatedness in patients' narratives about their experiences of living with and managing severe asthma. (Chapter 8)

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## **Part B: Methods**

## Overview of Part B

Part B outlines the research design for this thesis (Chapter 3). Chapter 3 explains the reasoning for using a qualitative interpretative approach for this doctoral work, describes the research design and details the methods of data collection and analysis. This section also covers ethical considerations and evidence of strategies used to ensure methodological rigour.

## Chapter 3 - Methods

### 3.1 Introduction

The terms methodology and methods are frequently used interchangeably yet should be thought of as two distinct concepts (1). Methods are techniques or procedures used for gathering data (2). Methodology, however, is defined as the way in which theory and epistemology are utilised in a study (3), or “the description, the explanation and the justification of methods, and not the methods themselves” (3, p.18). Methodology shapes and is shaped by research objectives and study design (4). According to Silverman, methodologies may be defined broadly and schematically (for example methodologies of qualitative and quantitative research) or narrowly and precisely (5). For example, in qualitative research, narrow methodologies include grounded theory approaches (6), narrative methodology (7, 8), various ethnographies (9, 10) and phenomenological approaches (11).

Quantitative researchers typically follow an epistemological approach of positivism. This approach seeks to quantify experiences of patients to present an objective scientific truth. It is based on the belief that there is a singular reality that can be discovered using experimental methods (12, 13). Traditionally, the psychological and medical model sit within the epistemological approach of positivism. Qualitative researchers, on the other hand, generally draw on the belief that there is no single reality and focus on understanding a research query using a humanistic or idealistic approach (12).

Qualitative research is particularly useful for identifying *how* and *why* events occur, *what* happens, *what* those events mean to the various “actors” involved (12, 14), and for understanding how power is subtly and implicitly distributed (15, 16). It can generate surprising

questions, insights and descriptions. It can also illuminate the unintended consequences of policy and practice on the human experience - what people care about, how they make decisions, what they are experiencing and how services and institutions can be improved (16).

Qualitative research has different paradigms from those that underpin quantitative research (12). The interpretive paradigm holds that individuals are different, and these differences are important to note. Interpretation is constructed according to an individual's beliefs, experiences, attitudes and values. This approach suggests that an individual's experience is influenced by their social setting. Knowing how people experience their condition and their social world helps explain their behaviours and decisions. In addition, the interpretive approach acknowledges that subjectivity applies to the researcher as well as to the participants (as outlined in Section 3.2.3).

In this thesis, the primary goal was to explore and understand the experiences of people living with severe asthma. The aim was to go beyond the objective description of the "essential concepts" of phenomena and to look for meanings embedded in these experiences (17, 18). These meanings are not necessarily readily apparent to the researcher (or indeed the participant) but are unveiled through the construction of narratives (18). Given the unexplored nature of this area of severe asthma research, coupled with a desire for an in-depth examination of this experience, qualitative enquiry and specifically, a study using an interpretative approach, was fitting.

The interpretative paradigm includes many methodologies, of which narrative inquiry is one. Narrative inquiry explores the experience of the individual and how their social, physical and cultural environment influence their experiences. This methodology is suitable for this doctoral work as it incorporates all dimensions that impact the individual's illness experience.

### *Narrative inquiry*

“Narratives offer a method for addressing existential qualities such as inner hurt, despair, hope, grief, and moral pain which frequently accompany, and may even constitute, people's illnesses” (19, p.48)

In the early 1980s, Arthur Kleinman introduced the term *illness narratives* (20). The use of illness narratives in medicine challenges the orthodox model of medical practice, which is orientated towards fixing health issues instead of supporting and treating the whole patient in their life context. This term provides a relatively new perspective in medicine that bridges the gap between physicians' and patients' outlook on the nature of living with an illness (20). To date, the use of illness narratives in qualitative research has become increasingly popular in understanding the subjective experiences of people living with a chronic illness (21).

Accounts of the subjective experiences of living with an illness have moved out of the private realm and into the common discourse (21). Narratives provide privileged insights into the patient's 'world of living with an illness', their subjective experiences, choices, actions and coping endeavours (21). Individuals recount in depth their encounters with the medical world, and offer a biographic and social context of the illness experience and describe their efforts to adapt living with the condition (21). This makes narratives valuable within a wide range of fields from medicine, to sociology and psychology.

Using an illness narrative approach (22) in this study will provide the opportunity for participants to describe what has happened to them since they first suspected a problem. Narrative interviews place the participants at the heart of the research and ask the *how*, *why* and *what* questions that are common in qualitative research. They provide an opportunity to



prioritise the story teller's perspective rather than imposing a more specific agenda (23). They help identify the participant's own concerns, meanings and priorities. For example, this study will address broad questions about the experience of living with severe asthma, rather than focusing on a more specific question such as 'side effects of taking medications'. Asking the broader question will nevertheless still provide insight into the issues about people's use of medicines, situated within each person's narrative (23).

Researchers using this technique do not set out with a fixed agenda, rather they let the interviewee control the direction, content and pace of the interview (23). It is the interviewees' account and they choose what to say and what not to say. This technique requires little-to-no interruption (24, 25) by encouraging participants through the use of non-verbal communication such as nodding and saying "hmmm", to narrate their experiences without further input or interruption beyond the initial question "Can you take me back to your first memory of having breathing problems?". It is not until this first part of the interview, which can last between a few minutes to nearly an hour, is ended by the participant that the interviewer can lead with further questions. Through active listening, the interviewer can use the participant's own language to fill in any gaps or to ask for more detail about an issue of interest. The interviewer can ask questions such as 'can you explain what you meant by...', 'can you say a bit more about...?' or 'how did that make you feel when...', rather than asking for opinions or even asking *why* questions (23).

### **3.2 Research methods**

This study was part of a larger project funded by the National Health and Medical Research Council (NHMRC) Centre of Research Excellence (CRE) in severe asthma. This thesis focuses

on one part of the CRE remit: examining the experiences of living with and managing severe asthma. The objectives of this part of the project were to 1) incorporate a 'living with severe asthma' section in the CRE in severe asthma toolkit for healthcare providers, 2) to develop an online, publicly available severe asthma online resource for the Database of Individual Patient Experiences (DIPEX) website (<https://healthtalkaustralia.org>), and 3) investigate people's experiences of living with and managing severe asthma using a self-determination theory perspective (Appendix 7). The DIPEX method was adopted for data collection; all other aspects of the research were underpinned by self-determination theory.

### *3.2.1 Database of Individual Patient Experiences (DIPEX) method*

For the purpose of this doctoral work, the DIPEX method for data collection was followed. The original idea for DIPEX came from Dr. Ann McPherson, an Oxford GP and Dr. Andrew Herxheimer, a clinical pharmacologist. Having experienced their own health challenges, both found that they wanted to know more about the experiences of others living with the same condition (26, 27). The DIPEX method was developed in the University of Oxford by the Health Experiences Research Group (HERG) that had interest in people's experiences of health and illness (28).

HERG has an international reputation as a centre of excellence in qualitative research. It is comprised of academic partners who bring considerable breadth and depth of perspective, skill and academic experience to the research. DIPEX projects are led by senior scientists covering a range of disciplines in the health sciences including sociology, psychology, anthropology, medicine and health services research (29). Currently, fourteen countries (United Kingdom, United States of America, Switzerland, Spain, Norway, Netherlands, Republic of Korea, Japan,

Israel, Germany, Czech Republic, Canada, Brazil and Australia), have adopted this method and have formed a consortium- 'DIPEX International' ([www.dipexinternational.org](http://www.dipexinternational.org)).

The research conducted using this method is available to the general public through the country members' and the DIPEX International websites ([www.dipexinternational.org](http://www.dipexinternational.org)). Each DIPEX module contains approximately 250 video, audio and written excerpts from the in-depth interviews. These excerpts illustrate the 20-25 topic summaries of the main themes emerging from the interviews.

### *3.2.2 Data collection*

The DIPEX method required three steps for collecting data: 1) preparation and recruitment 2) sampling and 3) the interview (pre and post), all of which were followed for this doctoral work.

#### *3.2.2.1 Preparation and recruitment*

The preparation phase requires establishing an expert advisory panel, training the interviewer on how to conduct in-depth interviews, seeking ethics approval, organising the paperwork, purchasing all the appropriate equipment, and recruiting and contacting participants.

In early 2016, the interviewer (DE) received fortnightly training with experienced qualitative researchers Professors Lorraine Smith and Kath Ryan, both members of DIPEX. During this time, an expert advisory committee in severe asthma was also established; which consisted of a consumer representative, a participant living with severe asthma, respiratory physicians, pharmacists and an experienced qualitative researcher. The panels' role included providing advice, assistance in recruitment, identifying gaps in the sample and giving feedback on topic summaries.

Recruitment was conducted through respiratory physicians and general practitioners in private practices and hospital clinics. Respiratory specialist assessment was required to exclude modifiable problems such as misdiagnosis, poor inhaler technique and non-adherence (30). Recruiters were asked to provide potential participants with an information pack, which included the participant information sheet, summary information leaflet, consent form, withdrawal of consent form, a reply form, a prepaid envelope and contact email and phone numbers of the researcher (Appendix 3.3). Respiratory physicians and general practitioners were also given a one-page document with key points to refer to when raising this study with their patients (Appendix 3.2). An advertisement was also placed in the Australian College of Rural and Remote Medicine (Appendix 3.1), inviting GPs in rural or remote areas to assist with recruitment. The advertisement included the definition of severe asthma as part of the inclusion criteria.

Willing participants made direct contact with the interviewer to discuss the project further. The names and contact details of participants were obtained from the reply forms sent to the researcher in prepaid envelopes, or by telephone or email contact from interested participants. The researcher then contacted the potential participant by phone or email to answer any questions.

Prior to each interview, the researcher had to check the equipment required for the interview. This included: a charged digital camera, audio recorder (for back up recording), participant details and consent forms, and \$50 gift vouchers.

### 3.2.2.2 Sampling

The interviews included in this study were collected between October 2016 and April 2019. A maximum variation sample of 38 participants was recruited from different settings across Australia (Appendix 4). Respiratory physicians and general practitioners were contacted by the researchers to ensure that participants from different ethnicities, geographical locations and sociodemographic backgrounds were included in the study. Participants represented various ages, gender, ethnic or cultural backgrounds, educational levels, and geographic locations. Efforts were made to include people from all backgrounds, including hard to reach populations, and people at different stages of illness. The aim was to represent a wide range of experiences rather than a numerical representation of the population (31). Recruitment continued until ‘data saturation’ was achieved, that is until no new codes emerged, to ensure the widest possible range of experiences were included. Participants were included if they were over 18 years old, diagnosed with severe asthma by a specialist respiratory physician, and could speak either French, Arabic or English (the doctoral researcher is fluent in all three).

### 3.2.2.3 Study setting

The researcher visited participants’ homes or other suitable locations such as their place of work, or a convenient location of their choice. Most of the interviews took place in the home setting. Alternative locations for three of the interviews included a private meeting room in a library.

#### 3.2.2.4 Interviews

The researcher conducted semi-structured interviews using an illness narrative approach to explore the meaning of people's experiences of severe asthma. One-to-one interviews were chosen because they are the best way to allow participants to express their experiences (32). Individual interviews were preferred over focus groups as they retain the essence of unique accounts (33).

Semi-structured interviews were used to elicit in-depth responses covering values, beliefs and opinion from the interviewees' experiences (34). A strength of this data collection was that using a semi-structured interview format was a fairly open framework which enabled specific topics to be covered yet provides scope for additional questions and topics to be further explored. Interview data were analysed and presented in Chapters 6-8. The interviews were audio and/or video recorded.

##### *Pre-Interview*

Before the interview the interviewer (DE) ensured that the participant had read and understood the participant information statement. The consent process was explained, and they were asked to read and sign two consent forms (one for the interviewer and the other for the participant to keep). If family members or friends were present at the interview and spoke, they were also required to sign a consent and copyright form<sup>1</sup>.

##### *During the Interview*

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<sup>1</sup> A signed copyright form gives permission to use agreed material from the interview. If copyright is given the interview can be used for broadcasting, research and teaching. Participants were encouraged to discuss this with members of their family prior to signing this form.

Interview topics were initially defined from a systematic review of the literature (35) but later modified as new themes emerged. During later stages of data collection, the constant comparison method of analysis was applied to continuously compare the experiences of participants, and subsequent revision of the coding template (36, 37). Follow-up open-ended questions and prompts were used to further explore participants' experiences. Narrative interviewing involved asking broad open-ended questions to make sense of events and experiences. The interview began broadly to understand the issues that were most significant for people. To minimise research bias, the researcher (DE) used 'member checking' (38) which involved restating and summarising key statements made by the participants to verify the accuracy of the researcher's understanding. The questions asked during the interview are included in Appendix 3.5.

#### *Post-interview*

For the purposes of the online module on severe asthma, after the interview participants were invited to look at a segment of the film on the camera. The participant had the choice to receive a copy of the transcript and/or video in order to consider whether or not to remove any part of it. They were also shown the copyright form with the option to sign immediately or after receiving a copy of the transcript. The participant was informed of their right to remove sections once they looked at the transcript and/or the video even after they had signed the copyright form. At the end of the interview participants were given a \$50 gift voucher as a token of appreciation for their time and involvement in the study. Details regarding the number of participants agreement to video and/or audio recording and transcript amendments can be found in Appendix 3.6.

Once the interview finished and all equipment was packed up, the researcher wrote field notes about anything that happened during the interview. This included any questions the participants had or if they had any special requests or how they felt during the interview. Field notes were also written about the context of the interview and issues that the researcher wanted to bring up in later interviews. The audio recordings were then transcribed verbatim and sent to the participant for feedback.

#### 3.2.2.5 Ethical consideration

The research protocol was approved by the University of Sydney Human Ethics Committee (HREC 2015/934). It was made clear to participants both in writing and during discussion with the researcher and/or recruiter handing them the information pack, that any decision on whether or not they decide to participate in this study would not be shared with their physician and would not affect their relationship with their healthcare provider. This relationship would also not be affected should they choose to withdraw from the project at any point in time.

Given the focus of the interview, it was possible that participants could become distressed or upset. This is not uncommon in qualitative research and most of the time is addressed by an experienced interviewer. The interviewer offered breaks and reminded the participant that they could stop or withdraw, as outlined in the participant information sheet. The interviewer did not leave the participants alone and offered to contact a family member or carer and provide contact details for professional support if they were distressed at the end of the interview. The interviewer phoned the participant the next day to see how they were.

Permission was obtained for the interviews to be audio and/or video recorded and transcribed. To protect the anonymity of the participants, participants were offered the opportunity to adopt



a pseudonym. Electronic data files were stored on a password protected computer and all recordings, transcripts and field notes were stored in a locked cabinet in the researcher's office. They will remain so for a period of seven years following completion of the study. At the end of this period recordings will be erased and transcripts disposed of by shredding in accordance with the University Human Ethics Committee requirements.

#### 3.2.2.6 Safety protocol for the researcher

A safety protocol was developed to ensure researcher safety while visiting the participants' homes. This included:

1. Providing Professor Lorraine Smith (supervisor) and/or Professor Helen Reddel (associate supervisor) with a list of scheduled visits including the address, date and time of each visit.
2. Phoning and/or sending a text message to the supervisor/associate supervisor when the visit was complete.
3. A verbal de-brief over the phone with either Professors Lorraine Smith or Helen Reddel following the interviews.

#### 3.2.3 Reflexivity

Reflexivity is critical to qualitative research as it enhances the quality and credibility of research through the continuous ability to recognise how the researcher's position and interest affect all stages of the research process (1, 39, 40). In narrative inquiry, reflexivity enhances trustworthiness of the data by retaining the insider's perspective. The interviewer recognises that interpretation of the material is inevitably affected by their own values, beliefs, experiences

and biases that they may bring to the study (39, 41). The interviewer (DE) is a registered pharmacist. She was trained by experienced qualitative researchers (LS and KR) to conduct the interviews. To counter these potential biases data analysis was first carried out by DE and then independently checked by three other experienced researchers (LS, HR and KR).

### 3.2.3.1 Reflection as the researcher

“Research touches ill people. Qualitative researchers pride themselves on their personal encounter with ill people. Remember, how you touch them affects their healing, and your own healing too.” (Arthur Frank) (42, p.361)

As a pharmacist, with experience in caring for patients with asthma, I’ve had to reflect on how to conduct in-depth interviews. Bourdieu wrote about the problems in conducting interviews with people about their experiences (43). He argued that two problems may occur; firstly, participants enter a “discourse of familiarity” (43) and leave part of their account unsaid as they assume this is known knowledge. Secondly, participants engage in an “outside-orientated discourse” and may generalise, leaving out specific details of events (43). As the interviewer and a pharmacist, I tried to minimise these effects and the potential loss of important issues due to being ‘familiar’ in asthma. I attempted to “make the familiar strange” (44) and put my clinical knowledge aside, by using more open-ended questions and exploring responses in depth especially if the participant assumed shared knowledge.

After each interview, I wrote my field notes and reflected on my position during the interview. Participants were unaware of my profession unless they asked at the end of the interview. Self-disclosure has been reported by a few qualitative researchers as ‘good practice’ and as a method to ‘enhance rapport and show respect for their participants’ (45, 46). After the interview, if the

participant asked specific clinical questions on their condition, I suggested they discuss this with their specialist(s) or general practitioner as it was not my place to make any clinical recommendations.

After each interview, I would pack up my gear once I felt that both the participant and I were comfortable for me to leave. On two occasions, participants described contemplating suicide. In these situations, I vividly remember the moments they contemplated suicide and thought - do I stop their narrations and express my concern, or should I just listen? I decided to listen to their story and ask more questions. After the interview, I sat in the car and thought did I want to stop the interview because I felt it was my 'duty of care' or was it because I personally felt uncomfortable? Did I make the right decision?

At the end of the interview, I expressed my concern about their thoughts and asked their permission to discuss this further with my supervisor with the possible view of contacting their doctor or a close family member. Both participants agreed that I could contact their partners. After each interview, I would contact my supervisor and discuss my feelings and what, if any, actions I should take in order to ensure appropriate duty of care. My reflections of their experiences gave me further insight into the distress that living with severe asthma had caused them. I became increasingly interested in the meaning that others ascribe to their experiences of living with severe asthma and the psychological burden. On further investigation, I found there was limited advice and support available for people who go through the experience of living with severe asthma, particularly for their psychological wellbeing.

### *3.2.4 Data analysis*

Qualitative research engages in a variety of theoretical platforms and techniques. This relies on the assumption that meaning is not inherent in data and must be interpreted by the researcher. This resonates with the interpretivist approach that there is no one truth and that multiple realities are produced (47).

Data analysis was conducted using a hybrid method of thematic analysis, incorporating both data-driven inductive and SDT-informed deductive approaches (48-50). Thematic analysis is a widely used qualitative analytic method, within and beyond psychology (51-53). It is a method used for identifying, analysing and describing the data in rich detail. However, due to the lack of transparency on reporting the process and detail of analysis, and the disagreements about what thematic analysis is and how it should be used, it has been critiqued by researchers as having an absence of clear and concise guidelines, and as poorly demarcated (53).

In order to ensure rigorous research is conducted, qualitative researchers need to be clear about what they are doing, why, and include how they report their analysis (54). Thus, a clear 6-step framework by Braun and Clarke was followed (53) to ensure that the thematic analysis was theoretically and methodologically sound. It offers a clear and useable framework for doing thematic analysis (summarised in Table 2). All authors were involved throughout the coding and analysis process. The qualitative analysis undertaken was then reviewed by researchers with experience in qualitative research (LS, HR, DE, KR) and in the clinical aspects of severe asthma (HR).

To conduct thematic analysis, coding and categorisation of the data were required from discerned themes (34, 53). Data analysis was iterative and conducted alongside data collection

(55).The process of data analysis required long periods of research immersion, re-listening to transcripts, coding, categorisation and identification of themes. This process began with the collection from the first few interviews, field notes and discussion with supervisors (34) and continued as new transcripts were added to the data set.

Data were coded manually using NVivo, qualitative data management software. To ensure that the analysis was conducted rigorously, the researcher met frequently with the supervisors and another experienced qualitative researcher (KR) during the analysis to compare and/or challenge coding frameworks and interpretations. Categories were created from the coded data, and from these themes were discerned to provide an interpretation of the data and answer the study research questions. Thematic analysis moves beyond descriptive analysis by linking categories of data, until eventually an explanation is established which interprets the patterns emerging from the descriptive level (53).

Chapters 4-8 contain detailed descriptions of data analysis specific to their respective study aims.

Table 2: Phases of thematic analysis adopted by Braun and Clarke (53)

<b>Phase</b>	<b>Description of Process</b>
1. Data familiarisation	Audio and/or video recordings were transcribed verbatim and proofread (DE). After each interview, the researcher (DE) wrote field notes on her observations and reflections.
2. Generating initial codes	The transcripts were coded using NVivo software and were read by three members of the research team (DE, LS and KR). The SDT constructs of autonomy, competence and relatedness informed the development of template codes as a means of organizing the text for subsequent interpretation. During later stages of data collection, the constant comparison method of analysis was applied to continuously compare the views and experiences of participants, and subsequent revision of the coding template.
3. Searching for patterns (categories)	Excerpts from each code were re-read (DE) and codes were collated into potentiation categories, using mind-maps.
4. Reviewing patterns (categories)	Three supervisors checked the categories (LS, HR and KR). Themes were then developed by DE and LS. This required stepping into more complex territory whereby themes were discerned from the conceptual codes as well as from relationships between the codes.
5. Defining and describing themes	On-going analysis was performed to refine the overall narrative of the analysis (DE, LS). The interpretive analysis was then reviewed by researchers with experience in qualitative research (LS, KR and HR) and in the clinical aspects of severe asthma (HR).
6. Producing the report	Five final written articles and a thesis were produced

## Summary

This chapter addressed the theoretical and procedural aspects of the research process. It began with an explanation of taking an interpretive approach. It justified the research, sampling, and methods of data collection (DIPEX method) and analysis (thematically). Figure 7 summarises these steps. The chapter concluded with an outline of ethical considerations and actions taken regarding protection of participants and the researcher.

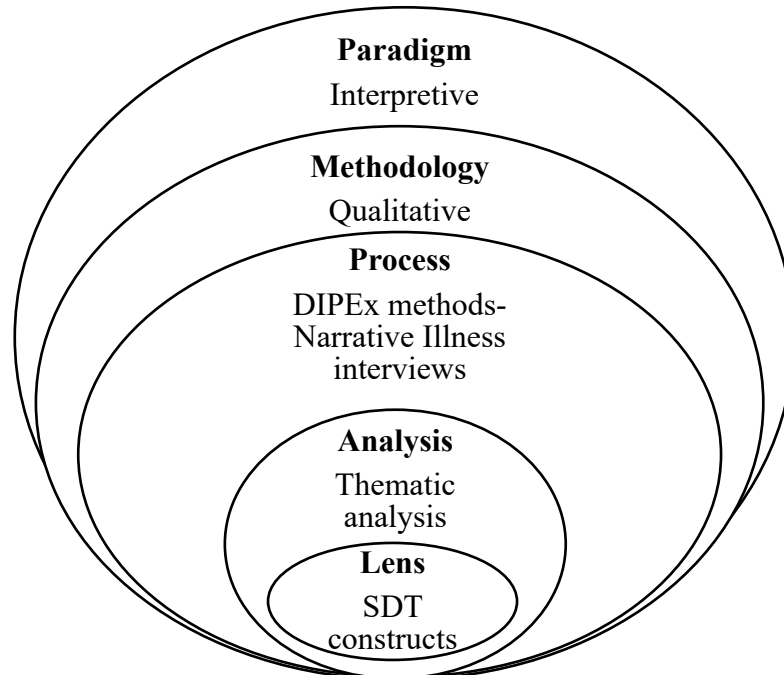


Figure 7. Schematic diagram illustrating the methodology and methods chosen for this doctoral work.

The following chapters will first present two systematic reviews: the first review will examine the literature of people living with severe asthma (Chapter 4) and the second, will explore the qualitative studies underpinned by self-determination theory that examined patients' perspectives of living with a chronic illness (Chapter 5). These systematic reviews will be followed by the findings of the interviews conducted for this doctoral research (Chapters 6, 7 and 8).

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# **Part C: Findings**

# Overview of Part C

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Part C contains the two systematic reviews and the studies exploring people's experiences of living with and managing severe asthma, drawing on the self-determination theory (SDT) constructs autonomy, competence and relatedness. This is divided into Chapters 4, 5, 6, 7 and 8 respectively.

The systematic review in Chapter 4 reviews the literature about people's experiences of living with severe asthma. There is little literature exploring these experiences from a non-medical perspective. Our synthesis revealed that what was important to people living with severe asthma was striving to achieve a greater level of personal control over their condition but these efforts received little support from their healthcare providers. Therefore, in Chapter 4 it is argued that more attention should be paid to understanding the self-management strategies and personal goals of people living with severe asthma. This review informed Chapters 6, 7 and 8 of the study.

Chapter 5 is a review of the qualitative literature drawing on SDT as a framework to explain people's experiences of living with a chronic illness. This review highlighted that there are no qualitative studies which explored in depth the three basic psychological needs (autonomy, relatedness, competence) from the patient's perspective.

Chapters 6, 7 and 8 include the findings from the studies exploring people's experiences of living with and managing severe asthma. These studies are underpinned by SDT constructs autonomy, competence and relatedness.

## **Chapter 4: A systematic review of people's experiences of living with severe asthma**

Part A presented the background information on the key biomedical concepts relating to severe asthma and self-management.

As part of the review of literature for this thesis, and to fulfil research objective 1, this current chapter comprises a systematic review to explore people's experiences of living with severe asthma. This review, the first of its kind in the field of severe asthma, identified a paucity of research exploring the patient's lived experiences of severe asthma, and a focus on clinical rather than personal issues. The synthesis revealed that what was important to people living with severe asthma was striving to achieve a greater level of personal control over their condition, through dealing with symptoms and treatment, acquiring knowledge, making decisions and reclaiming identity. These efforts, however, received little support from their healthcare providers.

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This chapter also contains an update to the systematic review of people's experiences of living with severe asthma.



## **Authorship statement**

The co-authors of the paper “‘...I've said I wish I was dead, you'd be better off without me’: A systematic review of people's experiences of living with severe asthma” confirm that Daniela Eassey has made the following contributions:

- Conception, design and implementation of the research
- Collection and extraction of data
- Analysis and interpretation of the findings
- Drafting and revising of the manuscript and critical appraisal of the content

As the primary supervisor for the candidature upon which this thesis is based, I can confirm that the above research attribution statement is correct.

Professor Lorraine Smith

The University of Sydney

11 October 2019



## “...I've said I wish I was dead, you'd be better off without me”: A systematic review of people's experiences of living with severe asthma

Daniela Eassey, Helen K. Reddel, Juliet M. Foster, Susan Kirkpatrick, Louise Locock, Kath Ryan & Lorraine Smith

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## “...I’ve said I wish I was dead, you’d be better off without me”: A systematic review of people’s experiences of living with severe asthma

Daniela Eassey, BPharm (Hons)<sup>a</sup>, Helen K. Reddel, MBBS, PhD<sup>b</sup>, Juliet M. Foster, BSc, PhD<sup>b</sup>, Susan Kirkpatrick, BSc (Hons), MA<sup>c</sup>, Louise Locock, MA, MPhil, PhD<sup>d</sup>, Kath Ryan, BPharm, PhD<sup>e</sup>, and Lorraine Smith, BA (Hons), PhD<sup>a</sup>

<sup>a</sup>Faculty of Pharmacy, University of Sydney, Sydney, NSW, Australia; <sup>b</sup>Woolcock Institute of Medical Research, Clinical Management Group, University of Sydney, Sydney, NSW, Australia; <sup>c</sup>Health Experiences Research Group, Nuffield Department of Primary Care Health Science, University of Oxford, Oxford, UK; <sup>d</sup>Health Services Research Unit, University of Aberdeen, UK; <sup>e</sup>School of Pharmacy, University of Reading, Reading, UK

### ABSTRACT

**Objective:** Our aim was to conduct a systematic review and synthesis of qualitative evidence exploring the lived experience of adults with severe asthma. **Data sources:** We searched MEDLINE via OvidSP, PsycINFO via OvidSP, PubMed, CINAHL, EMBASE, Sociological Abstracts, Google Scholar, the journals Qualitative Health Research and Qualitative Research, and a study of experiences of living with asthma by the Health Experiences Research group. **Study selections:** Studies were included if they used qualitative methods and explored the subjective experiences of adults ( $\geq 18$  years) with a clear diagnosis of severe asthma. **Results:** From 575 identified studies, five met the inclusion criteria. Synthesis revealed an overarching theme of efforts that people living with severe asthma engage in to achieve personal control over their condition. Individuals ‘strive for autonomy’ through dealing with symptoms and treatment, acquiring knowledge, making decisions and reclaiming identity. **Conclusion:** This systematic review found a paucity of qualitative studies reporting on people’s perspectives of living with severe asthma, and a focus on clinical rather than personal issues. Our synthesis reveals that severe asthma was disempowering, and a threat to identity and life roles. What was important to people living with severe asthma was striving to achieve a greater level of personal control over their condition, but these efforts received little support from their healthcare providers. Thus, more attention should be paid to understanding the self-management strategies and personal goals of people living with severe asthma. This may assist in designing interventions to better support patient self-management and improve health outcomes.

### ARTICLE HISTORY

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### KEYWORDS

Severe asthma; adults; lived experience; qualitative synthesis; systematic review

## Introduction

Asthma is a heterogeneous condition, usually characterized by chronic airway inflammation, that affects people of all ages (1). It is estimated that over 300 million individuals in the world have asthma and this will increase to more than 400 million by 2020 (1–3). Asthma severity, which can range from mild to severe, is based on the level of treatment required to control symptoms and prevent exacerbations. In the last 15 years, the term ‘severe asthma’ has evolved, with clinical guidelines published in 2014 (4) formalizing the definition as asthma for which good control is achieved only with high-dose inhaled corticosteroids and a second controller medication and/or oral corticosteroids (OCS), or when asthma remains uncontrolled despite this therapy (4). Making the diagnosis of severe asthma includes treating comorbidities and excluding modifiable contributors to uncontrolled asthma such as poor adherence and incorrect inhaler technique (5). It is estimated that 3–10% of the asthma population have

severe asthma (4,6); these patients have higher morbidity rates, and require more healthcare resources than patients with mild to moderate asthma (7–10).

To date, the vast majority of studies on severe asthma have focused on its definition (4), pathophysiology (11), and treatment options (5,12). While this clinical research into severe asthma indicates that patients commonly have frequent symptoms and exacerbations, have comorbidities such as obesity or rhinosinusitis, and experience side-effects of treatment – particularly with oral corticosteroids (13,14), there is little understanding of *how* these factors affect people with severe asthma, and *what* can be done to help improve their quality of life. Our aim therefore was to conduct a systematic review using qualitative evidence to answer the research question “What is the lived experience of adults with severe asthma?” We aimed to synthesis qualitative research studies to generate new insights and understandings of the existent empirical work (15).

## Methods

The review protocol and study extraction are reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA).

### Search strategy

A systematic literature search was conducted from inception to July 2017 in the electronic databases MEDLINE via OvidSP, PsycINFO via OvidSP, PubMed, CINAHL, EMBASE and Sociological Abstracts. We also searched Google Scholar, the journals *Qualitative Health Research* and *Qualitative Research*, and a study of experiences of living with asthma by the Health Experiences Research group (16), and screened reference lists of relevant studies. The search strategy is provided in Appendix A.

### Selection criteria

Studies were included if they used qualitative methods and explored the subjective experiences of adults ( $\geq 18$  years) with a clear diagnosis of severe asthma; for the purpose of this review, we defined severe asthma according to international guidelines published in 2014 (4). Articles were excluded if they: 1) were not in the English language, due to the absence of resources for translation; 2) did not address the personal experiences of living with severe asthma; 3) were observational, epidemiological or non-primary research articles (such as reviews and commentaries); and/or 4) involved study participants pre-selected through enrolment in another study with more specific inclusion criteria.

Two reviewers independently screened titles and abstracts of all identified references. Potential relevant studies underwent full text analysis. Disagreements were resolved by discussions with two other independent reviewers (LS and HKR).

### Data extraction and synthesis

A systematic and iterative process was used to derive main concepts across the included studies from the initial coding stage through to the final synthesis of overarching themes. Patient quotes and the original authors' analytic interpretation of the qualitative findings were extracted verbatim, and became the raw data for the synthesis. Codes were initially generated from the text inductively to capture the meaning of the participants' perspectives and the authors' interpretations.

Analysis and synthesis of the data were conducted by drawing on elements of the meta-ethnographic method (17) and using a comparative thematic analysis

approach (18). Meta-ethnography is a well-developed method increasingly used within healthcare research (Appendix B) (19).

## Results

The initial search identified 575 studies. Thirty-one had investigated people's experiences of living with asthma, but 26 of these were not in severe asthma and are the subject of a separate review (20). Five studies therefore were included in the qualitative synthesis (Figure 1). Table 1 provides a summary of the included studies. Three studies were published in the last decade (21–24), four in the UK (22–25) and one in Canada (21). They included between 2–23 participants with severe asthma. All studies had a considerably higher proportion of female than male participants, consistent with the community prevalence of asthma and severe asthma amongst adults (8). The included studies reported experiences on the burden of disease ( $n = 2$ ) (22,24), burden of treatment ( $n = 3$ ) (22–24), relationships with healthcare providers (HCPs) ( $n = 2$ ) (24,25) and self-management ( $n = 1$ ) (21).

### Synthesis of findings: Individuals with severe asthma are striving for autonomy

Our synthesis of the qualitative literature showed that, in the context of the substantial challenges of living with severe asthma, patients endeavor to obtain 'power' over their condition. Living with severe asthma has the potential to strip away an individual's self-worth, confidence, and sense of autonomy and it was apparent that patients were '*striving for autonomy*' by their attempts to regain self-control and self-worth through seeking ways to understand and manage their condition.

Our analysis revealed four inter-related subthemes (Figure 2) which described people with severe asthma as 'Striving for autonomy' through 1) 'Dealing with symptoms and treatment' 2) 'Acquiring knowledge' 3) 'Making decisions' and 4) 'Reclaiming identity'. Italicized text between quotation marks below show extracts of participants' quotes from studies included in the synthesis (additional quotes are available in Appendix C).

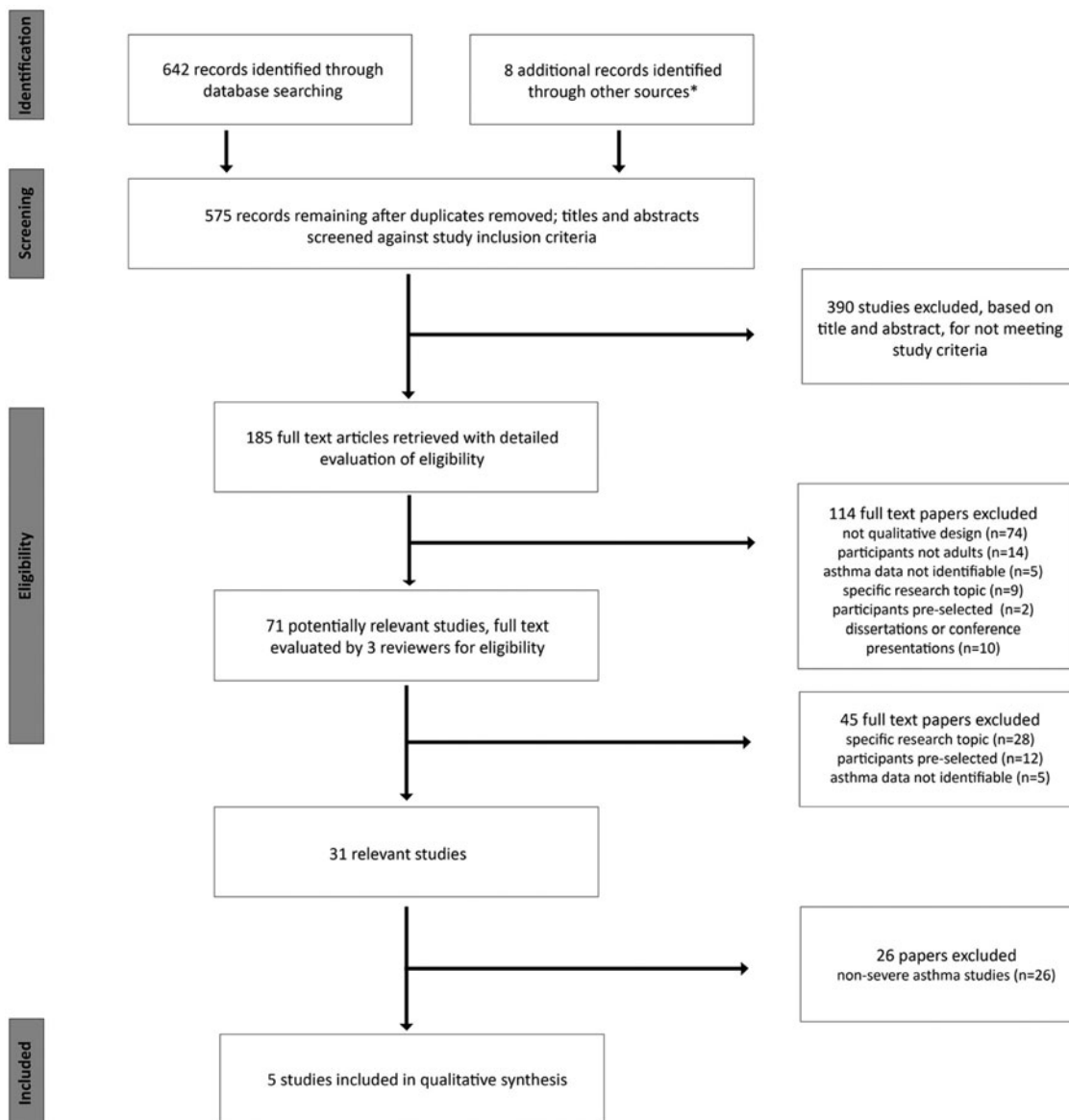
#### *Striving for autonomy through dealing with symptoms and treatment*

This sub theme describes how participants '*cope*' (23–25) with and '*adapt*' (21) to severe asthma and severe asthma treatments "*to gain control and power over their condition*" (23). Participants sought to combat the sense of loss of control that resulted from having severe asthma, through learning how to manage their condition. One participant

**Table 1.** Details of included studies: aims, definitions of severe asthma, sample characteristics and methods.

Study Details (Author, Year)	Sample characteristics			Aims	Definition of severe asthma	Design Framework/Method
	Diagnosed with severe asthma (total sample size) <sup>1</sup>	Age range	Female, number of those with severe asthma			
Moffat et al., 2006 (25)*	3 (14)	Not given	Not stated (8/14 of whole sample)	Experiences during primary care asthma consultations.	Considered by GP to have severe and/or difficult asthma, and taking Step 4 or above of the British Thoracic Society/Scottish Intercollegiate Guidelines Network treatment guidelines	Grounded theory approach/ semi-structured interviews (audio recorded)
Gamble et al., 2007 (23)	10 (10)	25–58	7/10	Practices associated with taking corticosteroids, decision-making processes, and adherence.	Asthma remained difficult to control with prominent breakthrough symptoms and frequent exacerbations, despite treatment with high dose maintenance inhaled therapy; at least one exacerbation requiring oral corticosteroids in the previous 12 months	Phenomenological/non-structured interviews (audio recorded)
Ross et al., 2010 (21)	8 (8)	23–53	6/8	Perceptions about self-management.	Severity classification by an asthma specialist based on American Thoracic Society/European Respiratory Society Task Force; all participants had received intense subspecialist assessment and optimization within the context of an asthma clinic for a minimum of 6 months, and had received asthma education from a certified asthma educator or an asthma specialist	Semi-structured interviews (audio recorded)
Hyland et al., 2015 (22)	23 (23)	28–70	19/23	1)Burden of asthma and its treatment 2) Items in existing asthma scales and whether they provide a valid assessment of the patient experience	Definition not clearly stated, but participants were recruited from a specialist severe asthma clinic to which patients were referred if their asthma remained uncontrolled despite high levels of preventative (primarily inhaler) medication.	Open-ended interviews (audio recorded) and use of asthma assessment scales
Health Experience Research Group (2015) UK (24)	2 (37)	16–73 (34 and 60)	2/2	Explore people's experiences of health, illness and healthcare.	Definition not provided in online resource; two participants Jenny (26) and Jane-Z (27) were identified by authors (HKR and DE) as having severe asthma, based on details about asthma symptoms, specialist assessment, and medications.	In-depth, semi-structured interviews (video recorded).

\*Where materials published online reported data and quotes from a mixed severe and non-severe population, two authors (DE and HKR) identified the comments and quotes from participants who appeared to satisfy current guidelines criteria for severe asthma(4).



\* Healthtalk.org webpages for 2 patients with severe asthma included as one record

**Figure 1.** Flow of information through the different phases of the systematic review (based on PRISMA reporting flowchart).

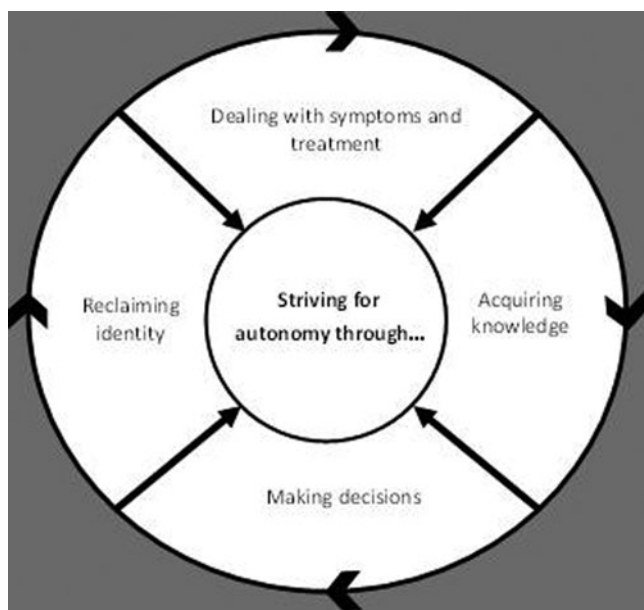
reported: “for me, asthma is a huge part of my life it impacts on everything... you learn to deal with the condition when it does kick off...” (26). Participants reported emotional distress associated with the side effects of oral corticosteroids; adapting their routines to accomplish daily activities; coping with debilitating symptoms; and managing their triggers.

### **Emotional burden associated with side effects of treatment**

The authors of included papers reported that most interviewees were taking daily inhaled corticosteroids plus

short courses of oral corticosteroids when their asthma became worse (21,23,27), with some interviewees taking oral corticosteroids every day (22,25,26). The burden of oral corticosteroids was mentioned in all studies and appeared to be one of the most challenging aspects of living with severe asthma (21–25). Interviewees described troublesome side-effects of oral corticosteroids including *weight gain*, *‘puffy face’*, *‘blood pressure drops’*, and feeling *‘hyper’*, as well as serious adverse effects such as osteoporosis and cataract. They reported particular difficulty coping with the psychological effects of oral corticosteroids such as anxiety, irritability and depression (22,23) which are well-recognized in the medical literature.





**Figure 2.** Conceptual diagram of the overarching theme and sub-themes synthesised in this review, from studies that explored patients' experiences of living with severe asthma.

### **Adapting to taking medications**

Participants reported that to accomplish taking their medications, they would plan their day and/or establish routines. For one this meant: "... keep[ing] them in the kitchen, beside the coffee, basically that's where it works best for me ..." (23). Another participant reported that having a routine meant "having more of a life" which helped her "become more normal" (26). Some had not fully adapted to medication-taking, for example, one participant reported: "I think it's an awful kind of weakness on somebody if they need an inhaler" (23).

### **Coping with symptoms**

Participants often linked coping with symptoms and achieving control over severe asthma with being able to accomplish desired activities. For example one participant reported that: "asthma control means to me that I would be able to complete activities, any kind of activities without having a bout of asthma ... of shortness of breath" (21). Interestingly, few participant quotes (or comments from study authors) were found about specific physical symptoms of asthma; one example was "... I get puffed and short of breath and then I go blue ..." (26).

Hyland et al., (22) highlighted that participants felt 'panic' and 'fear' in response to the unpredictable nature of their asthma, with some participants reporting avoiding any activities or situations that might trigger asthma symptoms.

### **Managing triggers**

Interviewees reported learning what their triggers were, and that they viewed asthma management as not only taking medications, but also avoiding triggers (21). Triggers mentioned were: household pets, cleaning products (26), "stress ... [and] anxiety" (26), and, for one woman, worsening asthma during menstruation (27). Participants reported avoiding triggers, for example, by not visiting family, by removing or reducing the pets in their home (21), or by controlling the home environment to be able to keep their pets "... I told her we are not getting rid of the dogs ... so we bought three air purifiers ..." (21).

### **Striving for autonomy through acquiring knowledge**

Participants described seeking knowledge to control and not be controlled by their condition, for example: "Knowledge is power and I like to know what's going on rather than just take the medicine and be quiet" (23). They highlighted the key role HCPs played in their journey to acquire this knowledge and for some, the time spent with their HCPs was considered vital to acquiring knowledge. Others expressed desire for more information. Gaining knowledge was thought to be an enabling process in the participants' efforts to regain 'control' over severe asthma.

### **Desire for more information**

The process of acquiring knowledge gave participants a sense of control and empowerment over their illness. Describing their journey to seek knowledge, participants reported ways in which they would find information and the role HCPs played in this. One author reported: "It seemed that the ability to access, communicate and gain the information and attention needed to regain asthma control was important to patients." (25). However another author reported that during some consultations, participants "received little information about asthma from their GP" (21). Particularly, when professional information was not provided, participants often sought it from a variety of sources such as medical journals, books, websites, friends and family, television and pamphlets (21,23,27). One participant reported that she initially wasn't getting enough information from her doctor, so she looked up her symptoms on the internet to try to find out more about them (27). For others, however, the information provided by HCPs either didn't seem to relate to their own condition, or was couched in medical terminology.

### **Time with HCPs**

Lack of HCP time was considered a barrier to participants acquiring asthma knowledge. As one author reported:

“Doctors (GPs or specialist) were perceived to have limited time for questions or lengthy discussion” (21). For most interviewees, primary health physicians were their first point of call (21,25), and their main source of knowledge, so having sufficient time with them was valued. However, many interviewees reported feeling rushed during their consultations, as illustrated by this quote: “he (physician) says ‘Right, what’s been going on, how’s your asthma?’ and he is just wanting you out of there, he just wants on to the next one [sic]” (25). In contrast, it was reported that nurses provided more time and information.

### Striving for autonomy through making decisions

The types of decisions participants reported making included weighing up the costs and benefits of severe asthma treatment; deciding on what treatment they wanted, how and when to take their medication. The extent of decision making often depended on the extent to which they relied on GP advice. According to Gamble et al., (23) interviewees who perceived that their general practitioner knew less about their disease than they did felt compelled to “undertake disease management decisions themselves at times, rather than consult their general practitioners”. Making decisions could thus be an unwelcome necessity or a free choice which led to feelings of empowerment over severe asthma.

### Weighing up the costs and benefits

In the process of making health related decisions, participants reported weighing up the costs and benefits of striving for a normal life. According to Ross et al., (21) “[benefits are] ... related to the extent to which they can engage in normal everyday activities that are aligned with their personal values and beliefs ... [and costs are] related to having asthma, its symptoms, and its recommended treatment.” Participants themselves reported that to keep this balance, it would often require ‘trial and error’ (21) and ‘push[ing] the limits’ (21). For some, weighing up the severity of their symptoms with the extent to which they could engage in normal activities, impacted on their decisions to go to the emergency department (21).

Study participants reported making independent decisions about how and when to take oral corticosteroids. For some, taking them meant better quality of life: “... when I’ve had to take steroids ... I just feel at the end of the day, it’s all about quality of life and I need to be able to keep a balance” (23). For others, the thought of taking oral corticosteroids and their side effects would either “make them stop or cut down on their steroids dose”(23). Another participant reported side-effects themselves impacted on their ability to engage in daily activities: “... The pros are that I

am alive and able to do things. The cons are the side effects though.” (21). According to Hyland et al., “some patients reported delaying the start of OCS and delaying visiting the clinic when they knew they were deteriorating” (22). Another participant reported that “I would be on my knees rather than take them ...” (23).

### Communication and relationships with HCPs

Interviewees reported wanting an equal relationship (23,25) and “two-way conversations” (21) with their HCPs when making decisions related to their condition. Participants, however, felt disempowered when they perceived their HCPs as “authoritarian ... or paternalistic” (25). One participant reported: “... they (GPs) just wrap you up in cotton wool. It’s just not what I want” (25), while another reported rejecting GP advice due to not being heard, as illustrated by this quote: “... I didn’t follow it [action plan] because I never got to express my opinion ... they [physicians] have stronger opinions ...”(21).

Some participants were reluctant to discuss their asthma with their HCP, perceiving HCPs as having pre-conceived ideas, for example: “... they always blame your weight” (25). Some reported being selective when sharing information about emotional issues (e.g. stress exacerbating asthma) to avoid giving “him [the GP] all my troubles” (25).

### Level of trust in HCPs

Some study participants believed that their decision making also depended on the level of ‘trust’ they had in their HCPs. This ‘trust’ was earned “if the physician appeared to be knowledgeable” (21) and if participants felt like they were involved in health related decisions. However, one participant reported that he didn’t trust his doctor because “... they just give you medication just to say yeah whatever here you go get out of my site [sic] ...” (21), and for him, trusting his doctors meant they had a good “connection”. If there was no “connection”, then participants would make their own decisions.

### Striving for autonomy through reclaiming identity

Most participants viewed their severe asthma as a condition which reduced their quality of life and disempowered them. Study authors described statements interviewees made about the impact of severe asthma on their identity, such as: “loss of roles within personal relationships” (23) loss of work (21,22,26,27), “not being themselves” (22,23) or “being perceived as different by friends and family” (23).



For some interviewees, the side-effects of oral corticosteroids challenged their identity to the point where it posed an existential threat, as illustrated by the following quote about oral corticosteroid-induced irritability: “... *I've cried, I've said I wish I was dead, you'd be better off without me*” (22). Another participant reported that their identity shouldn't be defined by their condition, as illustrated by the following quote: “... *I'm a person with asthma, I'm not the asthma first*” (26).

### Challenges to life roles

Participants reported feeling isolated from friends and family when on oral corticosteroids. For others taking oral corticosteroids meant being “*unable to fulfil their normal roles*”. One participant reported that, she would remove herself from her family when on oral corticosteroids.

For some participants, multiple asthma-related hospitalizations (9, 17 and 20 times in a year for three participants) (22,26) affected their career. One participant reported that the unpredictability of their condition disrupted their working life (22). For some, this “*loss of the ability to work or function*” (21) meant being “... *put on total disability [pension]*” (21). Others did not let their life stop because of their condition. To reclaim power over their condition, and restore autonomy, participants would learn how to “*adjust their lifestyle*” and shift their perspective to “*accommodate their asthma*” (21).

### Discussion

To our knowledge, this is the first systematic review of qualitative studies exploring people's experiences of living with severe asthma. The paucity of qualitative studies identified emphasizes that, despite increasing research interest in severe asthma, the voice of people with severe asthma is rarely heard. The key theme emerging from our analysis is that individuals with severe asthma strive for autonomy in their efforts to reclaim ‘power’ over their asthma. This resonates with the wider literature on living with chronic illness. People seek personal autonomy (28,29) through attempts to exert control over their condition to prevent disruption to their everyday life. Individuals feel empowered by attempts to gain a sense of ‘control’ or ‘mastery’ over an otherwise unpredictable chronic condition (28,30).

This review adds considerable depth to the features and impacts of severe asthma highlighted in quantitative studies. Our findings illustrate how individuals with severe asthma encounter challenges to their personal identity through the disruption of personal roles, body image, emotional and cognitive processes, and social relationships. While similar findings have been reported for adults living with other chronic illnesses

(31,32), severe asthma has some important differences. For example, severe asthma is an ‘invisible’ condition not readily observable to others (33). Asthma flare ups can be fatal; they sometimes develop within minutes, failing to respond to reliever inhalers. This unpredictability means some people with severe asthma live with fear. Severe asthma can also threaten 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 (34). In addition, many patients with severe asthma had to change a job role, leave a job or were unable to work at all (35), and up to two thirds of people with severe asthma were unable to hold a full time job due to their condition (14).

According to Charmaz, loss of control over normal day-to-day activities is a threat to self-identity (36). Some researchers have chosen to explore these concepts through viewing ‘chronic illness as biographical disruption’, where living with a chronic condition can significantly disrupt expectations of a normal life trajectory (37) (38). However like Williams (39), we also see evidence of the concept of chronic illness as ‘biographical continuity’. As highlighted in our findings, people living with severe asthma described their efforts to adapt to altered expectations of their life trajectory, and indicated that their self-identity was an ongoing and adaptive process (39,40).

Quantitative data highlight the physical symptoms of asthma, with many patients having day-to-day symptoms and/or acute asthma flare ups, including severe breathlessness and chest tightness. A 2007 severe asthma survey reported that one in five patients lived in fear that their next attack would be their last (41). In our review of the *qualitative* literature, however, we identified little evidence of participants' descriptions of the physical symptoms of asthma. It is unclear whether or not researchers in the reviewed studies asked directly about physical symptoms. Perhaps physical symptoms were considered too obvious for participants or authors to mention, or perhaps they were considered less important or less noticeable by participants in comparison to other aspects of living with this condition. Further research is needed to understand this finding.

Our synthesis highlights the patient-HCP's relationship as vital to overall health experiences. Although participants valued learning how to manage their condition to facilitate engagement in day-to-day activities, this was not always acknowledged during consultations. Interviewees described challenges to their autonomy during medical consultations, such as feeling their opinion or concerns went unheard. In response, participants sought to regain personal control, sometimes by deciding not to follow recommendations made by their HCPs. Other studies support that patients' perceptions about their HCPs (e.g. HCPs ability to listen and the extent to which patients feel

they are treated as equals), can impact on their decision to follow medical recommendations (42,43), and medication adherence (44–46). Our review also revealed discordance between the priorities of patients and those of their HCPs. HCPs tended to focus on symptoms and medications, whereas people with severe asthma were concerned with day-to-day issues such as going to work and maintaining social relationships (4,47). For the person living with the persisting disability of severe asthma, this creates a tension between personal disruptions to daily life, and a disease management-based treatment paradigm (48). The difficulty of navigating the healthcare system and HCP relationships, which was also reported in a recent review by Pickles et al. of qualitative research in the broader asthma population (20), can become a threat to autonomy.

This synthesis identified a paucity of literature reporting patients' experiences of add-on biologic treatments such as omalizumab, mepolizumab, reslizumab and benralizumab for severe asthma. Their greatest clinical benefit is in reducing severe exacerbations, with more modest effects on day-to-day symptoms and quality of life (4). This divergence points to the need for future qualitative research to explore the impact of these treatments on the *overall* lived experience of patients with severe asthma.

## Strengths and Limitations

Strengths of this review included its comprehensive search approach and the use of a methodologically robust qualitative synthesis, which is an emerging type of enquiry in the health research field (49). This has enabled a rigorous and systematic interpretation of the unique patient experiences of living with severe asthma. This approach has revealed challenges to a range of significant psychological and social elements of daily life, such as self-worth, confidence and autonomy. We hope this will engender on-going research and debate on this debilitating and life-threatening condition.

The number of studies was small, reflecting the paucity of qualitative research in a rapidly-evolving clinical area. It is possible that some individual patients fitting the now-accepted definition of severe asthma (4,50) were included in other, earlier, studies, as the term "severe asthma" was often previously used more generally for uncontrolled asthma (51). We excluded studies that, although using qualitative methodology, focused on specific medical research questions such as patient usage of action plans, which could therefore provide only limited insight on the lived experience of severe asthma from the patient's perspective. However, the studies we included in our review still appeared to focus on rather specific and mostly clinically-derived issues such as experiences with oral corticosteroids or treatment adherence, which likely

limited the information available about the full diversity of patients' experiences.

Other limitations include that the identified studies were mostly conducted in white, inner city, populations, whose experiences may not be representative of those from different geographical locations, sociodemographic status and cultural backgrounds.

## Conclusion

In this first systematic review and synthesis of the qualitative literature on people's experiences of living with severe asthma, we propose that people endeavor to obtain power over their condition through striving for personal autonomy. To gain power, participants deal with managing symptoms and treatment, acquiring knowledge, making decisions and re-claiming their identity. Our synthesis has highlighted several areas which require attention by policy makers and HCPs, as in their quest to learn about and self-manage severe asthma, patients often receive insufficient support from HCPs. Given the level of disability experienced by people living with severe asthma this is an important aspect of clinical care that must be addressed, rather than only focusing on pharmacological interventions. For this reason, it is imperative that more attention be paid to supporting self-management strategies and acknowledging the goals that are important to people living with severe asthma.

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## Conflict of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

## Author contributions

DE drafted the first and subsequent versions of the manuscript, with feedback from LS, HKR, KR and JMF. DE independently conducted the searches. Data extraction was conducted by DE and checked by experienced reviewers (LS and HKR). The process of coding was conducted by DE, LS, HKR and JMF. Data analysis and interpretation involved all authors. All authors read and approved the final version of the manuscript.

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## Appendices

### Appendix A- Search Strategy

ti = title, tw = text word

1. exp Asthma/
2. Asthma\$.ti. or wheez\$.ti.ab.
3. (asthmatic? or (asthma\$ adj2 (chronic\$ or patient?))).ab.
4. (lung disease or lung diseases).tw.
5. severe asthma.tw.
6. difficult asthma.tw.
7. or/1–6



8. exp adult/ or exp aged/ or middle aged/ or young adult/
9. (patient\* or inpatient\*).tw.
10. or/8-9
11. Qualitative Research/
12. ethnog\*.tw.
13. phenomenolog\*.tw.
14. participant observ\*.tw.
15. constant compar\*.tw.
16. focus group\*.tw.
17. action research.tw.
18. qualitative stud\*.tw.
19. (focus group\* or interview\*).tw.
20. (grounded adj (theor\* or study or studies or research)).tw.
21. 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20
22. patient experience\*.tw.
23. lived experience\*.tw.
24. life experience\*.tw.
25. patient perspective\*.tw.
26. experience\*.tw.
27. health experience\*.tw.
28. living with asthma.tw.
29. personal experience\*.tw.
30. illness experience\*.tw.
31. quality of life\*.tw.
32. 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31

33. 7 and 10 and 21 and 32

34. limit 33 to (English language and humans)

The search, using the above terms, was conducted in: MEDLINE via OvidSP, PsycINFO via OvidSP, PubMed, CINAHL, EMBASE and Sociological Abstracts. We also searched Google Scholar, the journals Qualitative Health Research and Qualitative Research, and a study of experiences of living with asthma by the Health Experiences Research group, published on the healthtalk.org website, and we screened reference lists of relevant studies.

### Appendix B- Further information on methods

The present authors followed the seven main phases of synthesis used in meta-ethnography (17). In the first three phases we chose the topic focus, selected studies to synthesize, and initially read the studies separately for concepts and themes. In the next two phases we translated and synthesized how these concepts related to each other leading to the development of overarching themes (17). This allowed the reviewers (DE, LS, HKR and JMF) to analyze the individual studies in depth and explain any similarities or contradictions between them. Finally, in the 7<sup>th</sup> phase, we utilized the 'Line of argument' synthesis to build each concept into a 'whole picture'.

### Appendix C- Tables

**Table 1.** Theme 1: People living with severe asthma strive for autonomy through dealing with symptoms and treatment.

Categories	Quotes
Emotional burden associated with the side effects of treatment	<p>"I didn't realise until I started taking them just the effect they could have on you mentally. I would say I suffer from depression. The psychiatrist reckoned that I have a steroid induced psychosis. I battle with myself every time I feel the asthma getting worse. I probably think I should have them upped at the minute ... but I keep thinking to myself maybe it'll go away. It's like a bomb waiting to explode." (23)</p> <p>"I know I was never depressed before I started on steroids" (22)</p> <p>"I can't tell you how much I hate being on them because of the depression" (22)</p> <p>"Patients reported that their increased weight was embarrassing" (22)</p>
Adapting to taking medications	<p>Taking puffers at work- "I wouldn't take them in work; I'd wait till I'm on my own. Sometimes I would have climbed the stairs and went in and everybody was sitting and I would have thought 'Oh God I need my inhaler', but I would have held off." (23)</p> <p>Routine- "... I prefer to get up and sort myself out in the mornings and take the steroids after I've had a cup of coffee." (23)</p> <p>"But things like my nebuliser, I have to buy myself. I've got two, I've got a portable one that I can carry around in my handbag and I've got my big one, compressor one upstairs, that I use at home." (26)</p> <p>"The nebuliser takes up quite a lot of time in the mornings when you are getting ready with the kids and things like that for school." (23)</p> <p>"... if someone says to me, 'Oh, we're going out, oh, do you want to stay over?' I can't, I, because the med, the type of medication I take, I can't miss a day. I mean, yeah, I do get sick of taking it, you know, after breakfast, ah, I'll just take my medicine, I jokingly say it's my second breakfast, you know, all the pills, takes, takes one and a half mugs of tea to take all my pills [laughs] in the mornings, you know." (26)</p>
Coping with symptoms	<p>"... I have to be very careful that I don't get over-tired; it's getting over-tired makes me, can make me wheeze ..." (26)</p> <p>Avoiding symptoms- "[going to his] brother's house ... or anywhere ... [so they would] ... meet up in town or ... [at their place since he knows] ... it's a safe clean environment" (26)</p>
Managing triggers	<p>Stress and anxiety- "... getting anxious about it, it just spirals, and I now know that anxiety and stress are one of my big triggers, psychological thing. You know, if I think I'm going to get ill, then I can, I can almost make it, make it happen, almost self-fulfilling because you think, 'Oh, I've sneezed, I've got a cold I'm going to be ill'" (26)</p> <p>"... I can't go to my brother's house, brother and his wife and my niece because they've got a cat, but they had the cat before or my sister-in-law had the cat before she married my brother. So, you know, we can't really ask her to get rid of the cat, but my aunt has always had cats as well ..." (26)</p> <p>Cleaning products- "... I mean other triggers for me include things like, cleaning products, bleach I mean, I went to my grandmother's house a few weeks ago and her cleaner had been in and left, left bleach in one of the loos which, you know, is perfectly normal, it's what people do, but I'd have only been in the house five, ten minutes and I knew that there was bleach somewhere; I couldn't smell it but I could feel it." (26)</p>

**Table 2.** Theme 2: People living with severe asthma strive for autonomy through acquiring knowledge.

Categories	Quotes
Desire for more information	<p><i>I'd like to know exactly what they do to you – and they don't tell you that! It took me a few years to realise you should always request information, you're never told these things, you have to find out for yourself" (23)</i></p> <p><i>"It was also encouraging to find that most participants wanted more accurate information and more education from health professionals." (23)</i></p> <p>Finding information on the internet- <i>"... I was doing research on the internet ... and I went to the doctor and they all agreed it was something it was called catamenia [sic] asthma ..." (27).</i></p> <p>Information not related to their condition- <i>"... everything was geared towards a moderate type asthmatic and it made me feel like I was doing something wrong, or I wasn't controlling things well enough ..." (21)</i></p> <p>Medical terminology used- <i>"Yes, sometimes the information is written at ... the doctor level and not at a patient's level. So sometimes the information can be overwhelming if it is not at a level that I can understand" (21)</i></p> <p><i>"Written or oral information was not always given in language appropriate for the lay or even for health care professionals unfamiliar with the jargon of the specialty." (21)</i></p> <p>Use of analogies stood out as particularly useful for clarifying meaning: <i>"... you can picture it better. Like she used this thing where your asthma symptoms are the top of an iceberg and 7/8 of it is what is going on in your lungs, you can't see that and the symptoms are only a little chunk. So it's like if you are having symptoms, it is like eight times worse inside your lungs. So, ... it's very, very, good. It's down to earth." (21)</i></p>
Communication and relationships with HCPs	<p><i>"... and so their [physicians] opinion of the drugs that they see work is not necessarily the drug that will work on everybody. So that open-mindedness and the listening to the patient as opposed to a closed conversation versus an open conversation" (21)</i></p> <p><i>"... he was a great Doctor ... slightly arrogant, but, you know, who was so focused on my allergies and minimising my allergy exposure and yeah, and sort of cleaning my life up so I wasn't exposed, didn't, he didn't actually look at me and how I was living and he didn't actually look at my asthma which I know sounds really odd ..." (26)</i></p> <p>Disclosure of adherence: <i>"Similarly, two other participants stated that they would only admit to not taking their inhaled steroid if asked directly by their GP." (25)</i></p> <p><i>"Patients do not discuss non-medical matters in the consultation and perceive that they should cope with these broader, non-medical issues themselves" (25)</i></p> <p><i>"Recently I've seen them [GPs] quite a bit ... the last few months. Just cause I've had colds ... and they threatened me with the asthma clinic." (25)</i></p>
Time with HCPs	<p>Nurse- <i>"Uhm, well sometimes she (nurse practitioner) points out things but just talking. We spend a longer time talking. She will catch a few things, stuff like that and then I can ask her questions (allied health professional) ... Dr. (asthma specialist) does not have time for all of these questions." (21)</i></p> <p><i>"What is it, a five-minute interview with the doctor? ... (with the practice nurse) you've got time ..." (25).</i></p>

**Table 3.** Theme 3: People living with severe asthma strive for autonomy through making decisions.

Categories	Quotes
Weighing up the costs and benefits	<p><i>"Participants stated that they often took management decisions themselves. It was evident that these decisions seemed to involve weighing up costs and benefits. This sub-conscious analysis was expressed in various ways" (23)</i></p>
Decisions about taking oral corticosteroids	<p><i>"I would have started them (corticosteroids) myself, because I thought this the only thing that helps me. The doctor used to say to me 'You know – you diagnose yourself!' (23)</i></p> <p><i>"I will cut them down and maybe the consultant has said stay on two tablets until I see you in four weeks, but if I feel okay I won't stay on those two, I mean I probably will cut them down again, maybe I shouldn't but ..." (23)</i></p> <p><i>"It's the lesser of two evils – it depends on how badly I'm suffering and if it gets really bad and affects my life-style and my work, then I do take them." (23)</i></p>

**Table 4.** Theme 4: People living with severe asthma strive for autonomy through reclaiming identity.

Categories	Quotes
Challenges to life roles	<p>Feeling isolated from friends and family when on oral corticosteroids- <i>"I'm good craic [meaning good company] and talk away usually, but when I'm on them [oral steroids], if I phone my friends, they say you 'Are back on those tablets?'; because I don't want to listen." (23)</i></p> <p>Work- <i>"What it meant then was loss of my occupation uhhh loss of the ability to work or function ... Uhhh and put on total disability and what it now means is [pause] managing it with my life. So my life does not stop as a result of the asthma. I just adapt ... I have had to adjust my lifestyle." (21)</i></p> <p><i>"I lost my job, I was medically discharged because I was in and out of hospital" (22).</i></p> <p><i>"I went through a period of several years, where I was in the hospital a lot and asthma was disrupting my whole family's life and I wanted to shut it out and I am in my 'rebellious, I am not going to deal with it' stage" (21)</i></p> <p>Being unable to fulfil normal roles- <i>"Oh even the children know now when I'm on them, they say 'Mummy's back on her drugs'. I am really bad tempered and wicked, just really, it's like if I'm pre-menstrual, its even worse, I just go upstairs and sit in a room to get away from them all rather than say things that I'd regret!" (23) .</i></p>

## **Postscript to Chapter 4: An update to the systematic review of people's experiences of living with severe asthma.**

This section is an update to the systematic review on people's experiences of living with severe asthma. This update does not include the published work described in this thesis. To update this systematic review, the same methods and search strategies as described in Chapter 4 were utilised to identify the relevant studies from the period of 2016 to September 2019.

Three additional studies were identified. These studies were conducted in Australia (n=2) (1, 2) and in the United Kingdom (n=1) (3). Table 3 provides a summary of the key characteristics from these studies. These studies had similar study designs compared to that of the literature in the systematic review. The included studies conducted interviews either face-to-face (n=2) (1, 3) or over the phone (n=1) (2). Data analysis included thematic analysis (n=2) (2, 3) and interpretive phenomenological analysis (n=1) (1).

Since our review, two studies reported on people's experiences of the living with severe asthma (1, 2) and one on a clinically-derived issue of the challenges people face to 'effectively' self-manage their condition (3). Interestingly, despite focusing on the barriers people with severe asthma face to self-manage such as concerns about medications and hospitalisations, Apps et al., (3) concluded that there is a need for psychological and social support to better support self-management.

Aligning with the findings from the systematic review, a study by Foster et al., (2) described the personal, interpersonal and extra personal hindrances of living with severe asthma. This study reported on the emotional consequences of severe asthma and of its treatment, particularly oral corticosteroids (2). Expanding on the challenges to interpersonal relationships, a study by

Holmes et al., (1) focused on patient experiences of sexual intimacy and reported that people living with severe asthma faced barriers such as fear of having an exacerbation and feeling fatigue. These physical limitations had negative consequences for their relationships. These three studies concluded that healthcare providers should explore the emotional, social and psychological challenges for those living with severe asthma.

This update to our review concludes that there is growing research in this area, which describes the challenges people face living with severe asthma. Of note, the current literature *describes* the impact of living with severe asthma rather than offering *explanations* into illness behaviours. Exploration of the experiences using a psychological theoretical lens would provide new understandings into ‘how’ a person lives with a debilitating and unpredictable condition such as severe asthma.



Table 3. Details of included studies: aims, definitions of severe asthma, sample characteristics and methods.

<b>Study Details (Author, Year)</b>	<b>Sample characteristics</b>			<b>Aims</b>	<b>Definition of severe asthma</b>	<b>Design Framework/Method</b>
	<b>Total sample size</b>	<b>Age range</b>	<b>Gender F/M</b>			
Holmes, L. J., et al. (2019) (1)	9	34 – 59	6/3	To explore the impact of severe asthma on sexual quality of life and intimacy	Confirmed diagnosis of severe asthma as per ERS/ATS classification* (4)	In-depth semi-structured interviews (audio recorded)
Foster, J. M., et al. (2017) (2)	25	23 –81	17/8	To explore people’s experiences of living with severe asthma	Confirmed diagnosis of severe asthma as per ERS/ATS classification (4)	Interviews conducted by telephone Semi-structured interview guide
Apps, L. D., et al. (2019) (3)	29	Not given	16/13	To explore the attitudes of patients with severe asthma about their experiences of managing their condition.	Severe asthma defined by step 4 or 5 of the British Thoracic Society (5)	Face-to-face semi-structured interviews (audio recorded)

\* ERS/ATS definition of severe asthma: asthma which remains uncontrolled high-dose conventional treatment, or that is only well controlled during high-dose (4)

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## **Chapter 5: A systematic review of people's experiences of living with a chronic illness using a self-determination theory perspective.**

Chapters 1 and 2 laid the medical and theoretical foundations, and background for this doctoral thesis. The findings of our first systematic review (Chapter 4) which looked at people's experiences of living with severe asthma synthesised a line of argument that people living with severe asthma strived for autonomy.

To examine the role of autonomy in the light of self-determination theory (SDT), a systematic review of qualitative research investigating people's experiences of living with a chronic illness using an SDT perspective was conducted. It is acknowledged that this systematic review was conducted after the analysis of our body of work, however, it was felt important to highlight the paucity of qualitative studies that draw on SDT, and to compare our findings and interpretations.

This manuscript for this paper is under review with *Health Psychology and Behavioral Medicine* submitted 27<sup>th</sup> August 2019.

## **Authorship statement**

The co-authors of the paper “‘It is like learning how to live all over again’ A systematic review of people's experiences of living with a chronic illness using a self-determination theory perspective” confirm that Daniela Eassey has made the following contributions:

- Conception, design and implementation of the research
- Collection and extraction of data
- Analysis and interpretation of the findings
- Drafting and revising of the manuscript and critical appraisal of the content

As the primary supervisor for the candidature upon which this thesis is based, I can confirm that the above research attribution statement is correct.

Professor Lorraine Smith

The University of Sydney

11 October 2019

**Title: “It is like learning how to live all over again” A systematic review of people's experiences of living with a chronic illness from a self-determination theory perspective.**

*Daniela Eassey, B.Pharm (Hons)<sup>a</sup>, Helen K. Reddel, MBBS, PhD<sup>b</sup>, Kath Ryan, B.Pharm, PhD,<sup>c</sup> and Lorraine Smith, BA (Hons), PhD<sup>a</sup>*

<sup>a</sup>School of Pharmacy, Faculty of Medicine and Health, University of Sydney, Sydney, NSW, Australia

<sup>b</sup>Woolcock Institute of Medical Research, University of Sydney, Sydney, NSW, Australia

<sup>c</sup>School of Pharmacy, University of Reading, UK

### **Ethical statement**

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

### **Funding**

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## **Abstract**

### **Objective**

To conduct a systematic review and synthesis of qualitative evidence exploring the views and experiences of people living with a chronic illness that utilised self-determination theory.

### **Methods**

We searched MEDLINE via OvidSP, PsycINFO via OvidSP, PubMed, CINAHL, EMBASE, Google Scholar, the journals Qualitative Health Research and Qualitative Research. Studies were included if they used qualitative methods, explored the subjective experiences of people living with a chronic illness and underpinned the analysis with self-determination theory.

### **Results**

From 4605 articles, six met the inclusion criteria. The synthesis culminated in a line of argument that patients endeavoured to be '*free from disease*'. People's desire to live a life free from disease required nurturing their: 1) need to feel empowered (autonomy), 2) perceived ability to self-care (competence) and, 3) their need to feel a sense of belonging (relatedness).

### **Conclusion**

This review has highlighted that the majority of studies included in this review focused on the clinical aspects of managing a chronic condition and changing patient health behaviours. Future studies should focus on exploring people's illness experiences more broadly to develop further understanding of the role of each construct (autonomy, competence and relatedness) rather than focusing on pharmacological interventions.

## Introduction

The incidence of chronic illness, such as diabetes, respiratory and cardiovascular disease, is rapidly increasing and they are among the most prevalent and costly of all global health problems (1). According to the World Health Organisation (WHO), chronic diseases are expected to account for almost three-quarters of all deaths worldwide (2). A chronic illness is defined as a long-term and persistent health condition which may lead to other health complications and may be associated with functional impairment or disability (3).

Given the global burden of chronic illnesses, they have become a priority for healthcare systems around the world. There are strong arguments, however, that current strategies are largely developed to deal with acute episodic care rather than providing care for people with long-term conditions (4, 5). In 2002, the WHO released a report entitled “*Innovation Care for Chronic Conditions: Building Blocks for action*” (4) and reported the urgent need for action to care for people with chronic conditions (6). Since then, there has been a significant effort to direct national and international policies towards improving the prevention, treatment and ongoing management of chronic illnesses (1).

The WHO, other health policy organisations, and various national governments advocate and endorse the need for health care institutions to place a greater emphasis on the individual (7-10). As part of these policy changes, healthcare providers are encouraged to shift from the traditional paternalistic approach of medicine, where medical practitioners prescribe treatment and give instructions with limited input from patients and families, to taking a more patient-centred approach (i.e. more collaborative, responsive to patient’s needs and values and empowering patients’ autonomy) (11).

To date, the patient-centred model is perceived as part of the solution to paternalism in clinical management (12). This approach is argued to provide increased understanding, confidence in decision-making and improved health related behaviours (7). Thus, it is unsurprising that a patient-centred model forms a fundamental principle of self-management of chronic illnesses (12). Self-management integrates numerous concepts and frameworks in research and policy to support health providers as their roles evolve in caring for people living with a chronic illness (13).

The concept of supporting ‘patient self-management’ continues to attract significant interest from health policy leaders internationally. Research has shown, however, that there is currently a disconnect between what is recommended in guidelines, what happens in practice and what people living with chronic illness face on a daily basis. Currently, health professionals ‘support’ self-management in a clinical manner by focusing on setting medical regimens (14), changing self-care health behaviours and setting medical goals but as a result they may fail to understand patients at an individual level. Research has shown that there is need to provide care more inclusive of psychological and social factors (15). One explanation for this disconnect, could be a lack of research evidence and focus on the patient's experience of living with a chronic illness.

Clearly, a person’s perceptions and experiences of living with a chronic illness are extremely important. Research has shown that personal, environmental and social factors, goals and values all play a role in the ways in which people with chronic illnesses live with their condition (15). Adopting a more individualised approach to healthcare services would require an exploration of the viewpoints of those concerned and would further provide insight into the needs and values of those affected.



A growing body of theoretical and empirical research emphasises that the effectiveness of biomedical strategies depends significantly on whether and how well they address issues on an individual level by examining the psychological, social and environmental factors that may explain health related behaviours (16-18). Self-determination theory (SDT) was developed in the mid-1980s by Professors Richard M. Ryan and Edward L. Deci (19, 20). This theory seeks to explain health related behaviours and motivations on an individual level (19, 20). It differentiates between an individual's intrinsic and extrinsic motivations to initiate changes and does so by incorporating socio-contextual factors which may influence self-motivation (20).

Over the past 15 years a growing body of evidence has confirmed the efficacy of this theoretical model in health behaviour change interventions for physical activity, glycaemic control (type 2 diabetes) and medication adherence (21-27). According to this theory, people have three basic psychological needs: autonomy, competence and relatedness. The need for autonomy refers to the experience of behaviour as volitional and self-endorsed (19). Competence, in turn, refers to feeling a sense of mastery and efficacy in one's activities (19). Relatedness reflects the extent to which a person feels accepted, understood and cared for and connected to others (19). These psychological needs are perceived as building blocks to intrinsic motivation. Fulfilment of these three needs has been shown to contribute to enhanced motivation and improved health outcomes (19). One systematic review quantitatively synthesised the copious empirical studies that have utilised SDT measures in the health care and health promotion contexts (28). There is, however currently no comprehensive systematic review (qualitative or quantitative) that draws on the basic psychological needs identified by SDT in order to examine the personal experiences of adults living with a chronic illness, that is, what matters to people and how they live with their chronic illness.

Integrating qualitative research studies into a synthesis will generate new insights into the existing theoretical and empirical work in this area. The objective of this systematic review is to identify, describe and synthesise the views and experiences of people living with a chronic illness from the available qualitative literature that utilised SDT.

## **Methods**

The review is reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA).

### *Search strategy*

A systematic literature search was conducted in May 2019 in the electronic databases MEDLINE via OvidSP, CINAHL, PsycINFO via OvidSP, PubMed, Scopus and EMBASE from their inception. We also searched Google Scholar, the journals *Qualitative Health Research* and *Qualitative Research* and screened reference lists of relevant studies.

### *Selection criteria*

Studies were included if they: 1) described qualitative research; 2) explored the subjective experiences of people about living with or managing a chronic illness; and 3) based their analysis with SDT. Articles were excluded if: 1) they did not address the personal experiences of living with a chronic illness and 2) due to a lack of resources for translation, were not published in English. In May 2019, a specialist librarian helped design a search strategy with assistance from one of the reviewers (DE). This was then discussed and confirmed with a second reviewer (LS).

## Data extraction

Two reviewers independently (DE, LS) screened titles and abstracts of all identified references. Search results from the different databases were combined and duplicates were removed electronically and manually. Potentially relevant studies underwent full text analysis by two reviewers (DE, LS), differences in opinions were discussed and a consensus was reached. The search strategy is provided in Appendix A.

## Data analysis

Qualitative research is interpretative; therefore, the experiences reported by participants and the original authors' analytic interpretation of the qualitative findings were extracted verbatim and became the data for the synthesis (29). We used a framework synthesis which consisted of a two-stage approach (30, 31). The first stage of the process required data extraction and organisation into pre-specified categories. These categories were informed by the SDT constructs of autonomy, competence and relatedness. These were then thematically analysed to identify patterns of data within and between categories (30, 32). A systematic and iterative process was used to derive the final synthesis of the overarching theme. The synthesis was led by DE and LS.

## Reflexivity

Reflexivity is critical to enhancing the quality and credibility of qualitative research, by continuous assessment of the impact of the researcher's own position and interest on all stages of the research process (33, 34). The strategies used to counter potential biases during data extraction and synthesis included independent checking of the original data extraction and

synthesis (from DE) by two other experienced reviewers (LS and HR). The process of coding, analysing and interpreting the data involved all authors, who each had experience in qualitative research (DE, LS, KR, HKR).

### Quality assessment

Despite a lack of consensus about quality assessment of qualitative studies, several tools and techniques are available (35). This review used the Critical Appraisal Skills Programme (CASP) tool (36). CASP includes ten questions assessing the rigour, credibility and relevance of the studies (36) This assessment was carried out by one reviewer (DE) and cross checked by a second reviewer (LS) (Appendix B).

## Results

### *Description of the studies*

From the 4605 potentially relevant studies, twenty-three investigated people's experiences of living with a chronic illness, used qualitative methods, and mentioned SDT in the abstract. After full text review, six articles were included, that had based their analyses on the principles of SDT. Figure 1 provides a PRISMA flow diagram indicating the inclusion and exclusion of articles at each stage of the screening process. The included papers were published between 2011 and 2019, from Australia (37), the Netherlands (38), South Africa (39) and the United States (40-42). The included papers described people's experiences of living with: cystic fibrosis (38, 42), asthma (37, 40), diabetes (41) and hypertension (39).

The majority of studies did not focus on the lived experience of people with a chronic illness but rather more specifically on barriers to self-management (38 - 42). Of the six studies, four

aimed to identify factors that could be used in subsequent intervention studies by focusing on the challenges to patients' basic psychological needs (39 - 42), one study explored patient experiences of participating in a life coaching intervention (38) and one explored in depth the role of autonomy in experiences of living with a debilitating condition (37). Five studies reported on all three of SDT's basic psychological needs (autonomy, competence and relatedness) (38 - 42) and one study analysed and interpreted one of the needs (autonomy) in depth using people's narratives (37). A range of qualitative analysis methods was used; all sought to underpin their analysis or interpretation with SDT's theory of basic psychological needs. Details of the included studies are presented in Appendix C.

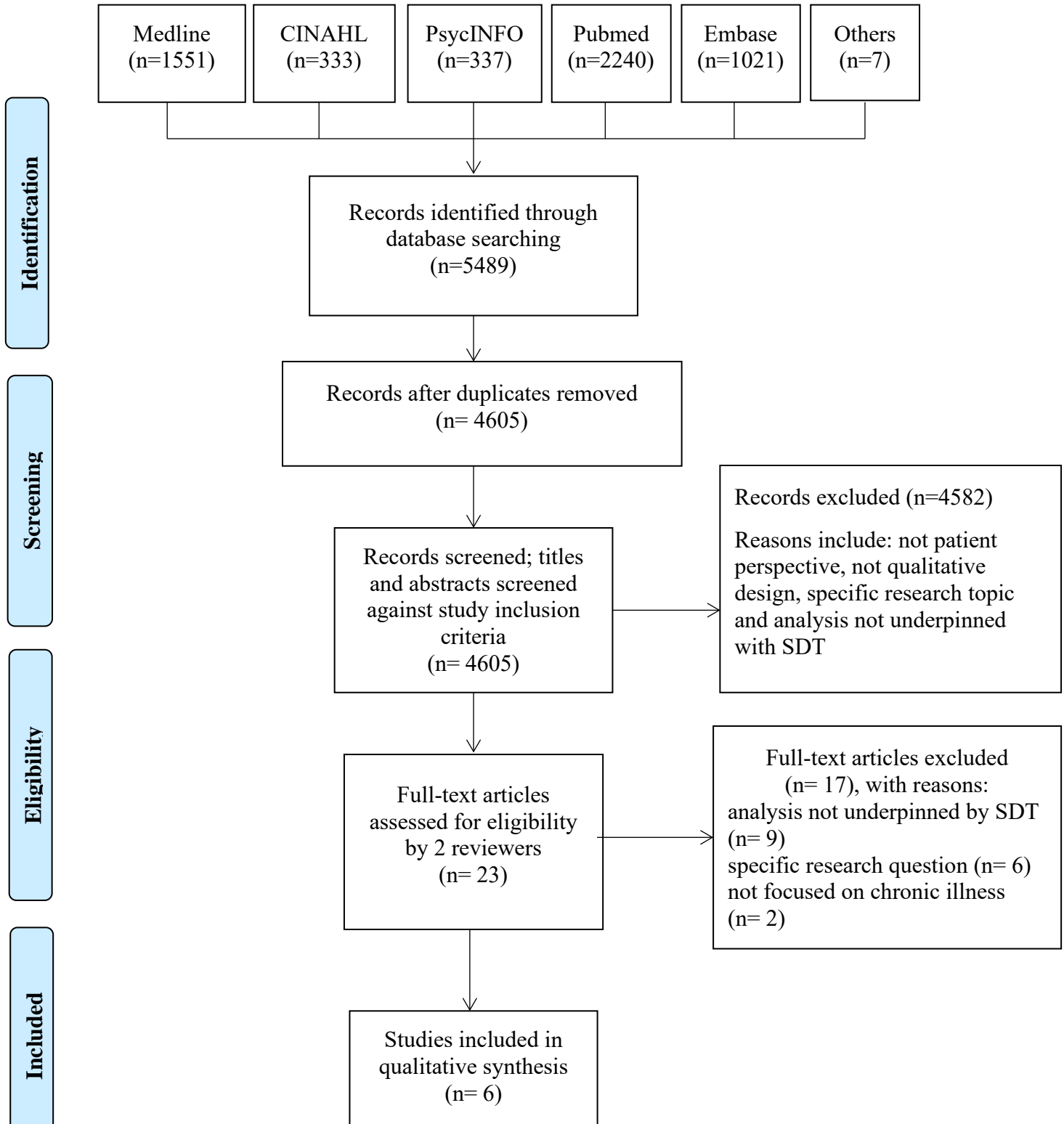


Figure 1 - Flow of information through the different phases of the systematic review (based on the PRISMA reporting flowchart)

## Synthesis of findings

Our synthesis of the included studies culminated in a line of argument that patients endeavoured to be '*free from disease*'. A chronic illness was considered by patients to be a 'disease' if it challenged their sense of autonomy, competence and/or relatedness. It was apparent that in their attempt and desire to *live a life free from disease*, people were seeking ways to understand their condition and learn "*how to live all over again*" (41). People's desire to live a life free from disease required nurturing their: 1) need to feel empowered (autonomy), 2) perceived ability to self-care (competence) and, 3) their need to feel a sense of belonging (relatedness) (Figure 2).

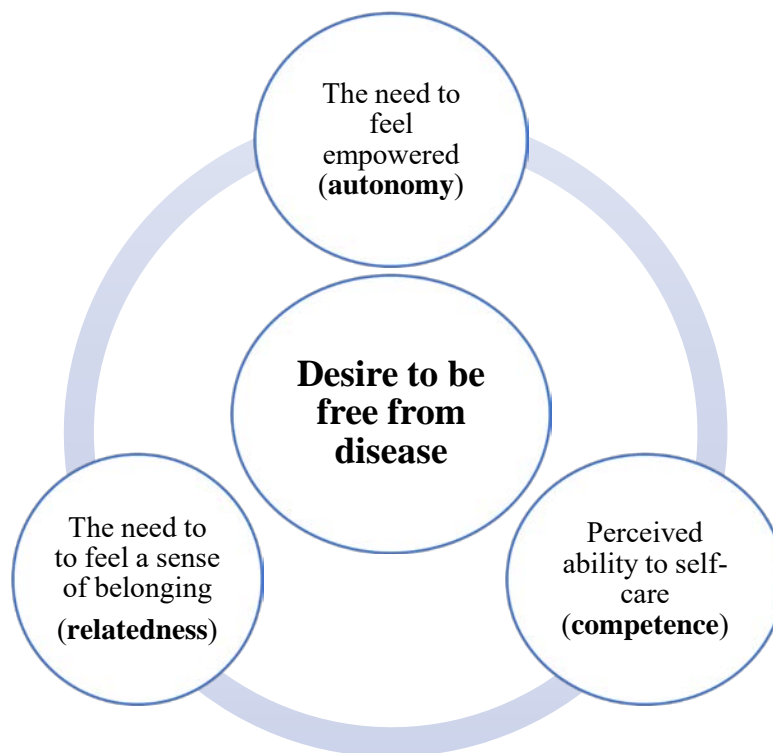


Figure 2. Conceptual diagram of the overarching theme and the sub-categories using framework synthesis.

## 1. The need to feel empowered (autonomy)

This subtheme describes that, in their desire to live a ‘life free from disease’, people valued feeling “*empowered*”. The conflict between the constraints of their illness and the desire to live a life free from disease was a constant ‘power’ battle. Feeling empowered meant having a sense of control over their condition and a sense of choice in health-related decisions. The authors of the included studies described a lack of control and lack of choice over health decisions and their condition as a ‘barrier to autonomy’ (38, 39, 41). One author further suggested that “*the lack of autonomy meant negative [health] outcomes were inevitable to participants*” (41).

### 1.1 Feeling empowered over making health-related decisions

People reported the extent to which they felt their healthcare providers provided them with a sense of control and choice over their health-related decisions (37, 39). Murphy et al.,(39) highlighted that none of their participants felt that their healthcare providers actively encouraged their collaboration. It appeared that people felt that they were not provided with enough information to engage in decisions related to their health. For example, one participant reported “*I am not sure what it (diabetes) is, but at least what I am doing is just to always get my medications*” (39).

The traditional biomedical model of providing information without any interaction with the patient, made people feel apprehensive about asking questions: “*I am not happy. I feel dizzy and tired.... I think that this is the wrong medication. I wish that the doctor can change that tablet that I am using...Even today, I was telling myself to ask the doctor if she can change my medication, but I am worried about what she will say to me...*” (39). People also reported actively opposing the perceived controlling efforts of their healthcare providers, even if this



could have negative health implications: *“I was told that I was not to have budgies because they carry bird fancier’s disease. Yeah but his cage gets kept clean and he runs the house. So, what my specialist doesn’t know won’t hurt me”* (37).

People reported that they valued making autonomous decisions which at times conflicted with recommended guidelines for optimising health (38). All but one study reported that, as a result of the lack of choice and collaboration, some participants exerted their personal control by deciding not to take their medications strictly as directed, or as the authors described it as *“being non-adherent”* (39 - 42). Pushing back against medical paternalism was perceived by patients as enacting their autonomy. According to Bhattacharya, non-adherence was interpreted as *“feelings of helplessness [that] could have led to perceived failure of positive behaviour changes outcome”* (41). Authors described various explanations for non-adherence, such as cultural beliefs (41) and perceived impact of taking medications on daily life (37, 38, 40, 42).

Studies which reported on the experiences of children living with a chronic illness, suggested that choice was given to the parents; thus, to carry out their treatment routines required a *“sense of imposed necessity”*, for example *“parents’ insistence, bribes and punishments”* (40, 42). Adolescents with cystic fibrosis (for which the daily treatment is very time-consuming) seemed to prioritise life choices over their illness, in that they chose going out with friends or going to work over taking their medications, disclosing that not taking their medication was often intentional: *“I never forget to take my medication, I opt out [of] my medication. If I don’t take it, [that’s] because I have consciously chosen not to take it today...”* (38). Another adolescent reported: *“Bad conscience is nagging me, there is always more you could do. But I have made a choice, I don’t know if it is the right one, but I have chosen that (the disease) should not*

*restrict me, meaning that if I must choose between taking my treatment or doing something with my friends, then I will without doubt choose my friends.”(38)*

Adults expressed a range of feelings about adherence to treatments. They felt worried having to take medications and to monitor their condition for the rest of their lives, some suggesting that the illness had become a *disease* in that it had taken control over their lives. One study, however, described that health-related behaviours such as taking medication were valued as a way to maintain a sense of control over their condition (37). For example, one person reported that he saw not having his medications as a potential threat to his sense of personal control: *“I’m out of control, I start to worry. But if you’ve got everything there you need to control it, you don’t worry...nothing worse than not being in control of your body, not being able to breathe...”(37).*

It was also noted that, in people’s desire to live a life free from disease, negative emotions such as fear and helplessness played a role in their sense of control over their condition. The authors of two studies had opposing views on the influence of emotions on engagement in health-related behaviours such taking medication or making lifestyle changes (37, 41). On the one hand, one study reported that people’s sense of helplessness led to the failure of positive health behaviour changes such as taking medications regularly (41), whilst on the other hand another study reported that negative emotions such as fear, despite challenging people’s sense of personal control, were a *“strong motivator to engage in health-related behaviours and exert personal control.”* (37).

### *1.2 Feeling able to resist the controlling effect of their condition*

One study looked at the role of autonomy in depth through the narratives of people living with severe asthma. The authors suggested that patients' autonomy was either challenged or enacted in a range of situations such as: *“dealing with threats to self-identity and in living an ‘unconstrained’ life”* (37). People described that maintaining employment whilst living with their condition was a highly valued aspect of life. In their desire to live a life free from disease, many examples emerged of people pushing their own personal limits to resist perceived controlling effects of their condition.

People also reported that when they felt their identity confronted by the illness, they would *“push back”* to limit the effects of the illness (37). One person reported that due to being in and out of hospital, she felt that she could not fulfil her role of being a mother: *“You know, you’ve got kids that want to play with you, and you can’t and the worst thing has been the amount of times I have been in hospital when it’s my kids’ birthdays or I’ve just been too sick... we try and make up for it, you know, I buy way too much stuff to try and make up for it... Thank you credit card...but yeah, you live in fear all the time, of so many things, and you live hating how you’re failing your family. I want to be able to take my kids out. I’ve always wanted to be able to”* (37). According to the authors, autonomy was also enacted when trying to search for a ‘new normality’ or preserving their sense of normality (37). For some, this required constant negotiation and reconceptualisation by incorporating the illness into their lives.

## **2. Perceived ability to self-care (competence)**

The authors of the included studies described competence as an individual's sense of confidence in their ability to engage in behavior changes (self-care) (38 - 42). They focused on clinical

issues hindering self-care practices. According to the authors, self-care meant understanding the participant's knowledge about their condition and barriers to making lifestyle changes (38-42).

### *2.1 People's need to feel effective in understanding their body*

People reported on the importance of understanding their condition through being aware of symptoms and the power of knowledge about their illness. For children living with asthma, being aware symptoms such as *"wheeziness, tightness and cough"*(40) made them feel able to identify their condition. The authors suggested that being provided with information and knowledge by their healthcare providers was a core component for patients to feel competent to self-manage (39, 40).

A study by Murphy et al.,(39) highlighted that many people with diabetes or hypertension had low health literacy. They suggested that there was a lack of information provided by healthcare providers, and that *"without an attempt on their part to understand patients' existing levels of knowledge or beliefs about their illness, problematic misconceptions [by patients] about the causes of Type 2 Diabetes and hypertension prevailed"*. For example, a participant reported that their hypertension was inherited and that they could have done nothing to avoid it: *"My grandmother used to have high blood pressure. So, the day that I was diagnosed, I was waiting for it"* (39). Due to the lack of understanding about their condition, another participant reported using alternative remedies to cure their illness such as 'holy water', Aloe Vera or other strategies. For example: *"There is a lady who told me that this (diabetes) is caused by dirty blood. She told me that I must clean my blood with a Vitamin B injection from the chemist and then my blood will be okay"*(39). Furthermore, for children, Bingham et al.,(40) suggested that

linguistic competence may influence their perceived competence to manage their condition. All these factors had “*negative implications for self-care*” (39).

## 2.2 *The need to feel effective in changing lifestyle behaviours*

In their desire to live a life free from disease, participants felt conflicted with the need to feel free versus having to follow strict regimens such as changing lifestyle behaviours. The authors of the included papers described the need for competence as the ability to understand and follow the pharmacological and non-pharmacological advice given by their doctors (38-42). Lifestyle changes such as: “*exercising, sleeping well, eating health[ily] and avoiding too much alcohol*” (38), were described by the authors as the “*individual’s responsibility*” (41). There was an emotional disconnect between how people perceived ‘managing’ their condition and the recommended lifestyle changes.

According to Bhattacharya, participants “*lacked self-competence to follow guidelines*” (41). Following instructions given by healthcare providers, such as changing diet, at times was perceived as challenging due to people’s cultural upbringing in which food and dietary patterns “*had been practiced from their grandmother’s time*”(41). Other authors suggested that patients were willing to make lifestyle changes but needed more information from their healthcare providers. As one patient reported: “*The doctor said that I must leave (out) the salt in the food because the danger is the salt. But she didn’t explain what kind of food I must eat. So, I don’t know what I must eat at home...*”(39).

People also reported feeling more confident in their ability to make decisions and cope with their condition when they searched for more information on lifestyle changes and medication from other sources: “*From the day hospital, I went onto the internet, read books, um, talked to*

*other people. I found out a lot of the things...*”(39). However, being told what to do by their healthcare providers, with no context about the reality of their lives, contributed to people feeling helpless (41). The authors described that feeling helpless “*hampered [people’s] self-motivation to make [health related behavioural] changes*” (41).

### **3. The need to feel a sense of belonging (relatedness)**

People reported wanting to live a ‘*normal life*’, or life that they felt was not controlled by their disease. Many examples indicated that to live a ‘normal life’, participants felt it was important to develop a sense of connection (or relatedness) with others. The authors mainly focused on barriers to people’s sense of relatedness and its impact on their health behaviours (38 - 42). Across the studies, relatedness was defined as “*feelings of social support and connectedness to boost [people’s] intrinsic beliefs in [their] capacity to make health related behaviour changes*” (41). Living a normal life meant not feeling judged or different, being cared for, and understood by their healthcare providers, social contacts and immediate family.

#### *3.1 Interactions with healthcare providers*

Interactions with healthcare providers were important for people to feel that they were living a ‘normal life’ rather than living a life with a disease. The authors of one study reported on the barriers that affected “*patients’ ability to accept their condition, as well as their motivation to engage with healthcare providers*” (39). One study reported on people’s sense of relatedness with their healthcare providers (39). According to Murphy et al.,(39) participants reported wanting to feel understood, cared for and valued by their healthcare providers.

The authors noted that participants' experiences pointed to "*a number of issues which suggested that providers had failed to establish a sense of relatedness with them*" (39). Participants also reported that healthcare providers did not have enough time with them. One participant reported: "*I know the doctors are under pressure and there's the next patient waiting, but I just wish that they could be more detailed, sort of give us more information, talk with us about what this whole thing entails.*"(39). Other reasons provided by authors were "*healthcare providers failing to explain the cause and nature of their illness and counsel [patients] on self-management, a lack of emotional support and reassurance for patients, particularly at the time of diagnosis and accounts of providers alienating patients by being impatient and rude*" (39). Participants also described how non-empathetic attitudes of some healthcare providers inhibited them from being open and trusting. For example, one participant reported: "when it comes to the nurses it is really bad. When you go inside to see the doctor, he will talk to you fine, but when it comes to the nurses, hm-mm, they are so rude. It's not a good experience" (39).

### *3.2 Interactions with their social contacts*

All but one of the included studies reported that people living with a chronic illness were concerned about feeling left out by their peers (38 - 42). Interviewees stated that social isolation thwarted their sense of '*normality*' (38). This may be due to the physical challenges they faced with their condition or the requirements of their treatment or the "*stigma*" related to their condition.

Children with asthma reported a range of reasons for feeling left out by their friends such as having to miss school days or feeling tired due to the lack of sleep (40). Having friends with the same condition was reported to be a "*positive influence*" because they felt able to relate to

one another and were able to “*take a break [such as missing events] without feeling left out*” (40). Other reasons identified were associated with time-consuming treatment regimens. For example, as one author reported, people living with cystic fibrosis used “*masks for delivering nebulised medicines which stopped [them] from talking and [a] vibratory vest kept them from hearing.*” Yet, despite these barriers “*participants considered themselves similar to their peers*” (42).

A few children, commented on how they didn’t want to be perceived as “*weak*” or “*an outcast*” (40). Participants wanted to develop close and supportive relationships with other people yet were cautious about disclosing their illness to others (38). Participants reported being cautious, due to the fear of “*stigmatisation*” (38, 41). One participant said “*It is a rural community, word will spread, and all will look at me with sympathy.*” (41). When people with diabetes were asked whether they were aware of anyone else within their [rural] community living with the same condition, they responded that they learned it “*through the grapevine*” (41). Gender also played a role in the responsibility of having to take care of their family. Interviewees considered how going on a “*special diet*”, taking medication and having to exercise would be perceived by their family members. “*How can I say I am now sick for my whole life? They will think who will take care of this man?*” (41). Another participant reported: “*My family is young—young kids, wife. They may not say much but think I am a sick person.*” (41). According to the authors, people’s perceptions of how they were viewed by their social environment “*affected their ability to carry out lifestyle changes*” (41) .

One author highlighted the cultural challenges for African-Americans living with a chronic illness (diabetes) in a rural area (41). They reported on the spiritual aspects of going to church and its impact on coping with their chronic illness. Praying offered some people a moment of



relief and assurance. One person reported feeling as if they were living free from disease and that “god [would] take care of them”. However, another participant reported: “*I do not believe church can do anything for my diabetes care. Church is the sacred place to worship God. I come to the church to pray to God. I do not want to bring up my problems, worries, and anxieties in the church. I want peace and quietness in the church to be with God-spiritually*” (41). Feeling a connection with a higher order provided patients with a sense of relatedness, where they felt cared for and understood at a spiritual level. For example, one person reported that they were at the mercy of God: “*I worry a lot about my diabetes and losing [my] legs, and maybe earlier death. Doctor told me to prick myself three times a day to test blood sugar. But I believe in destiny. I left it to God. When He thinks it is my time to leave this world, I will be ready to go!*” (41).

## **Discussion**

To our knowledge, this is the first systematic review to examine qualitative studies drawing on self-determination theory (SDT) as a framework to understand people’s experiences of living with and managing a chronic condition. The key theme emerging from our analysis of the six identified studies is that people living with chronic illness want *to live a life free from disease*. Our synthesis captured that, in their desire to live a life free from disease, people faced constant psychological and emotional challenges to their sense of autonomy, competence and relatedness.

At the heart of concepts such as self-management and patient-centred care is autonomy. According to SDT, autonomy is a concept central to satisfying basic psychological needs for wellbeing (19, 20). Our findings go beyond those of previous quantitative studies that demonstrated how supporting patient autonomy improves health outcomes (28, 43-45). This

review has highlighted that, while the majority of included studies focused on barriers to self-management only one study reported how autonomy was challenged and enacted to preserve people's sense of identity (37). This resonates with the work conducted by Charmaz on the impact of living with a chronic illness on an individual's sense of identity (46, 47). Charmaz suggested that living with a chronic illness could threaten the unity between the body and the self. She further suggested that learning to adapt or to live well with a condition required resolving the tension between the body and the self, and this required a sense of autonomy (46, 47). We suggest that future studies drawing on the SDT concept of autonomy should consider broader issues such as the psychological effort required for patients to enact their sense of autonomy and preserve their sense of identity.

According to Ryan et al., (48) the effectiveness of most health care interventions depends on people's perceived competence to undertake self-care activities such as lifestyle changes and symptom management. As an important element of self-management, self-care involves the ability both to care for oneself and to achieve, maintain and promote optimal health (49, 50). The authors of the included studies suggested that empowering patients to feel competent in their self-care practices depended on their healthcare professionals providing enough information or knowledge about their condition to allow the patients to make health-related decisions, and on acknowledging people's cultural background, health literacy and, for children, their linguistic competence. Our findings highlight that people's decisions to look after their condition, such as lifestyle behaviours, also depend on their relationships with their healthcare providers, friends and family and their overall illness experience. We note, however, that much of the applied research in self-care and self-management has focused on clinical concepts such as improving symptom management and treatment adherence. An integral part

of living with a chronic illness is setting goals (21, 22, 51, 52). Thus, we note that in light of these findings future studies should consider broader aspects of living with a chronic illness such as examining the role of competence in goal setting, which may enhance our understanding of the psychological effort required to live with an illness

Social contacts play an important role in shaping people's illness experience. Most of the studies included in this review focused on the impact of relatedness on self-management. Our synthesis highlights that in their desire to feel '*normal*', patients valued having a supportive relationship with their healthcare providers, friends and family. Interviewees described that their values and beliefs were not being acknowledged by their healthcare providers. Healthcare providers tended to adopt a paternalistic approach to treating the medical condition rather than considering patients' psychological needs and overall illness experience. Feeling unable to relate to their healthcare providers or other individuals hindered people's sense of relatedness. The psychological effort required to feel '*normal*' resulted in some people feeling helpless and emotionally disconnected. According to Turner et al., (53) the emotional dimensions of living with a chronic condition are frequently overlooked. Participants reported fearing the stigma related to their condition and as a response isolated themselves socially. One study reported that people turned to religion for acceptance and emotional support (41). According to Pachankis et al., (54) when people feel stigmatised by others an aspect of the self is socially devalued.

This systematic review adds depth to the current literature drawing on SDT in the health domain. Despite the recent growth of studies empirically testing the utility of this theory (28), this review demonstrates the paucity of relevant qualitative research. This is important because qualitative research provides rich information and understanding of the lived experiences of chronic illness. SDT is couched within a biopsychosocial model yet our findings have

highlighted that studies examining or implementing this theory have focused on clinical issues such as barriers that might hinder self-management. Our findings illustrate that the included studies emphasise fixing ‘issues’ that are perceived to hinder people from managing their condition. However, we suggest that what matters to patients in terms of their desires to manage (or live well with) their chronic illness has been overlooked (15, 55, 56). Our findings indicate the need to move beyond the narrow approach underpinned by medical paternalism, and pre-determined medical goals, towards taking a broader approach to understanding what it means to live well with a long-term condition.

### **Strengths and limitations**

This review used a systematic and comprehensive approach using an SDT framework to identify and synthesise qualitative studies examining people’s experiences of living with a chronic illness. There are a few limitations to acknowledge. First, the number of studies identified for this review was small and was limited by the original reporting of data by authors and the selection of quotes used in their papers. We suggest that this reflects the paucity of qualitative research based on SDT in this field, although it is possible that relevant studies may have been missed if SDT was not mentioned in the abstract. Another limitation was that some of the included studies, according to the CASP qualitative checklist, were of only moderate quality (n=3). Further, some were evaluation studies (n=1) or focused on designing an intervention (n=2) suggesting that they were focused on understanding outcomes rather than people’s diverse experiences. This review highlighted that the topics of the included papers were notably clinically focused which is indicative of the type of studies that have been conducted in this area. Our findings suggest that more attention could be paid to the nuances surrounding living with a chronic illness.

## **Conclusion**

In this first systematic review and synthesis of qualitative literature based on SDT, we propose that people living with a chronic illness desire to live a life free from disease. Our synthesis has highlighted that the majority of studies included in this review focused on *how* and *why* people living with a chronic illness are ‘unable’ to manage their condition and change their health behaviours. Given the theoretical underpinnings of the SDT concept of basic psychological needs, we recommend exploring people’s illness experiences more broadly to develop further understanding of the role of each construct, rather than focusing only on pharmacological interventions.

## **Declaration of conflicting interests**

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article

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## Chapter 6: The impact of severe asthma on patients' autonomy

*"...the same doctor asked me the same questions on three of my admissions, 'what do you need?' And it was like, I need this, this and this... It makes me powerful..."* (Sarah, 59-year-old woman)

(Link to video clip: <https://youtu.be/cyKviO6Be4M>)

The previous chapters highlighted the paucity of qualitative studies exploring people's experiences of living with severe asthma. Building on these findings, the following chapters (Chapters 6, 7 and 8) make a philosophical shift towards examining the subjective experiences of people living with severe asthma drawing on the self-determination theory's (SDT) constructs of autonomy, competence and relatedness.

Mention should be made here of the outcomes of the recruitment strategies employed during the interview phase of this research (Figure 8).

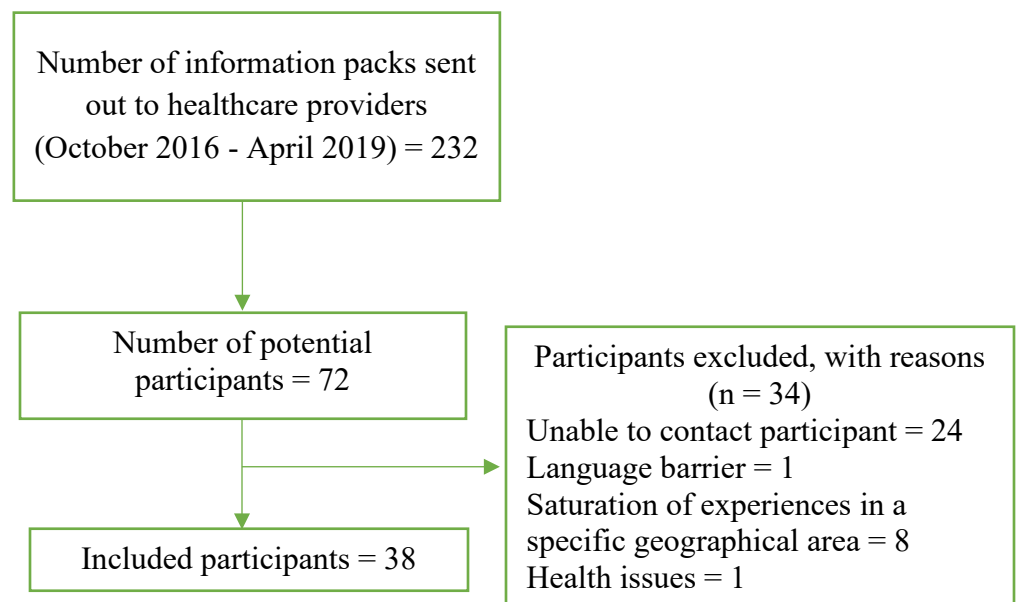


Figure 8 - Flowchart of the participant recruitment process

This current chapter presents the first published study which draws upon the SDT's construct of autonomy to explore how people with severe asthma live and manage their condition. Thematic analysis of the narratives indicated that patients' autonomy was enacted or challenged in a range of situations, such as interacting with health-care providers, maintaining employment, managing symptoms, and dealing with threats to self-identity. This study has highlighted important clinical implications for healthcare providers in identifying and understanding the day-to-day psychological and physical challenges patients face to support self-management and maximise quality of life. Overall, this study has advanced knowledge in understanding the complex dynamics of patient autonomy in contemporary medical practice, using the narratives of people living with severe asthma.

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## **Authorship statement**

The co-authors of the paper “The impact of severe asthma on patients’ autonomy: a qualitative study” confirm that Daniela Eassey has made the following contributions:

- Conception, design and implementation of the research
- Collection and extraction of data
- Analysis and interpretation of the findings
- Drafting and revising of the manuscript and critical appraisal of the content

As the primary supervisor for the candidature upon which this thesis is based, I can confirm that the above research attribution statement is correct.


Professor Lorraine Smith

The University of Sydney

11 October 2019

## ORIGINAL RESEARCH PAPER

# The impact of severe asthma on patients' autonomy: A qualitative study

Daniela Eassey BPharm, (Hons), PhD candidate<sup>1</sup>  | Helen K. Reddel MBBS, PhD Professor<sup>2</sup> | Kath Ryan BPharm, PhD Professor<sup>3</sup> | Lorraine Smith BA, (Hons), PhD Professor<sup>1</sup>

<sup>1</sup>School of Pharmacy, Faculty of Medicine and Health, University of Sydney, Sydney, NSW, Australia

<sup>2</sup>Woolcock Institute of Medical Research, University of Sydney, Sydney, NSW, Australia

<sup>3</sup>School of Pharmacy, University of Reading, Reading, UK

## Correspondence

Daniela Eassey, School of Pharmacy, Faculty of Medicine and Health, University of Sydney, Sydney, NSW, Australia.  
Email: daniela.eassey@sydney.edu.au

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## Abstract

**Background:** People living with severe asthma may have ongoing debilitating symptoms despite high-dose treatment. Clinical guidelines for severe asthma recommend concepts such as patient centeredness, shared decision making and self-management, at the heart of which lies autonomy.

**Objective:** This study aimed to explore the role of autonomy in patients' narratives about their experiences of living with and managing severe asthma.

**Methods:** In-depth semi-structured interviews were video- and/or audio-recorded and transcribed. Data were categorized using a hybrid approach to analysis incorporating both inductive and deductive methods, informed by the self-determination construct of autonomy. Analysis and comparison across and within categories were conducted to develop final themes.

**Results:** Twenty-nine face-to-face interviews, lasting 1.5-4 hours, were conducted across Australia. Patients' autonomy was enacted or challenged in a range of situations, such as interacting with health-care providers, maintaining employment, managing symptoms, and dealing with threats to self-identity. Two main themes were discerned from the analysis: (a) the desire to live an "unconstrained" life; and (b) preservation of self-identity.

**Conclusion:** Our findings suggest that autonomy is broader than conventional medical concepts such as decision making and information seeking. Future research should consider these findings when developing and implementing patient-driven self-management interventions for those living with severe asthma.

## KEYWORDS

autonomy, qualitative study, self-determination theory, severe asthma

## 1 | INTRODUCTION

Asthma is a chronic condition of the lungs, affecting people of all ages.<sup>1,2</sup> It can range from mild to severe, based on the level of treatment required to control symptoms and prevent asthma

attacks. Severe asthma affects 3%-10% of the asthma population.<sup>1</sup> The term severe asthma in clinical guidelines is now formalized as asthma that requires high-dose treatment for it to remain controlled or that remains uncontrolled despite high-dose therapy.<sup>3</sup> Severe asthma accounts for high morbidity and is estimated to

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contribute half the health-care cost of all asthma.<sup>4-7</sup> A study in the United Kingdom reported that, due to frequent hospitalizations and debilitating symptoms, two in three patients living with severe asthma are unable to hold full-time employment because of their illness.<sup>8</sup>

To improve outcomes for patients with either mild or severe asthma, guidelines emphasize the importance of patient-centeredness, shared decision making and self-management. Central to these concepts is autonomy, a term widely used and valued across the health-care literature with no gold-standard definition. Most people prefer autonomy over feeling controlled by someone or something.<sup>9</sup> However, upon acquiring a chronic medical condition, achieving or maintaining personal autonomy might be challenged through the long-term burden of symptoms, treatment and their psycho-social impacts.

Whilst most severe asthma research has been devoted to understanding pathophysiology and biomarkers, and testing novel treatments, some studies have been conducted to promote patient autonomy in asthma, and these have reflected an emphasis on increasing autonomy through education and action plans.<sup>10,11</sup> In the clinical context, autonomy has been defined as the level of involvement patients desire to gain information and make decisions about their asthma.<sup>10</sup> Theoretically, however, autonomy is broader than information seeking and decision making; research in other fields has been conducted to explore these broader aspects.

According to self-determination theory (SDT),<sup>12</sup> autonomy is a concept central to satisfying basic psychological needs for well-being,<sup>13</sup> and is viewed as an intrinsic source of motivation to master one's own destiny, to have control over one's life and behaviour, and to feel self-directed. Importantly, autonomy aligns with one's values and beliefs, and sense of self or identity.<sup>14,15</sup> Over the past 20 years, autonomy has been explored through studies such as workplace motivation,<sup>16-18</sup> health care,<sup>19,20</sup> physical activity,<sup>21</sup> education<sup>22</sup> and leadership.<sup>23</sup> Whilst such work has examined and tested the efficacy of clinical interventions for diverse issues related to behavioural change, motivation and supporting autonomy, SDT has not been utilized to analyse people's personal experiences of living with a chronic condition and the role that autonomy plays in their day-to-day lives. In the context of a long-term and debilitating condition such as severe asthma, even daily activities might present a threat to feelings of personal control, choice and decision making. A recent review identified few studies investigating patients' perceptions of living with severe asthma<sup>24</sup>; these studies focused on the clinical rather than personal aspects of the lived experience of severe asthma. The review highlighted that severe asthma can be disempowering and poses threats to identity and life roles.<sup>24</sup>

The increasing importance and popularity of supporting autonomy in health care,<sup>25,26</sup> combined with the paucity of exploratory studies of experiences of living with severe asthma, highlight the need for research in this area. Thus, the overall aim of this study was to explore the role of autonomy in patients' narratives about their experiences of living with and managing severe asthma. As autonomy can be expressed in many forms, we looked for when instances

of volition, exercising autonomy and resisting external sources of control (or not) occurred.

## 2 | METHODS

### 2.1 | Study design

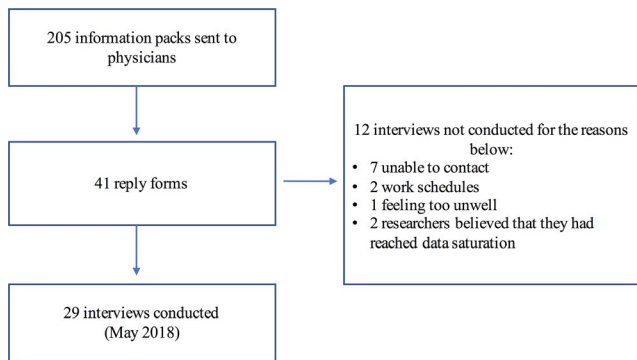
A qualitative interview approach was chosen for this study because it can provide deep insights and offer rich sources of information.<sup>27</sup> The research protocol was approved by the University of Sydney Human Ethics Committee (HREC 2015/934).

### 2.2 | Participants

Potential participants were invited to take part in the study through their general practitioners or respiratory physicians. The aim was to include participants from different ethnicities, geographical locations and sociodemographic backgrounds. They had to be  $\geq 18$  years and diagnosed with severe asthma by a specialist respiratory physician. A trained qualitative researcher (DE) conducted the interviews.

**TABLE 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 this?
4. What have your experiences been of telling family/friends/colleagues that you have SA?
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?
7. What does "support" mean to you?
8. What has your experience been of the medications you have had to take for SA?
9. Tell me what happens when you go to your Dr?
10. How is it decided on what medication/treatment you get?
11. How has the distance geographically been a problem in terms of accessing services?
12. What does "severe asthma" mean to you?
13. How have things changed over the years for you in terms of living with your SA?
14. What are your goals? (life goals? asthma goals?)
15. What do you think your Drs' goals are?
16. What are your biggest concerns?
17. To what extent do you feel your condition inhibits you from doing the things you want to do?
18. To what extent do you feel you have control over your condition?
19. What does "asthma control" mean to you?



**FIGURE 1** Flow diagram for participants included in study

### 2.3 | Data collection

The researcher conducted the interviews in the respondents' homes, or elsewhere if preferred. Interviews were collected between October 2016 and May 2018. Interviews were conducted face to face, to explore in depth the individual's experiences and perspectives of living with severe asthma. Participants were asked to tell their own story from the point when they first noticed they had breathing problems. They were encouraged to talk about their experiences of living with this condition, with as little interruption as possible from the interviewer. Interview topics were initially defined from a systematic review of the literature<sup>24</sup> but later modified as new themes emerged. Follow-up open-ended questions and prompts were used to further explore participants' experiences. An overview of the questions asked during the interview is included in Table 1. The interviews were video and/or audio recorded and then transcribed verbatim. To protect the anonymity of the participants, pseudonyms have been used in place of their real names.

### 2.4 | Data analysis

Data analysis was conducted using a hybrid method of thematic analysis, incorporating both data-driven inductive and SDT-informed deductive approaches.<sup>14,15,28</sup> The SDT construct of autonomy informed the development of a template of codes as a means of organizing text for subsequent interpretation.<sup>28</sup> The transcripts were coded using NVivo software and were read by three members of the research team (DE, LS and KR). During later stages of data collection, the constant comparison method of analysis was applied to continuously compare the views and experiences of participants, and subsequent revision of the coding template.<sup>29</sup> Themes were then developed by DE and LS. This required stepping into more complex territory whereby themes were discerned from the conceptual codes as well as from relationships between the codes.<sup>30</sup> The interpretive analysis was then reviewed by researchers with experience in qualitative research (LS, KR and HR) and in the clinical aspects of severe asthma (HR).

**TABLE 2** Characteristics of the participants (n = 29)

	N
Age range in years (mean)	19-74 (52)
<b>Gender</b>	
Female	15
Male	14
<b>Time since diagnosis of severe asthma</b>	
≤10 y	12
>10 y	17
<b>Cultural identity</b>	
Anglo-Saxon (including Italian, German, Irish or British)	27
Asian	1
Persian	1
<b>Geographical location</b>	
Metropolitan	18
Regional	7
Rural	4
<b>Employment status</b>	
Employed	10
Retired	11
Unemployed	8

## 3 | RESULTS

Overall, 205 participant information packs were sent to respiratory physicians and general practitioners to distribute to their eligible patients: 41 reply forms were sent back to the researcher (DE). Twenty-nine interviews were conducted as of May 2018 (Figure 1). Most of the participants agreed to being video-recorded. The interviews were 81-232 (mean 155) minutes in length. Table 2 shows basic demographic characteristics. All participants spoke English fluently. Eighteen reported having at least a high school education.

Our findings show that autonomy was enacted or challenged in a range of situations, such as interactions with health-care professionals (HCPs), managing symptoms and medications, employment and challenges to identity. Above all, individuals endeavoured to obtain control over their condition and valued their autonomy: *I wasn't going to let it beat me. I wasn't going to give in and there were times when I could've...* (Richard, 54-year-old man).

Our analysis revealed two themes illustrating the ways in which autonomy was enacted, or challenged, in people's experiences of living with severe asthma. These were as follows: (a) *the desire to live an "unconstrained" life*; and (b) *preserving self-identity* (Figure 2).

### 3.1 | Living an "unconstrained" life

Participants described at length how the debilitating effects of their condition, and how expectations of self and others, disrupted their everyday lives and challenged their autonomy. A strong desire to live an "unconstrained" life emerged, reflected in two key sources of

autonomy: first, through their interactions with HCPs; and second, through their desire to maintain employment.

### 3.1.1 | Health-care interactions

Making decisions and choosing courses of action regarding their health were most evident amongst participants' experiences with health-care interactions and managing medications. Overall, exercising autonomy was described as being empowering and reassuring, although sometimes autonomy was exercised even when the outcome was unwanted. At times, participants took steps to actively oppose perceived controlling efforts by others, such as HCPs, even if this might not have been in the best interests of their health.

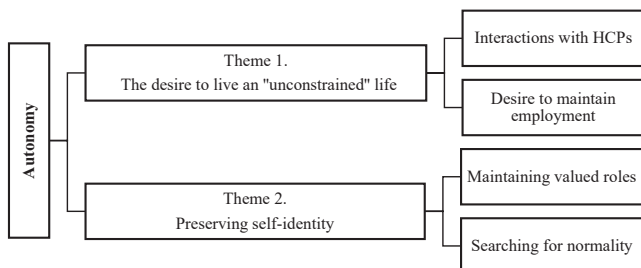
Individuals living with severe asthma valued having a sense of choice over being told what to do and feeling heard by their HCPs. Some described that they needed to feel like they were given a choice and that their values and beliefs were taken into account, before personally endorsing any health-related behaviours. They also highlighted the importance of self-initiating and regulating these behaviours. Jane reported: *Never give up...If you think there's something wrong, that someone's not saying, speak up. You've seen something [health-related issue that her healthcare providers didn't pick up] obviously but they didn't take the time to see ... speak up. (Jane, 51-year-old woman).*

Autonomy was exercised, and challenged, through a range of health-care interactions. Participants felt empowered when their HCPs asked what was important to them and gave them opportunities to make choices over health-related decisions. As Sarah stated, being able to make choices helped to thwart the helplessness of hospitalizations:

...the same doctor asked me the same questions on three of my admissions, 'what do you need?' And it was like, I need this, this and this... It makes me powerful. I think when you go to hospital you basically give away all your power a lot of the time. Not because you want to but because you're too sick to bother. So, when you get given it back it's like you've got your power back now, ... you're in charge.

(Sarah, 59-year-old woman)

Having input into treatment options and knowing about medications and their side-effects were empowering. To be reliant on health professionals and uninformed was viewed as disempowering:



**FIGURE 2** Conceptual diagram of the overarching theme and subthemes disseminated in this study

...one's empowering and the other one's totally disempowering. It sort of means, I'm relying on the fact that you [doctor] know what you're doing and if you don't, then I don't have a say anyway and sometimes I feel like, well, I think we need to discuss what the side effects are and why I'm taking it.

(Sarah, 59-year-old woman)

Being unable to breathe was described as fear-provoking, challenging their sense of personal control: *"...it's more fear than anything else. Like oh this is bad... yeah that's not a good feeling at all. Especially when you know that like the medication I've taken and that wasn't working."* (Ben, 60-year-old man). At times, the memory of having an asthma attack was a strong motivator to engage in health-related behaviours and exert personal control. Health-related behaviours, such as adhering to treatment, increasing physical activity and avoiding triggers, were valued as a way of maintaining a sense of control over severe asthma. For example, Chris reported that he would keep a six-month supply of his medication as this helped him feel like he was in control of his body; he saw not having plenty of medications as a potential threat to his sense of personal control:

I'm out of control, I start to worry. But if you've got everything there you need to control it, you don't worry... nothing worse than not being in control of your body, not being able to breathe... (Chris, 66-year-old man)

Access and adherence to prescribed medications were perceived as enablers to gaining a sense of control over one's life. For example, Jane had a system which provided reassurance that she could carry out her daily activities:

I call it lock and load [a term originally used in relation to firearms, later popularised by a John Wayne movie set in World War II] and I normally have one puffer in here [in one pocket] and one puffer in there [in the other pocket]. (Jane, 51-year-old woman)

Exercising autonomy, however, in some cases could also symbolize the ultimate loss of personal control and choice. Phil reported that it took him time to come to terms with the diagnosis. He did not understand the severity of his condition, and despite his HCP's advice to not push himself physically on the farm as this may trigger an asthma attack, he exercised autonomy, and as a result of this, he was hospitalized:

Just couldn't-couldn't believe it [being diagnosed with severe asthma], I was just super human. I just didn't think, that could ever happen to me...We have a fair few grapes, they're virtually picked at night-time...[and] it started to get really, really bad. So, I... barely got home and went into the hospital, and, they put me in intensive care. (Phil, 74-year-old, man)

Whilst avoiding triggers and adhering to medications helped to provide a sense of control over severe asthma for some participants, for others different aspects of their lives were more highly valued. Asserting autonomy to preserve these, despite the potential health problems that might arise as a result, was evident. For example, Grace reported that her specialist told her not to keep her pet budgerigar (native Australian bird). However, for her this was not an option, as the budgie was part of her family:

I was told that I was to not have budgies because they carry bird fancier's disease. Yeah but his cage gets kept clean and he runs the house. So, what my specialist doesn't know won't hurt me.

(Grace, 41-year-old woman)

Rich narratives on the importance of feeling understood, heard and valued by HCPs mainly related to events when participants felt that their views were not considered. In these instances, autonomy was expressed through active "pushing back" behaviours as a way of re-asserting control. Some reflected on a time when their views conflicted with their physicians' view of what treatment was best for them, and as a consequence took action to assert their autonomy.

My first specialist said 'oh your condition is bad', and his reaction was to stick me on cortisone medication straight away and...I went back to my GP and said look I wasn't really comfortable with him and I asked to be referred to another one.

(Dylan, 65-year-old man)

The need to feel recognized by one's doctor as an expert on living with severe asthma was also valued, as was having an equal partnership. Mel expressed that her doctor would become "aggro" every time she was hospitalized due to her asthma, and he suggested that she should go into a nursing home. She felt that her views were not considered, and one way of exercising her autonomy was to "train" her doctor:

I'm training him [general practitioner]. Um, certainly not an equal partnership no but...-- I-I tell people I'm trying to train him and to be quite honest I think I am. I think there is a lot of things he doesn't understand... they don't like anyone that is an expert over them...we are the ones that live with it.

(Mel, 66-year-old woman)

### 3.1.2 | Employment

Maintaining employment whilst living with severe asthma was a highly valued aspect of life, but the debilitating effects of the condition were a constant threat to people's capacity to work. Many examples emerged of participants pushing their physical

limits, improving fitness, planning ahead, and resisting perceived controlling efforts by others. These autonomous actions helped to preserve a sense of productivity and contribution to society and maintained social ties. Sometimes severe asthma "won," and employment was no longer an option. Dylan reported that there were days he should have stayed home due to his condition, but he decided to push through and go to work:

I never took as much sick leave as I should have unfortunately. I left the bank with over a year's worth of sick leave accumulated. Being manager of the department, I felt I had to be there as often as possible and I know I should not have been there certain days.

(Dylan, 65-year-old man)

Other participants viewed going to work as not allowing severe asthma to control their lives. Joseph reported that even when his severe asthma was flaring up, this did not stop him from going to work:

I am a very hardworking person. Normally even when I am sick, next morning I'll try to do my job, because I'm a very responsible person.... I feel if I stay at home and do nothing, I feel worse, even my body becomes worse.

(Joseph, 70-year-old man)

Threats to individuals' autonomy were also evident and emerged as not being able to have a choice and feeling like the condition had intruded in their life. For example, Jane reported that work (physiotherapist) was a big part of her life to the point that despite regular hospitalizations she had her uniform in the car and would still go to work. It was *getting incredibly incredibly difficult... [and I had] to reduce the types of patients [I] was seeing*, she had to turn down patients who came in sick, so work was *much more of a risk*. Eventually, she had to stop working and *life became very reduced*.

Despite HCPs' recommendations to cease work in a participant's preferred occupations, participants resisted these external efforts to control. Hugh (chef) reported that his HCP told him to give up work, but he felt that this advice was *kind of belittling...it was kind of insulting when he said, you know, you can't do this, you need to be more realistic* (Hugh, 19-year-old man). Despite acknowledging that he lives with an unpredictable condition and recognizing his specialist's recommendations, he was not prepared to give up his profession and responded with: *I'll take my chance*. Acting autonomously, even when that involved resisting controlling efforts of expert others, and the possibility of poor health, enabled this young person to have a sense of purpose.

### 3.2 | Preserving self-identity

Autonomy was enacted and challenged at times to preserve "self-identity." For some, having their identity embedded within the illness provided periods of psychological vulnerability and loss of personal control. This was often due to severe asthma challenging the unity between the body and self. At times, participants described that

when they felt their identity confronted by the illness they would “push back” to limit the effects of the illness on self. Self-identity was represented by being able to maintain valued roles, preserve their sense of “normality,” or for some, search for a “new normality.”

### 3.2.1 | Maintaining valued roles

Notions of self-identity, maintaining valued roles and autonomy were inextricably linked. The debilitating effects of severe asthma were a constant threat to people's sense of identity, yet there was a strong desire to maintain valued roles. Many examples emerged of individuals not surrendering their self to the illness and, instead, finding ways to preserve their roles. For example, Donna identified herself as a mother of two daughters, however, being in and out hospital due to severe asthma challenged her identity as she felt she could not always fulfil the role of being a mother.

You've got kids that want to play with you, and you can't. And the worst thing has been the amount of times I have been in hospital when it's my kids' birthdays or I've just been too sick... we try and make up for it, you know, I buy way too much stuff to try and make up for it...our big purchase was we bought them a trampoline, and that cost a fortune. Thank you credit card. (Donna, 39-year-old-woman)

Another participant, Phil, a third-generation farmer who owned eight farms, valued the ability to preserve a multigenerational family legacy whilst living with severe asthma. He compared his HCPs as experts in their field to him being the expert in farming *...they're the professionals, they're the equivalent of Phil of farming, I know anything in farming....* He spoke at length about how he would always preserve his identity of being a farmer and would not let his condition get in the way: *I started when I was 15, so. Uh, just farmed all me life... I'm doing what I love to do, and, uh, the alternative to that, take it away from me, and I definitely will die. So, there's no way I'm going to give up what I'm doing.* (Phil, 74-year-old, man).

### 3.2.2 | Searching for normality

Receiving the diagnosis of severe asthma was overwhelming and challenged participants' autonomy and sense of identity. Participants recounted working towards preserving parts of their life that had preceded the diagnosis of severe asthma, including engaging in activities and socializing. Exercising autonomy was tied up with acquiring a sense of volition and preserving a sense of “normality.” Jane described that, prior to being diagnosed with severe asthma, she defined having a “normal” life as being an active person, enjoying the outdoors and being independent: *I was living like normal.... I used to dance. I used to pick fruit. I used to mow lawns. I used to be able to take care of myself.* Since being diagnosed with severe asthma, she described struggling to define her identity. However, one way of exercising her autonomy was by being *realistic* and, rather than surrendering to the illness, preserving normality by doing things at a slower pace:

I'll be realistic ...being able to travel, to be able to go fishing, being able to cook around the campfire, being able to look after myself, still being able to help people that's been a big thing for me and I've lost that...I've got to do something whether it be you know I might try to cook dinner and fail at it but if I don't try, what am I going to do? Sit here and mourn away.

(Jane, 51-year-old woman)

Autonomy was also enacted when trying to search for a new normal. Resetting normality required negotiation and reconceptualization of a normal life by incorporating the illness. For example, Richard stated that because he had severe asthma, his father, a farmer, had to sell the farm: *It would much have affected our whole family. I should have been a fourth-generation farmer. So, it changed our whole family.* This challenged his identity, and at times, he compared what he perceived as a “normal life” to the way he now lived. The shift in his identity and the struggle for self-preservation involved an ongoing process of negotiation to find a new “*normal*.”

A normal life would be being...able to work in a normal job for the rest of your life, being able to afford to pay your mortgage, being able to afford to do all those things that money comes with. I've still got as normal a life as I can. I've got friends, I've travelled, I've got my home, which I'm still paying... I had to beat it to still be here. I've still got it [severe asthma], but it's like we've reached an agreement.

(Richard, 54-year-old, man)

Efforts to preserve “*normality*” had an impact on emotional, physical and mental health. Individuals expressed that, despite their illness, they had been able to maintain autonomy by doing things such as home chores or gardening at a slower pace, but at a physical and emotional cost. Archie still attempted to accomplish physically demanding tasks to maintain autonomy. This resulted in him feeling both physically weak and emotionally drained:

I just want to be left alone. I just want to sit in the corner of the couch and, and I'll sit there for a week...I helped the guy next door...he didn't know how to build a little retaining wall...I was just sopping sweat and he goes, 'what's wrong with you?' And like I was just dripping wet and couldn't breathe and just using the, the puffers. And it wasn't a, a big job to do. But... so you're just embarrassed...

(Archie, 58-year-old, man)

## 4 | DISCUSSION

The purpose of this study was to examine in depth the role of autonomy amongst those living with severe asthma. To the author's

knowledge, this study has provided the first insights into the role of autonomy in people's experiences of living with this condition. We argue that autonomy was challenged and enacted in efforts to: (a) *live an "unconstrained" life*: this was influenced by participants' interactions with HCPs and desire to maintain employment; and (b) *preserve self-identity*: participants sought to maintain their valued role and strived for "normality."

In the words of Dworkin,<sup>31</sup> autonomy means endorsing one's actions at the highest level of reflection; this is one of the main defining aspects of autonomy in SDT. It is crucial to autonomy that individuals feel that they can raise questions and identify or reject reasons for which they will act upon a decision, with no external influences such as manipulation or pressure from anyone else.<sup>31</sup> Our findings highlight the challenges people living with severe asthma face to preserve their autonomy to live an "unconstrained" life. One such challenge was how individuals described the importance of having a sense of choice over being told what to do, and feeling heard by their HCPs. Previous research has also uncovered various threats to autonomy such as HCPs' often paternalistic approach to treatment, both in severe asthma<sup>24</sup> and in chronic illness in general.<sup>32</sup> Similarly, patients with other chronic conditions also appreciate when HCPs support their personal autonomy.<sup>33</sup> Naik et al<sup>34</sup> expanded the concept of autonomy and recommended strategies to support patients who struggle with "executive autonomy"—the capacity to carry out treatment plans. Self-determination theory research has highlighted the importance of supporting patient autonomy in health-related decisions.<sup>9,12,13,19</sup> According to Deci and Ryan et al,<sup>13</sup> this improves motivation for making health-related behaviour changes. Health professional support for autonomy by empowering patients with severe asthma, hearing their concerns and giving them choice helps thwart feelings of powerlessness and helplessness.

Current guidelines suggest broadening the traditional biomedical approach of health care by encompassing patients' needs and values.<sup>35</sup> Our study has highlighted that the use of narratives can help to further understand the impact of severe asthma on patients' experiences of personal control, choice and decision making. Previous studies examining health-care workers' views on practising holistically reported barriers to involving patients, including time constraints.<sup>36-38</sup> However, according to Kalitzkus et al,<sup>39</sup> allowing a narrative flow in the consultation enables self-reflection on daily practice and improves patient-physician relationships without necessarily requiring a lot of time.<sup>39</sup>

Whilst adhering to medications and feeling supported by HCPs provided a sense of control over severe asthma for some participants, other valued aspects of their lives could take precedence. Our findings highlight that maintaining employment whilst living with severe asthma was a highly valued aspect of life. Research has shown that people living with chronic illnesses continually negotiate autonomy in their daily activities and in their relationships.<sup>32,40</sup> Our study participants would push their physical limits, plan ahead and resist any perceived controlling efforts by others in order to live a life where they could either maintain employment or preserve their sense of productivity. A UK study reported that due to the unpredictable

nature of severe asthma, two-thirds of patients were unable to hold full-time employment.<sup>8</sup> However, our findings go beyond those of previous studies that describe the impact of severe asthma on an individual's life<sup>8,24,41</sup> and demonstrate how autonomy was enacted by people with severe asthma to preserve a sense of productivity and contribution to society.

This study has important clinical implications for HCPs in identifying and understanding the day-to-day psychological and physical challenges patients face to support self-management and maximize quality of life. The constant challenge of having difficulty breathing despite adhering to treatment triggered strong emotions such as fear and panic. It became clear that participants were constantly battling the tension between both exerting and losing personal control. On the one hand, the memory or anxiety associated with having an asthma attack was a motivator to exert control and engage in specific health-related behaviours to control symptoms. On the other hand, the experience of severe breathlessness represented a loss of personal control, resulting in fear-provoking emotions. Studies have shown that anxiety and depression are common amongst people living with severe asthma.<sup>42-44</sup> A study by McDonald et al<sup>45,46</sup> reported that anxiety was 1.4 times more common, and depression 3.3 times more common, in people with severe compared with non-severe asthma.

Our findings highlight that, despite challenges to autonomy, patients had a strong desire to preserve their identity. This resonates with the work by Corbin and Strauss,<sup>47</sup> Bury<sup>48</sup> and Charmaz<sup>49</sup> on biographical disruption, where they describe that living with a chronic illness assaults the body and disrupts a sense of wholeness of self. Our study highlights that for some, in the context of biographical disruption, the onset of severe asthma brought about a "major kind of disruptive experience."<sup>48</sup> For others, however, it triggered autonomous actions to preserve or reconstruct their identity as a means of reorientating their lives. Furthermore, enacting autonomy by incorporating severe asthma fully into their identity was a way to maintain or reset normality. Moreover, looking at the narratives of people's experiences of living with severe asthma through the lens of autonomy has the potential to further our understanding of the complex ties between the experiences that embody the shifts in identity and the psychological efforts required to unite the body and self.

Preserving the "self" in severe asthma becomes harder when there is a constant struggle to fight the debilitating physical effects of the illness and side-effects of its treatment, and the identifications that come with the diagnosis. When trying to maintain and preserve "self" in the face of illness, individuals acknowledged the emotional cost associated with their efforts in preserving "normality." Previous quantitative and qualitative researches on patients' experiences with severe asthma note that its debilitating and unpredictable symptoms, the side-effects of treatment and the burden on their quality of life can ultimately have emotional consequences,<sup>41,50,51</sup> but there is a lack of in-depth psychological research furthering our understanding of *how* people living with severe asthma perceive their condition and *how* they behave when challenged in a range of situations. Our findings attempt to broaden and challenge the



biomedical model, and highlight that asserting autonomy to preserve their sense of “normality” and sense of self might also lead to unwanted outcomes. This suggests that exploring the individual's perspective could be used to further understand the psychological impact of living with severe asthma.

## 5 | STRENGTHS AND LIMITATIONS

Strengths of the study include its rigorous qualitative methodology and the use of a theoretical frame of reference. The interviews were conducted face to face to build a relationship, and to facilitate openness and in-depth discussions. Using a narrative illness approach, participants controlled the structure, length and content of the interviews. Their stories showed how people living with severe asthma accounted for their individual experiences of illness and health care. This revealed a range of significant psychological, emotional and physical elements of living with a debilitating condition. There are several limitations to acknowledge. First, our participants did not reflect the ethnic diversity in the Australian population; however, this might reflect access to specialist care, as 85% of patients registered in the Australian Severe Asthma Web-based Database were Caucasian.<sup>52</sup> In addition, qualitative researchers do not aim for generalizability but for transferability,<sup>53</sup> that is parallel to external validity or the extrapolation of findings to similar situations. Second, participants were invited to take part in the study through their general practitioners or respiratory physicians. This could have influenced patient selection; however, our study criteria included the current international guidelines definition of severe asthma,<sup>3</sup> which requires investigation by a clinician to exclude common modifiable causes of uncontrolled asthma. To counter possible influence, prior to the interview, participants were advised that what was said during the interview would not be shared and would have no effect on their relationship with their health-care providers.

## 6 | CONCLUSION

This study has advanced our knowledge in understanding the complex dynamics of patient autonomy in contemporary medical practice, using the narratives of people living with severe asthma. Using the SDT as a framework allowed us to question assumptions made within the biomedical model about people's experiences of living with severe asthma and their associated behaviours. It has improved our understanding by identifying alternative ways of supporting patient's self-management. Given that the majority of research aimed at developing policy and practice for severe asthma describes the need to promote patient autonomy, our findings suggest that autonomy is broader than the conventional concepts in asthma literature of decision making, information seeking, symptom management and adherence to treatment. Participants demonstrated that autonomy was enacted to maintain their values and beliefs, as well as during the process of preserving their

self-identity. The findings of this study should be considered when developing and implementing patient-driven self-management interventions for those living with severe asthma.

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## AUTHORS' CONTRIBUTION

All authors contributed to the conception and design of the study. DE was involved in acquisition of data. All authors performed analysis and interpretation of data. DE drafted the article. All authors were involved in revision and final approval of the article.

## ETHICAL STATEMENT

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

## ORCID

Daniela Eassey  <https://orcid.org/0000-0002-9164-9205>

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## **Chapter 7: Living with severe asthma: the role of perceived competence and goal achievement**

*“...we were really fit, and my son and I were right into it, now it’s just go do the basic in the...it’s just a struggle just, just to get through the next hour...”* (Archie, 58-year-old male)

(Link to video clip: <https://youtu.be/Tgo39FXnRds>)

The previous chapter explored the role of autonomy in patients’ narratives about their experiences of living with and managing severe asthma.

This current chapter presents the study examining the role of perceived competence in achieving goals. Despite the increasing importance and popularity of strategies to support patient competence in healthcare, it is important to note that people’s illness perceptions play an important role in influencing goal setting behaviours. Understanding the illness is key to uncovering the day to day physical, psychological and emotional challenges people face to preserve their sense of competence to live well with their condition. For the participants in this study, the need to feel competent to achieve asthma goals was a necessary driving force to achieve broader goals. The findings provide insight into another key component to feeling competent in managing symptoms. For people living with severe asthma, being able to manage their condition was influenced by their ability to feel a sense of psychological ownership over their condition. In light of these findings, therapeutic guidelines could be reviewed to include more holistic self-management strategies.

This chapter is accepted for publication with *Chronic Illness* (see appendix 6.1 for confirmation, manuscript accepted 19 September 2019). The participants’ supplementary quotes are included in Appendix 6.

## **Authorship statement**

The co-authors of the paper: “Living with severe asthma: the role of perceived competence and goal achievement” confirm that Daniela Eassey has made the following contributions:

- Conception, design and implementation of the research
- Collection and extraction of data
- Analysis and interpretation of the findings
- Drafting and revising of the manuscript and critical appraisal of the content

As the primary supervisor for the candidature upon which this thesis is based, I can confirm that the above research attribution statement is correct.

Professor Lorraine Smith

The University of Sydney

11 October 2019

**Title: Living with severe asthma: the role of perceived competence and goal achievement**

*Daniela Eassey, B.Pharm (Hons)<sup>a</sup>, Helen K. Reddel, MBBS, PhD<sup>b</sup>, Kath Ryan, B.Pharm, PhD,<sup>c</sup> and Lorraine Smith, BA (Hons), PhD<sup>a</sup>*

<sup>a</sup> School of Pharmacy, Faculty of Medicine and Health, University of Sydney, Sydney, NSW, Australia

<sup>b</sup> Woolcock Institute of Medical Research, University of Sydney, Sydney, NSW, Australia

<sup>c</sup> School of Pharmacy, University of Reading, UK

**Ethical statement**

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

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## **Abstract**

### ***Objective***

The overall aim of this study was to examine, among individuals living with severe asthma, the role of perceived competence in achieving their goals.

### ***Methods***

Qualitative research methods were used to conduct in-depth semi-structured interviews. Interviews were video and/or audio recorded, transcribed and analysed inductively and deductively, informed by the self-determination theory construct of perceived competence. Thirty-six face-to-face interviews, lasting 1.5-4 hours, were conducted across Australia.

### ***Results***

Feeling competent to achieve asthma goals played a role in participants' ability to achieve broader goals. Their desire to achieve their broader goals was strongly driven by their perceived ability to master managing their condition, which at times required more than medical strategies. Two main themes were discerned from the analysis: 1) "learning how to look after yourself": self-care is important and 2) "reaching an agreement with severe asthma": being at one with the illness.

### ***Discussion***

This study highlighted the influence of perceived competence on self-management and goal achievement in severe asthma. Healthcare providers could explore patients' perceived competence to set and achieve goals, as a self-management strategy. Future research should consider these findings when developing and implementing patient-driven, self-management interventions for those living with severe asthma.

## **Introduction**

Competence is argued to be an important characteristic of ‘motivational drive’(1, 2), towards long-term conditions/chronic disease self-management and promoting goal setting. A key construct of self-determination theory is competence. The theoretical underpinnings of competence suggest that strengthening an individual’s ability to self-manage their chronic illness provides them with a sense of mastery and effectance, that is, need to interact effectively with one’s environment, when responding to the complex challenges of achieving goals (1, 3, 4). The term ‘competence’ is defined as a self-belief in one’s ability or capability to perform an activity or achieve goals (5). Within the healthcare literature, ‘perceived competence’ has been described as an individuals’ perceived ability to carry out their own self-care routines in order to manage their disease (6, 7). In asthma self-management, some studies have described competence in narrow terms as the confidence to accurately interpret symptoms and follow through with appropriate self-care (8, 9).

Asthma is a chronic condition that affects approximately 330 million people worldwide with an estimated total healthcare cost in Australia approaching \$27.9 billion a year (2, 10, 11). Whilst most people can effectively manage their asthma with treatment, between 3 and 10% of people with asthma experience uncontrolled symptoms despite being on high dose treatment, and are therefore classified as having severe asthma (11, 12). Severe asthma accounts for high morbidity and is estimated to contribute to half the healthcare costs associated with asthma (13, 14). A Canadian report identified the annual cost per

patient with severe asthma to be ten times more than for those with mild to moderate asthma, and suggested that a broader paradigm of asthma management was needed (14).

Much of the applied research on self-management of asthma focuses on clinical concepts such as improving lung function, symptom management and use of action plans and medications (15). In the past few years there has been a great deal of research conducted into patients actively participating in their care and the benefits of self-management. One integral part of managing a chronic condition is setting goals (16-19). The effect of goals upon behaviour has received much empirical attention (20, 21). Goal-setting is defined as the process by which people set themselves goals and are motivated to work towards achieving them, and has been recognised as an effective technique to help facilitate health related behaviours and self-management (22-24). However, there is a no published research around goal setting and achievement amongst those living with severe asthma.

Research has shown that strengthening a patient's sense of perceived competence improves self-management (25), quality of life (26, 27) and satisfaction with patient-clinician goal setting and goal achievement (6, 7). This has been found across a range of chronic conditions including type 2 diabetes (6), respiratory (25) and cardiovascular disease (25, 27) . However, despite the push for enhancing both patient and physician perceived competence to improve health outcomes (7, 25, 28), it is important to note that people's illness perceptions play an important role in influencing goal-setting behaviours (29). Understanding illness experiences is key to uncovering the day to day physical, psychological and emotional challenges people face to preserve their sense of competence to live well with their condition.

The increasing importance and popularity of strategies to support patient competence in healthcare (7, 30), combined with the paucity of studies of how people with severe asthma live with their condition (31, 32), highlights the need for research in this area. Thus, the overall aim of this study was to examine the role of perceived competence in achieving goals when living with severe asthma, based on in-depth interviews with adults with this condition.

## **Methods**

A qualitative interpretative approach was chosen for this study because it can provide rich and deeply-nuanced insights (33). The research protocol was approved by the University of Sydney Human Ethics Committee (HREC 2015/934).

### *Patient recruitment*

Participants were invited by their general practitioner (GP) or respiratory physician to take part in the study if they were 18 years or older and diagnosed with severe asthma by a specialist respiratory physician according to international guidelines(12). The aim was to include participants from different ethnicities, geographical locations and sociodemographic backgrounds; interviews were offered in English, French or Arabic. All participants were provided with an information pack by their GP or respiratory physician and were asked to sign a consent form and complete a reply form if they agreed to take part in the interview.

### *Data collection and analysis*

The data were collected between October 2016 and August 2018. In-depth face-to-face interviews were conducted in the participants' homes, or elsewhere if preferred. Participants were asked to tell their own story from the point when they first noticed they had breathing problems. To begin with, they were encouraged to talk about their experiences of living with this condition, with as little interruption as possible from the interviewer. The interview schedule was initially developed from a systematic review of the literature and provided a guide for discussion (31). Prompts included questions about how they managed their condition and their goals. For this study, goals were defined as personal objectives (34) and desired outcomes (35). An overview of the questions asked during the interview is included in Appendix 3.5.

Trustworthiness was ensured through respondent credibility, transferability, dependability and reliability (36 - 38). During later stages of data collection, the constant comparison method of analysis was applied to continuously compare the experiences of participants, and subsequent revision of the coding template (39, 40). Following each interview, field notes were written to initiate reflection. Interviews were audio and/or video recorded and transcribed verbatim. The transcribed data were then read several times, and in addition the recordings were listened to once more to ensure the accuracy of the transcription. The transcripts were initially coded by the interviewer (DE) using NVivo software and were read by all authors of the research team. The researchers have experience in qualitative research (LS, KR and HR) and in the clinical aspects of severe asthma (HR).



A hybrid process of thematic analysis was used to interpret the data (41). This incorporated both a data-driven inductive and SDT informed deductive approach. The theoretical frame of SDT's construct of competence informed the template of codes as a means of organising text for subsequent interpretation (2, 4). The initial stage of coding involved constructing a coding framework with reference to competence, personal abilities, capabilities, and goals. Initial codes were grouped into categories according to similarities. Analysis and comparison across and within the categories were conducted to develop themes. This meant stepping into complex territory, in which the process of interpretation required a higher level of abstraction (42). Interpretation of the data is inevitably affected by the interviewer's own values, beliefs, experiences and biases (43, 44). To counter potential biases data analysis was first carried out by DE and then independently checked by three other experienced researchers (LS, HR and KR). Pseudonyms have been used to protect the anonymity of the participants.

## **Results**

### *Participants*

Thirty-six interviews were conducted. A total of 19 women and 17 men, aged between 17 and 74 years participated. All participants spoke fluent English and most agreed to being video recorded. The interviews were 81-235 (mean 147) minutes in length. Sociodemographic characteristics are summarised in Table 1.

**Table 1. Characteristics of the participants (n=36)**

	<b>N</b>
<b>Age range in years (mean)</b>	19-74 (52.5)
<b>Gender</b>	
Female	19
Male	17
<b>Time since diagnosis of severe asthma</b>	
≤10 years	16
>10 years	20
<b>Cultural Identity</b>	
Caucasian (including Italian, German, Irish or British)	33
Asian	2
Persian	1
<b>Geographical location</b>	
Metropolitan	21
Inner Regional	8
Outer Regional	7
<b>Employment status</b>	
Employed	13
Retired	13
Unemployed	10

## **Findings**

Analysis revealed that perceptions of goal-setting and perceived competence to manage severe asthma were inextricably linked. It was apparent that the success of achieving broad life goals depended on meeting asthma goals (Figure 1). Achieving asthma goals was of prime importance to participants, mainly because these goals focused on basic physiological tasks such as breathing. Feeling competent to achieve asthma goals played a role in their ability to accomplish broader life goals such as being able to travel or spending more quality time with their family. Participants' ability to achieve their asthma goals was strongly driven by their desire to master self-management of personal health. Two themes were discerned: 1) "learning how to look after yourself": self-care is important (see

Appendix 6- Table 2) and 2) “reaching an agreement with severe asthma”: being at one with the illness (see Appendix 6- Table 3).

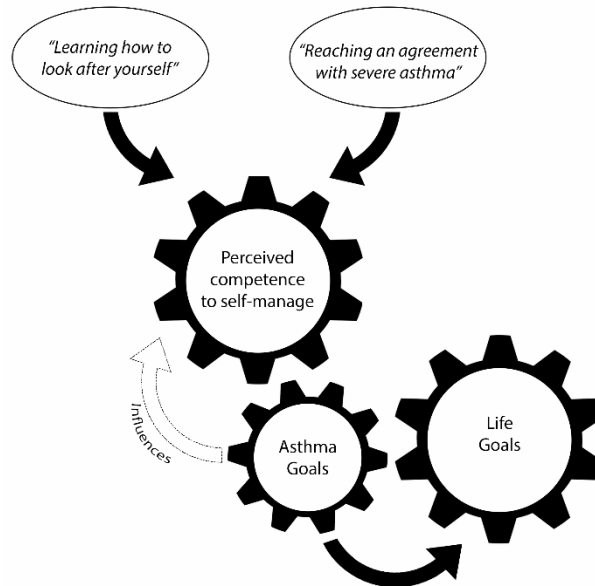


Figure 1 - Conceptual diagram of the role of perceived competence in goal setting and achieving.

*Theme 1: “Learning how to look after yourself”: self-care is important*

Feeling competent in achieving personal asthma management goals was valued and deemed an important enabler to achieving asthma goals. Taking medications was perceived to give people with severe asthma a sense of effectance in managing their asthma. Medications such as salbutamol (an inhaled quick-reliever medication, e.g. Ventolin™) and/or oral corticosteroids (prescribed for short-term treatment of serious attacks, and, for some patients, used long-term to help prevent serious attacks albeit with potentially serious side-effects) at times provided a sense of security and necessity to accomplish their goals. For

example, Jane reported that her reliever inhaler was on her at all times irrespective of what she was doing that day:

*...the rules [her personal rules] are I have to have the [reliever] puffer and spacer in my hands all the time, if I get up to move. So, if I get up from a bed to go to the toilet I have to carry the [reliever], the spacer. (Jane, 51-year-old female)*

Individuals reported that if these medications were misplaced or not on them at all times, they felt unsettled and less confident about their ability to self-care. Teresa reported panicking if she left her house without her reliever medication. She would always ensure she was prepared:

*...I've got backups... I've got them at my mum's, I've got them in the car, I have them at home. If I go to the doctor's, she's already got them set anyway... she knows that I'll panic about it and all the rest of it. (Teresa, 39-year-old female)*

Individuals also described the importance to them of taking more than the prescribed dose of their medications (e.g. salbutamol and oral corticosteroids) to achieve their tasks and perform day-to-day activities:

*I will admit that...I'm talking a lot because I'm up the Prednisone to make sure that I'm able to do this [the interview] because normally for me talking this long just, it wouldn't happen... (Jeff, 35-year-old male)*

Whilst asthma medications, particularly oral corticosteroids, have side effects that can be serious, this did not appear to limit participants' decisions to alter the dose or stop their treatment. For example, Chris reported that prednisone has 'destroyed' his eyes, nose,

thinned his skin and given him the shakes; yet he continues to take more to manage his asthma to achieve his asthma goals of feeling in control:

*I said before, it's [severe asthma] a life changing thing, a life controlling thing...I hate being out of control ...I probably wrecked me [sic]life...taking too much Prednisone...I take lots of medication, more than I need...I'm very fearful of having another real severe attack again. (Chris, 66-year-old male)*

For patients who had been commenced on biological treatments (at the time of interview, omalizumab or mepolizumab), most were enabled to re-gain a sense of competence to complete activities which they never thought would have been possible:

*[Omalizumab] made a huge difference to my life...I could go most of the day without having to use [reliever puffer]. It was absolutely incredible. I had to remind myself to take it with me...It's made a huge difference mentally as well as physically, feeling like you can participate in more things... (Charlotte, 52-year-old female)*

For one patient, however, a biological therapy [mepolizumab] aggravated her asthma flare ups and was associated with pain in her back, fingers and feet, which thwarted her ability to achieve her asthma goal of being able to breathe without feeling pain:

*... [I want] it [breathing] not to hurt...I had it [biological therapy] once a month. I only had two and I had four exasperations [sic] yeah...like this new fantastic drug that works on everyone didn't work so now we're trying this other drug... (Jane, 51-year-old female)*

Asthma action plans were considered an empowering tool to facilitate goal achievability. These plans were individualised and provided instructions on how to adjust medications in response to asthma symptoms; they were used to help a person with asthma take early action to prevent or reduce the severity of an asthma flare up. Participants reported that having an asthma action plan helped develop their sense of competence to manage their condition. Freddy described the importance of having an asthma plan because of the lack of services and support around him. He described having to heavily rely on his action plan to manage his asthma which in turned enables him to focus on life goals:

*You're merely attempting to manage a potentially debilitating, and-and a potentially fatal disease... preferably have an effective asthma plan that, you know, will work from a specialist that you adhere to strictly on a day to day basis. But, with it's not a thing that's designed to inconvenience you. It's something that will help you to maintain a normal, average lifestyle. (Freddy, 64-year-old male)*

*Theme 2: "Reaching an agreement with severe asthma": being at one with the illness*

In addition to being adherent to treatment and relying on their asthma action plan (self-care), participants expressed that they required more than medical strategies to feel competent to self-manage. They felt they needed to be more self-aware of their illness. For some, competence was expressed as their ability 1) to self-manage, and 2) to feel at one with their illness. This required transitioning from focusing on their needs as defined by the illness, to learning how to understand their body and integrate the illness into the context of their lives and broader goals.

## 2.1 Perceived competence to self-manage

Participants described the experience of “owning their body” as a crucial component to being at one with their illness and feeling competent to self-manage to achieve their broader life goals:

*I would be defined by my asthma if I didn't respect the fact it is part of my life and I didn't do anything to look after it. It would then dominate my life, because I would then be getting sick, so you find the things that work for your asthma and you get on and live life as anyone else does. It just so happens you've got asthma.*  
(Lachlan, 64-year-old male)

For others, the struggle to understand their body and achieve their asthma goals led to feelings of frustration and discouragement:

*I don't understand asthma...it's a bit depressing, Don't want to admit it but... everything's just a struggle... there's been a lot of changes but it's all out of, out of my control. There's nothing that I can do to, to fix it [fixing his asthma and being able to breathe] ... (Archie, 58-year-old male)*

Participants who reported feeling competent, felt able to manage their condition and its associated physical and psychological effects. Being able to understand their personal limits and able to control their emotions, such as panic during an asthma flare up, made them feel able to manage their condition:

*Sometimes I could be just sitting in a conversation and I'll suddenly think, gosh, but I just don't do anything, and I hope it'll pass and usually it does. Because the worst thing you can do is panic. That's what I've learnt...it's always mind over*

*matter and you've just got to try to be calm all the time... (Sara, 71-year-old female)*

Fear of simply being unable to breathe was perceived as a barrier to achieving psychological ownership of one's body. Participants described having to exercise a host of mechanisms that included meditation to reduce the potency of their fear, and renew their sense of ownership:

*... stress can actually trigger asthma, so again, if you can calm down through meditation and meditation doesn't have to be sitting quietly going "ohm" with your fingers like that... just taking yourself away from that position of stress or the thing that's triggering you... (Ben, 60-year-old male)*

Efforts to self-manage required acceptance of their perceived level of competence and constant self-negotiation of their own personal capacity to perform tasks. For example, Jeff's goal was to develop muscle strength; however, despite being aware that his severe asthma might flare up, he would still push his own personal limits:

*I was hurting [after going to the gym] and we were stopping because of my asthma playing up or my muscles were going wrong ...I think it's a big part of the fact that it's my body getting stronger, but it's also the condition going well "we know you're getting stronger, but-" it's sort of working against it... Sometimes I push myself too far, because I know "I know I can do it!". (Jeff, 35-year-old male)*

Jane reported that she had to adjust to her condition and accept her diminished sense of competence. She described enjoying doing things herself; however, it has come to a point where her asthma has taken control:



*I'm a very stubborn woman and I like to do things myself... I was cooking and I was yeah. I said no I feel great. He'd [carer] been gone an hour or an hour and a half or something and I thought geez I'm not well so I went to bed... I lay down and the next thing bang I was down and I had no-one. I couldn't ring for help; I couldn't do anything. (Jane, 51-year-old female)*

The inner conflicts of learning how to understand their body came at an emotional and physical cost. Participants described having to find different strategies such as accomplishing goals at a slower pace:

*I feel that the condition impacts my life goals on how quickly I can achieve the goals that I set out and how fast I can actually knock off each individual item...which is very frustrating, because I know I'm physically capable of doing it, it's just [my] asthma...(Jeff, 35-year-old male)*

## **2.2 Perceived competence to feel at one with their illness**

Being in and out of hospital due to the unpredictable nature of severe asthma at times eroded participants' perceived competence to manage their condition. For some, being admitted to hospital on a regular basis left them feeling defeated by their condition. So, the constant challenge of being unable to predict the next exacerbation left them feeling unable to understand their body and accomplish goals. Donna's life goal was to complete a degree at university but her uncontrolled asthma prevented her from achieving it at that time:

*...that [asthma] limited me to what I wanted to do because I had to face the embarrassment of that [breathlessness]...also, by the time you did something, you were exhausted, running with sweat, because you've had so many asthma*

*attacks...I pretty much was in and out of hospital...I wouldn't have the attendance required because of my hospitalisations and also there were days I wasn't going to be well enough... (Donna, 39-year-old female)*

Time since diagnosis emerged as a defining influence in achieving goals and perceived ownership of their body. Narratives of perceived competence to self-manage also varied depending on participants' illness trajectory and their life context. These experiences varied from inherently describing a loss of competence to developing a sense of competence by learning how to master challenging situations given their previous experience. A perceived loss of competence was prominent among those diagnosed with severe asthma for fewer than 10 years. Archie described that before being diagnosed with severe asthma, he used to compete in weightlifting competitions. Since his diagnosis, he has struggled to maintain his physical activity and as a result described a loss of competence:

*...instead of doing, ah doing the gym and we were really fit and my son and I were right into it, now it's just go do the basic in the gym just to stay, so you don't lose all your muscle and, because you can't do the cardio and physical work anymore... I'll sit, sit on the couch and next thing I'm back at, falling asleep again...it's just a struggle just, just to get through the next hour... (Archie, 58-year-old male)*

Lachlan lived with severe asthma for most of his life, and he stated not being able to do the things he would like to do. He reported having to work around his limitations and listen to his body:

*I couldn't do all the things I wanted to do, particularly socialising, partying. You just learn what your limitations are, and you work around it...you learn quickly and if you want to, you cannot listen to your body and its needs or you'll cause enormous problems, I don't want to do that, I didn't want to do that and why would anyone? So, as I said, you get to know your body with something like asthma. (Lachlan, 60-year-old male)*

## **Discussion**

The purpose of this study was to examine the role of perceived competence in achieving goals among individuals living with severe asthma. To the authors' knowledge, this study has provided the first insights into the role of perceived competence in self-management and goal setting for people with severe asthma. Overall, our findings revealed that the success of achieving competence in life goals depended on meeting asthma goals.

The need to feel competent in self-management was a necessary driving force for goal setting and achievement. Interviewees who reported diminished feelings of competence in managing severe asthma felt unable to set and achieve asthma and broader life goals. These findings parallel Ryan and Deci's proposal that an individual's competence can facilitate intrinsic motivation, whilst diminished feelings of competence serve to restrict it (45). Studies reporting on patients perceived competence and goal setting have focused on designing and implementing strategies to enhance patient competence to self-care in order to improve health outcomes (9, 30, 46). For the participants in our study, however, one of the key components to feeling competent to manage their condition was their ability to self-care, including taking medications. Research pointing to poor medication adherence has

often been published in the asthma literature, with rates of poor adherence amongst patients ranging between 30% and 70% (47, 48). Much of the research focuses on identifying ways to improve adherence to therapy for those living with asthma (49-51). However, our study shows that those living with severe asthma have expressed being adherent to treatment and at times taking a higher-than-recommended dose of their medications (salbutamol and/or oral corticosteroids were specifically mentioned) despite experiencing serious side effects. Novel monoclonal antibody therapies have been shown to have a positive impact on health-related quality of life for patients with severe asthma (52, 53). Our findings suggest that for many patients these medications enabled them to accomplish their broader life goals; but a couple of patients reported adverse effects from biologic therapy that thwarted their ability to achieve even their asthma goals. Another self-care behaviour reported in the literature is the use of asthma action plans. Several studies have reported that asthma action plans tend to be under-used by patients with asthma or not offered by healthcare providers (8, 54, 55). In contrast, our study participants with severe asthma reported that having an asthma action plan enhanced their sense of competence to manage their condition.

Whilst research has shown that, for patients' living with symptoms such as breathlessness, feeling able to manage their symptoms was influenced by their coping style and help-seeking behaviours (56). Our findings, however, have highlighted another key component to feeling competent in managing symptoms. For people living with severe asthma, being able to manage their condition was influenced by their ability to feel a sense of psychological ownership over their condition. Participants expressed the importance of being able to integrate the illness into their lives and feel at one with their illness. Psychological ownership has not been studied extensively in the healthcare literature.

Feeling at one with their condition has been described as a complex state comprising self-awareness, thoughts and beliefs (57). Sensations of fear and panic contributed to the disruption of the sense of bodily ownership. Participants described having to enlist strategies to reduce the potency of their negative emotions and develop their sense of bodily ownership. The experience of owning an illness is rooted in the idea of control (57). The time since being diagnosed emerged as a defining influence in perceived control of their body. Those who have lived with this condition for more than 10 years reported being able to understand their body emotionally and physically with greater acuity. Looking at the narratives of people's experiences of living with severe asthma, through the lens of competence, potentially furthers our understanding of the psychological efforts required to manage this condition.

Strengths of the study include its rigorous qualitative methodology, including the use of a theoretical frame of reference, and incorporating both an inductive and deductive approach to analysis. In addition, the authors discussed the analysis to compare and challenge individual interpretations. The authors frequently discussed the analysis to compare and challenge individual interpretations. A limitation of this study is that our 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, in which 85% of patients registered were Caucasian (58).

### **Practice Implications**

For people living with severe asthma the need to feel competent to achieve asthma goals was a necessary driving force to achieve broader goals. Healthcare providers should discuss

with their patients what goals are important to them and their perceived ability to achieve these goals. This can be used to understand how people living with severe asthma manage their condition and their level of perceived competence. For example, perceived competence may affect how people take their medication, interpret their symptoms, and communicate with their healthcare providers. This may provide insight into the psychological impact of living with this condition. In light of these findings, therapeutic guidelines could be reviewed to include more holistic self-management strategies. This study supports the need for deep reflection on the current practice of caring for patients with severe asthma. Identifying patient perceived competence for achieving asthma goals has the potential to unravel unmet psychological and emotional needs. Future research should consider these findings when developing and implementing patient-driven self-management interventions for those living with severe asthma.

## **Conclusion**

This study has advanced our knowledge in understanding the complex dynamics of patient perceived competence in self-management and ability to achieve goals. Our study has shown that the success of achieving goals depends on patients' perceived competence to manage their illness. Given that the majority of research aimed at developing policy and practice for severe asthma describes the need to promote self-management, our findings suggest that this is broader than the conventional concept used in the asthma literature. In addition to symptom management and adherence to treatment, self-management also includes the ability to achieve psychological ownership of the illness.

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## **Declaration of Conflicting Interest**

The Authors declare that there is no conflict of interest

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## **Chapter 8: The need for relatedness amongst people living with severe asthma**

*“[the] same lady turns around and says she has asthma too and she knows what it’s like...so [I’ll] be fine, it’s scary for me because then I think to myself is Centrelink [government service providing support to Australians who face financial hardship] going to cut me off...what am I going to do then? [cries]”* (Teresa, 39-year-old female)

(Link to video clip: <https://youtu.be/HjsLlusDWR0> )

The previous chapter examined the role of perceived competence in achieving goals, amongst those living with severe asthma.

The study examined the role of relatedness in patients’ narratives about their experiences of living with and managing severe asthma. Living with severe asthma is associated with a significant burden affecting social and working life. According to SDT, supporting the need for relatedness improves overall well-being. This is the first study to examine in depth how living with a debilitating and unpredictable condition can challenge an individual’s sense of relatedness. This shows that for people living with severe asthma feeling cared for, understood, connected to others and having a sense of belonging was valued. What is also revealed is that the overall psychological well-being was dependent upon their sense of connection to others. These findings can be instructive in furthering healthcare providers understanding of their patients’ perceived ability to manage living with their condition and provide more holistic patient-centred care for people living with severe asthma.

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## **Authorship statement**

The co-authors of the paper: “Barriers to belonging: the need for relatedness amongst people living with severe asthma” confirm that Daniela Eassey has made the following contributions:

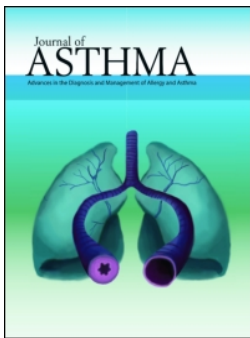
- Conception, design and implementation of the research
- Collection and extraction of data
- Analysis and interpretation of the findings
- Drafting and revising of the manuscript and critical appraisal of the content

As the primary supervisor for the candidature upon which this thesis is based, I can confirm that the above research attribution statement is correct.

Professor Lorraine Smith

The University of Sydney

11 October 2019



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

Daniela Eassey, Helen K. Reddel, Kath Ryan & Lorraine Smith

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

Daniela Eassey, B.Pharm (Hons)<sup>a</sup>, Helen K. Reddel, MBBS, PhD<sup>b</sup>, Kath Ryan, B.Pharm, PhD<sup>c</sup>, and Lorraine Smith, BA (Hons), PhD<sup>a</sup>

<sup>a</sup>School of Pharmacy, Faculty of Medicine and Health, University of Sydney, Sydney, NSW, Australia; <sup>b</sup>Woolcock Institute of Medical Research, University of Sydney, Sydney, NSW, Australia; <sup>c</sup>School of Pharmacy, University of Reading, UK

### 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  $\geq 18$  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.

### ARTICLE HISTORY

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### KEYWORDS

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  $\geq$  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](#).

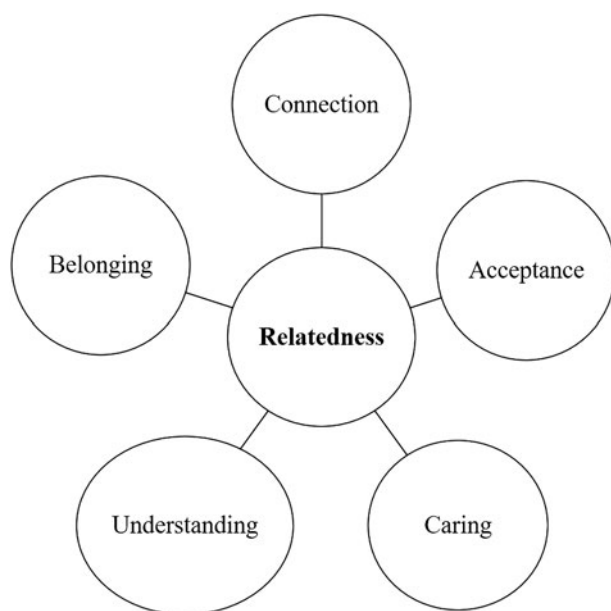
### *Findings*

“...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

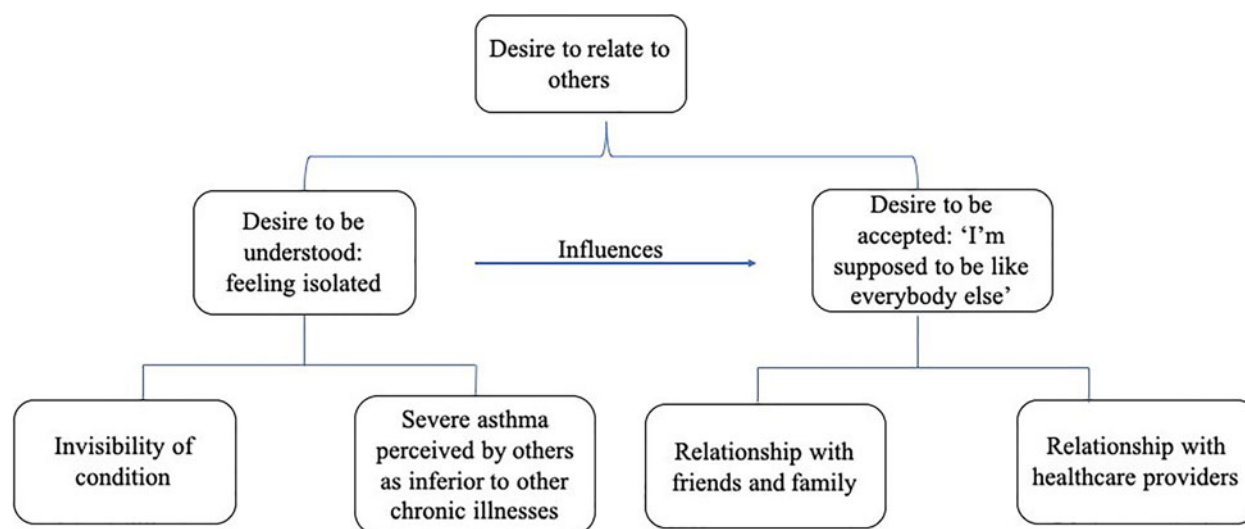


Figure 2. Conceptual diagram of the overarching theme and sub-themes discerned in this study.

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.

## Funding

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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?

**Part D:**  
**Discussion and Concluding remarks**

# Overview of Part D

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The findings of this doctoral research provide new understandings of the lived experience of severe asthma and show that the current biomedical approach of supporting patients is disconnected from the experiences narrated by participants in this study. This thesis has deepened our understanding of the physical, social and psychological challenges of living with severe asthma. The current healthcare system does not meet the needs of these people. Individuals were not solely focused on acute problems (for example, flare-ups); but also, on the ongoing sequelae of the psychological work involved in living well with the condition. The findings of this research also add to the body of theoretical knowledge, whereby identity is proposed to be an outcome of how people engage in and work through autonomy, competence and relatedness. Part D (Chapter 9) provides an overview of the principal findings, followed by theoretical advances, practice implications, study limitations and conclusion.

## **Overview of principal findings**

A main finding from the qualitative systematic review (Chapter 4), was the paucity of existing studies exploring patients' experiences of living with severe asthma. The review is the first in the published literature to explore the lived experience of severe asthma and found a previously untapped focus on personal experience rather than on clinical issues. What emerged from the analysis of the studies in the systematic review was that severe asthma was disempowering, and a threat to identity and life roles. What was important to people living with severe asthma was to achieve a greater level of personal control over their condition but these efforts received little support from their healthcare providers. However, the lack of detail in the studies on the psychological impact of living with severe asthma and the psychological effort involved in

living with this condition was presented as a gap in the literature. To these ends, a second systematic review was conducted (Chapter 5) exploring qualitative studies underpinned by self-determination theory (SDT) that examined patients' perspectives of living with a chronic illness. The second review highlighted that there are no studies which explore in depth three basic psychological needs (autonomy, competence, relatedness) from the patient's perspective. The findings of this review provided a theoretical framework for the analysis of the data in this study, which formed the bulk of this thesis (Chapters 6-8).

Findings from Chapter 6 showed that autonomy was broader than the conventional medical conception of this construct of decision making and information seeking. Participants demonstrated that autonomy was enacted to maintain their values and beliefs, as well as during the process of preserving their self-identity. The study reported in Chapter 7 examined the role of perceived competence in achieving goals. Feeling competent to achieve asthma goals played an important role in participants' desires to achieve broader 'life' goals. Their desire to achieve their broader goals such as being able to travel or spending more quality time with their family, was strongly driven by their perceived ability to master managing their condition, which at times required more than medical strategies.

Findings from Chapter 8 provided evidence that severe asthma is associated with a significant burden affecting social and working life. The SDT concept of relatedness was examined in patients' narratives about their experiences of living with and managing severe asthma. Findings show that threats towards an individual's sense of relatedness engender vulnerability and impact on a person's psychological well-being, which at times may be beyond their own personal control. For people living with severe asthma, feeling cared for, understood, connected to others and a sense of belonging was valued. It was apparent that participants' desire to be

accepted, and their overall perceived sense of relatedness, was strongly influenced by their desire for others to understand that they lived with a severe and unpredictable condition.

In this chapter, the three SDT constructs (autonomy, competence and relatedness) are “re-integrated”, and propose a new way of understanding the lived experience of severe asthma that is grounded in the narratives of participants in this study. Specifically, this chapter (Chapter 9) highlights the contributions this body of work has made to:

1. the theoretical understanding of SDT and
2. overall practice implications in patient-centred care and self-management for those living with severe asthma

Theoretical models (Figures 9 and 14) have been abstracted from the research findings and will be used to guide the discussion.

## Chapter 9: Discussion, implications and concluding remarks

### 9.1 Advances in theoretical understanding

A strength of self-determination theory (SDT) is that it has been empirically utilised as a framework for interventions in many domains including education (1), sport and physical activity (2), health (3) and parenting (4, 5). Across each of these domains, most of the research focuses on testing how autonomy-supportive versus controlled environments impact wellness and performance (6). The literature also suggests that support for competence and relatedness fosters engagement within specific settings such as education (6). However, as reported in the second systematic review in Chapter 5 there are no qualitative studies examining the theory constructs (autonomy, relatedness and competence) from the personal perspectives and experiences of people living with a debilitating and unpredictable chronic illness, such as severe asthma.

At a recent international conference devoted to SDT, Professor Richard Ryan (one of the founders of SDT) described SDT as an “incomplete theory” (7). He stated that SDT was primarily designed to enhance intrinsic motivation at the individual level. He noted that in order to enhance a person’s intrinsic motivation, it was important to examine “*what people need to flourish*”, in other words, to examine their needs, values and goals (7). Whilst SDT was used in this study as a platform to understand the personal experiences and their health behaviours, this body of work proposes that it has also provided an opportunity to understand the needs and beliefs of patients living with chronic illness.



### *9.1.1 Enriching our understanding of autonomy, competence and relatedness*

The current literature drawing on SDT lacks veracity in examining the psychological work required to live with a chronic illness and adopts a positivist approach, assigning responsibility to the patient to manage their condition (Chapter 4). Past studies have focused on implementing interventions to support people's psychological needs as a means to adopting healthy behaviours (8, 9). They have provided evidence that patients' motivation may be associated with health outcomes (8-10). For example, the majority of studies have focused on understanding how patients can be motivated to self-manage their diabetes more effectively (8, 11-13) and others have applied this framework to explore factors which can facilitate or impede healthcare providers' engagement in clinical self-management, patient-centredness and support for self-management (14). Although these concepts have been shown to have positive features for understanding and influencing patient's motivation for health-related behaviours, no studies have sought to interrogate the SDT constructs in the context of people's personal experiences of living with a long-term condition. Theoretical reflexivity is needed in the field of psychology to avoid treating concepts such as basic psychological needs as truisms (15). This study has enriched our understanding of three needs (autonomy, competence and relatedness) as well as enhanced our understanding of the patients' experiences of living with severe asthma. The following section (as per Figure 9- references 9.1-9.3) focuses on theoretical advances from the individual level.

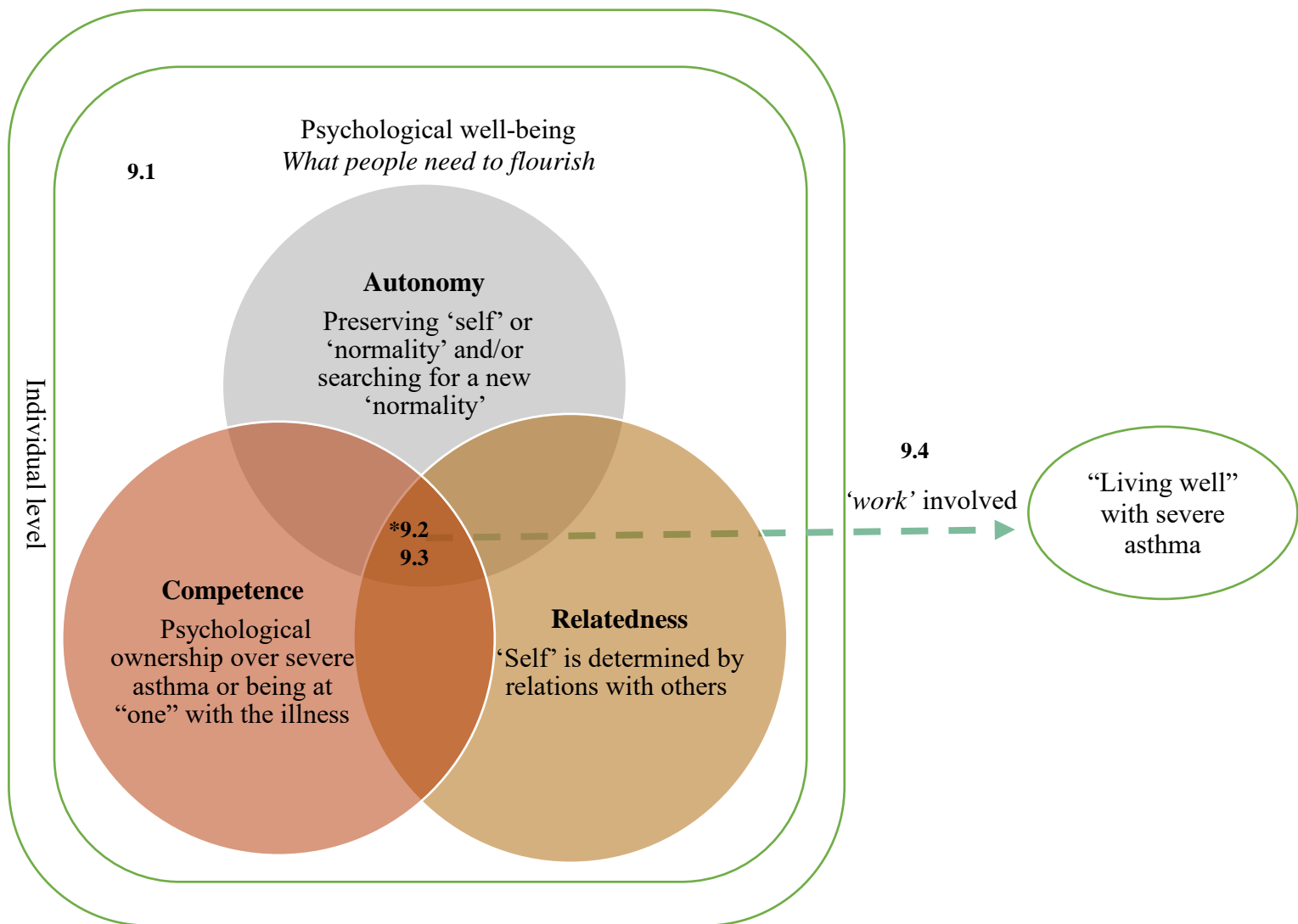


Figure 9 - Conceptual diagram summarising findings. Numerical values denote the sections in the Discussion.

\*9.2 Emotional response (for example fear, panic and anxiety)

#### 9.1.1.1 Autonomy: beyond supporting health-related behaviour change

In 2002, the WHO released a report entitled “Innovation Care for Chronic Conditions: Building Blocks for Action” (16) and reported the urgent need to address the problem of chronic diseases (17). The report advocated the need for a shift to a more patient-centred model of chronic care and emphasised supporting patient autonomy and empowering the patient to play an active role in self-management (18). However, current guidelines follow the biomedical model, in which managing a chronic illness is perceived as being under the individual’s control, and one’s ‘*successes*’ or ‘*failures*’ are one’s own (19-21). The SDT concept of autonomy relies on assumptions that people are not motivated unless they have personal control over their behaviour and feel self-directed. An underlying assumption made is that people can control their bodies (22) and changing health behaviours with the support of healthcare providers will improve health outcomes. The findings have shown that individuals living with severe asthma endeavoured to obtain control over their condition and valued their autonomy. Yet, at times the constant struggle to fight the debilitating physical effects of the illness and side-effects of its treatment challenged their sense of autonomy. This body of work questions the current assumptions made in the biomedical model and SDT, that self-management is under the individual’s control and is dichotomised as *success* or *failure*, which suggests that individuals have some ‘control’ over their illness.

This study reveals other areas in which autonomy was challenged or enacted, such as maintaining employment. Whilst adhering to medications and feeling supported by HCPs provided a sense of control over severe asthma for some participants, other valued aspects of their lives could take precedence such as maintaining employment. Research has shown that people living with chronic illnesses continually negotiate autonomy in their daily activities and

in their relationships (23, 24). It is recognised that illness can affect autonomy by challenging life plans and disrupting self-identity (25-27). Looking at the narratives of people living with severe asthma through the lens of autonomy, has potentially added new dimensions to the construct of autonomy. The findings contribute to enriching the construct with notions that autonomy plays a role in understanding the complex ties between the constant threats of illness to identity and the psychological efforts required to preserve self-identity.

Autonomy reflects more than a human behaviour in health-related behaviours but rather a fundamental reconstruction of identity. Research drawing on SDT has focused on narrow clinical concepts such as supporting patient autonomy to improve health behaviours. From the patient's perspective, autonomy is conceptualised as the psychological effort required to live well with a chronic illness, which requires maintaining valued roles, preserving self-identity and 'new' normality. Living with a chronic illness can dominate identity and permeate all aspects of life or affect the self (28, 29). Our findings highlighted that despite challenges to autonomy, patients had a strong desire to preserve their self-identity.

This body of work has added new facets to the SDT concepts of 'self', identity and normality, all of which are valued amongst people living with severe asthma. From the perspective of SDT, "the formation of identities can fulfil an individual's need for autonomy if they engage in the relevant activities as an expression of their values and experience a sense of choice while doing so" (30), p.386). The findings of this study propose that preserving the 'self' becomes a challenge when there is a constant struggle to fight the unpredictable and debilitating physical effects of the illness and the side-effects of its treatment. This resonates with concepts such as 'biographical disruption' and 'new normal'. According to theorists Corbin and Strauss, Bury, and Charmaz, living with a chronic illness assaults the body and disrupts a sense of wholeness

of self (31-35). In this study, severe asthma as a chronic condition, underpins most forms of disablement due to the unpredictable symptoms and uncertain outcomes (35).

The impact of living with severe asthma has challenged people's assumptions of themselves, and we suggest that their world parallels Bury's notion of *biographical disruption* (35). According to Bury, notions of reconstructing a 'new normality' are often linked to a view of "disablement as a relatively stable entity" (35). For some participants, the sudden onset of being diagnosed with severe asthma disrupted and controlled their life, creating an aura of uncertainty. Because of this the individual starts to focus on their bodily state, rethink their biography, identity and self-concept, ultimately as a response to their life disruptions. In this doctoral work, autonomy was enacted and challenged to preserve, or re-build participants' self-identity; if participants felt their sense of identity was challenged by their illness they would 'push back' to limit the effects on self, and rebuilding the 'self' required feeling at one with the disease. Individuals would exercise their autonomy to preserve their normality or search for a 'new normality'(35).

This idea, however, has not accounted for all experiences. For those who have lived with severe asthma most of their lives, autonomy was enacted to preserve the self in which the illness was not perceived as 'biographical disruption' but rather a 'biographical flow' (36) or even 'biographical reinforcement'(37). This body of work argues that instead of disrupting their biography, severe asthma reinforced aspects of biography. That is to say, autonomy was enacted to provide continuation of their biography and to preserve their sense of self, since they were used to a lifetime of the constant challenge of obtaining control over their condition. The findings of this doctoral work broaden and challenge the underpinning assumptions about autonomy and highlight, from the patient's perspective, that asserting autonomy to preserve

their sense of ‘normality’ or ‘self’ might also lead to unwanted emotional outcomes. The convergence between SDT, as a theoretical model, and this body of work prompts a more granular interpretation of autonomy. SDT suggests that the formation of identity can fulfil people’s need for autonomy if they engage in activities they value and have a sense of choice (30). This study has broadened and added a new dimension to this construct. Autonomy plays a role in the experiences that embody the shifts in identity and the psychological efforts required to unite the body and self. This includes maintaining values and beliefs, as well as the process of biographical rethinking to preserve self-identity and searching for a new ‘normality’ (Figure 10).

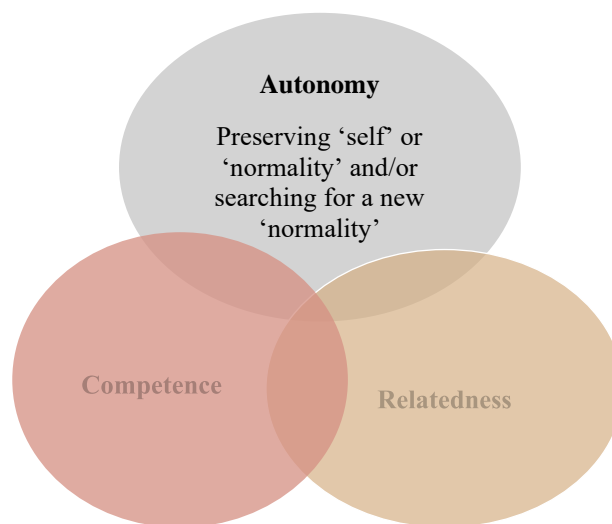


Figure 10 - Conceptual diagram summarising the role of autonomy amongst people with severe asthma

#### 9.1.1.2 Supporting competence: beyond holding individuals responsible

This study reveals that competence amongst people’s experiences living with severe asthma is a multidimensional concept. The theoretical underpinnings of competence suggest that healthcare providers should support an individual to self-manage as this may provide them with

a sense of mastery or effectance (competence) when responding to complex challenges to achieving goals (38-40). Much of the applied research relevant to health, and drawing on SDT, has focused on designing interventions to change attitudes of HCPs towards their care for patients (41). Only a few studies have looked at experiences of patients living with a chronic illness (Chapter 4) however these have focused on reporting the construct of competence through a biomedical lens (for example explaining non-adherence and lack of self-management). In contrast, this doctoral work examined perceived competence from the patient's perspective which enabled us to look beyond health outcomes and add to the theoretical underpinnings of the current concept suggested by SDT.

SDT suggests that people feel competent when they are capable and effective in achieving desired outcomes (42). Within the health literature, perceived competence for self-management of a chronic illness, such as diabetes, is applied through a biomedical model of treating symptoms and improving adherence (8). A study by Patrick et al., (39) applied the SDT model of health behaviour to predict medication adherence, quality of life and physiological outcomes. The authors reported that healthcare providers' support for patient's competence related positively to quality of life and medication adherence, and overall health outcomes (8, 39). This study highlights that in addition to feeling confident about being adherent to treatment and using their asthma action plan (self-care), participants expressed that they felt they needed to be more self-aware of their illness. Feeling competent in their ability to cope with the illness was expressed as being 'at one' with their illness. This meant transitioning from focusing on their needs as defined by the illness, to learning how to understand their body and integrate the illness into the context of their lives and broader goals.

The research reported in this thesis reveals that the need to feel competent in self-care is a necessary driving force for goal setting and achievement. Interviewees who reported diminished feelings of competence in managing severe asthma felt unable to set and achieve goals. These findings parallel Ryan and Deci's proposal that an individual's competence can facilitate intrinsic motivation, whilst diminished feelings of competence serve to restrict it (43). From the perspective of SDT, it is critical for patients to experience themselves as the originators of their actions toward behaviour change (40). Ryan and Deci suggested that feelings of competence can be enhanced by setting optimal goals together with the patient and by giving practical advice and supportive feedback (3). However, this body of work adds new meaning to this construct by highlighting the daily psychological struggle participants face to understand their body and achieve their asthma goals. This led to unwanted outcomes such as feelings of frustration and discouragement. The inner conflicts of learning how to understand their body came at an emotional and physical cost. Participants described having to find different coping strategies such as accomplishing goals at a slower pace. I note that the current concept of competence does not embrace the emotional cost that may come from self-management. This is discussed in detail in Section 9.2.

Individuals living with severe asthma expressed feeling fear of the unknown and loss of ownership over their body. The findings conceptualise competence as the perceived capacity to be at one with their illness. Psychological ownership has been described as a state in which individuals feel as though they have personal control over a target (e.g. an illness) (44). This area has not been studied extensively in contemporary health and psychology (29). According to Pierce et al., (45) psychological ownership is grounded in the motivation to be efficacious in relation to one's environment. Due to the need for feelings of competence, individuals are driven



to explore and manipulate their environment (45). They propose that notions of ownership manifest in the emotion commonly associated with ‘my’ or ‘mine’ (45), which requires constant reflection between the individual and the illness. The motivation and work required for ownership of the illness is in part grounded in self-identity (29, 45). Drawing on the findings of this study, motivation or perceived competence for psychological ownership over their illness was driven by their need to maintain or facilitate the development of their self-identity which they did by learning how to integrate their illness into the context of their lives and broader goals. (Figure 11).

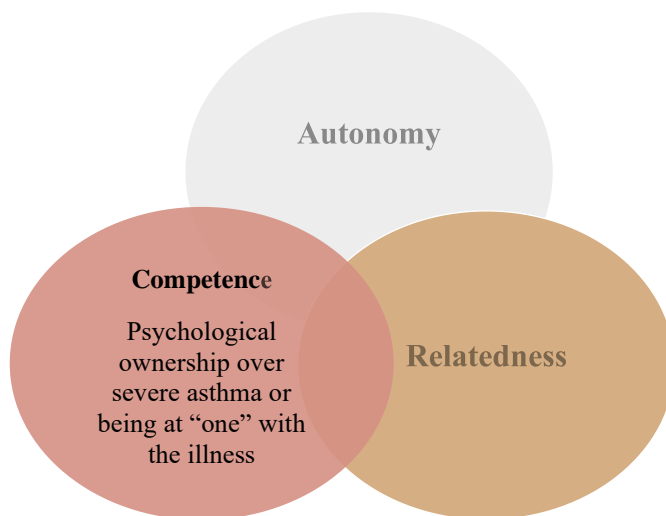


Figure 11 - Conceptual diagram summarising the role of competence amongst people with severe asthma.

#### 9.1.1.3 Relatedness: beyond feeling connected to others

Another psychological need that is largely overlooked, yet increasingly recognised in applied settings, is the need for relatedness. According to SDT, feelings of relatedness, at both within- and between-person level, positively and significantly predicts overall well-being (40). Deci

and Ryan suggest that people are more likely to flourish if they develop a sense of relatedness (4, 40), or the need to feel like they belong and connect with others. They further state that relatedness is important for motivation and thus, a social environment that fails to nurture this is expected to result in a person's well-being being threatened (40). This study indicates the challenges people living with a chronic illness face to preserve their sense of relatedness. There was a range of experiences reported, from feeling accepted by others to being judged and uncared for, all of which influenced their overall desire to live well with their condition. Those who reported feeling understood by others felt accepted and a sense of belonging. Those who reported diminished feelings of relatedness felt frustrated, angry and anxious. This was a common experience amongst participants. This study showed that relatedness can be challenged by people who occupy a position of power and, as a result of feeling a loss of control, can leave individuals with a chronic illness feeling powerless and psychologically vulnerable. Findings from the analysis suggest that workers, such as those in social support and healthcare provider roles, influenced participants' sense of connectedness and belonging. Participants reported changing healthcare providers if they felt unaccepted, uncared for and misunderstood. At an organisational level, they expressed feeling judged and misunderstood which left them feeling vulnerable and powerless.

This study has enriched the current thinking of relatedness, where, according to SDT, is the feeling of belongingness and connectedness with others, but more this doctoral work further suggests that participants' perceived connectedness to others seems to enhance their perceived ability to connect to themselves (46, 47). According to ten Have et al., (48) the self is determined and constituted in relation to others. Looking beyond the SDT concept of relatedness, this doctoral work recognises the psychological effort required to preserve the self from others. For

those living with severe asthma, the disconnect between body, self and feelings of connectedness may impact on their overall psychological well-being. Thus, this body of work proposes that the stability of the self is influenced by the ability to be able to control social surroundings (Figure 12).

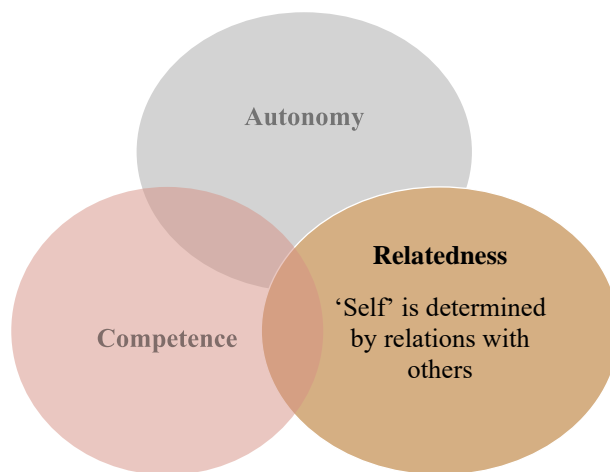


Figure 12 - Conceptual diagram summarising the role of relatedness amongst people with severe asthma.

## 9.2 Emotions as a mediator to wellness

This study has also provided evidence that emotions are a driving factor for the need for wellness. The findings suggest that flourishing psychologically is mediated by emotions (Figure 9- reference 9.2). According to SDT, emotions are understood as neither “*good or bad but rather as a source of information*” (30, p.443). Ryan and Deci perceive emotional regulation as a matter of internalisation involving experiences of autonomy, competence and relatedness, where internalisation serves as an indicator of optimal development (i.e. self-regulation of health-related behaviours). They suggest that emotional regulation reflects greater self-determination because it requires awareness of feelings and need satisfaction (49); and they

argue that by taking interest in emotions, healthcare providers can have a better “radar” for feelings to resistance to behavioural change (30). However, within the SDT literature, emotions are predominantly viewed as an outcome variable that needs to be managed rather than a mediator of achieving wellness.

This doctoral study has added new meaning to the theory. Whilst SDT has provided a broad explanation of emotional regulation and its role in improving behaviours, our findings suggest that emotions play a dynamic role in people’s experiences of living with severe asthma. The findings of this doctoral work suggests the need to maintain or facilitate the development of identity was mediated by emotions. Positive emotions such as feeling understood, cared for and at one with their illness, influenced their determination to live well with severe asthma. Negative emotions such as fear, panic and anxiety, however, played a paradoxical role. On the one hand, these emotions were interpreted as a driving force to well-being, as the fear of living with this condition was a strong motivator to exert personal control over their condition. On the other hand, it was clear that participants were constantly battling these strong emotions and, as a result, socially isolated themselves, felt unable to achieve life goals and integrate their illness into the context of their lives.

This suggests that psychological flourishing (through autonomy, competence and relatedness) is mediated by emotions. The findings of this doctoral work resonate with the self-regulation model of illness developed by Leventhal, which provides a framework for understanding how individual symptoms and emotions experienced during a health threat or diagnosis influence people’s perception of illness and their coping behaviours (50, 51). This theory suggests that it is necessary to identify the emotional reactions that emerge during threat episodes (51, 52), as they function as a response to restoring emotional and psychological well-being (52). This

thesis suggests the concept of emotion in the SDT model and its surrounding literature, is only broadly stated and fragmented. Future research drawing on SDT in health should further examine the concept of emotion and its impact on psychological needs.

### 9.3 Summary: re-integrating the constructs

This doctoral study adds new dimensions to this theory, whereby identity is proposed to be an outcome of how people engage in and work through autonomy, competence and relatedness (Figure 13). In the context of well-being, or living well with severe asthma, people felt powerless and psychologically vulnerable if they felt that the illness took control over their lives or thwarted their sense of autonomy, competence and relatedness. This meant there was an imbalance of their needs, or in other words, a disconnect between body, self and feelings of connectedness.

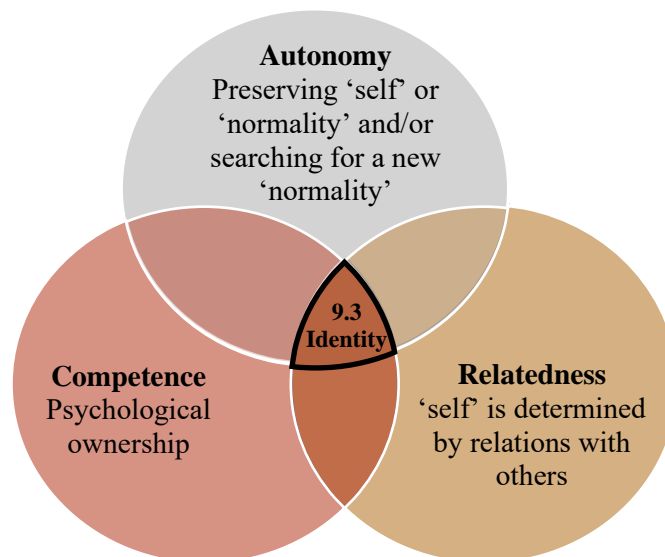


Figure 13 - Conceptual diagram integrating the constructs

The findings have shown that severe asthma as a long-term condition becomes an illness, or a pervasive part of their life, if it threatens the individuals' sense of autonomy, competence or relatedness, or as the findings have shown, their identity or sense of being whole. Thus, the

findings show that people's stability of self is influenced by one's ability and the psychological effort required to control their social surroundings. It also requires transitioning from focusing on their needs as defined by the illness to learning how to understand their body and integrate the illness into the context of their lives. By examining *how* and *what* people living with severe asthma need in order to flourish, this thesis suggests that fostering these three psychological needs will enable people to, in the words of Entwistle et al., (53) 'live well' with their condition, rather than simply 'manage their condition well'.

#### **9.4 Applying the constructs to the principles of chronic care**

Moving forward, this thesis proposes the concept of the *work* involved in *living well with severe asthma* rather than *managing* severe asthma. It was clear from the findings that living well with severe asthma was more complex than current thinking suggested by the health literature, that being adherent to medications and staying away from triggers will improve quality of life (54, 55). The journey in living well with severe asthma requires psychological, physical and emotional *work*.

Living well with severe asthma requires more complex *work*, which involves conquering daily unwanted emotions such as fear of living with the condition, the panic associated with being unable to breath or the frustration of the impact it has had on their lives. This resonates to a large extent with Corbin and Strauss theory on the '*work*' involved in managing a chronic illness (31). They point out three lines of work performed by the individual living with an illness and their social support (i.e. family, friends and caregivers). The first is illness work, which is the work directed at the illness such as taking medications. The second line of work is biographical work, which refers to the actions taken to accommodate the illness into one's sense of self and

body (31). The third line of work is the everyday life work, which covers the remaining work context (i.e. the work not directly related to the illness) such as housekeeping, personal care, general shopping and raising children (56). Furthering this concept and drawing on the theoretical framework, this thesis highlights the work required by those living with severe asthma to transition from focusing on their needs as defined by the illness, to learning how to understand their body and integrate the illness into the context of their lives.

This doctoral research also provides insight into the *work* involved into setting goals carried out by people living with severe asthma. In addition to being able to self-care, individuals reported that they required more than medical strategies to feel competent to self-manage. The experience of ‘owning their body’ was perceived as a crucial component to being at one with their illness and feeling competent to self-manage to achieve their broader life goals. This thesis suggests that identifying and supporting the ‘work’ required to live with severe asthma can facilitate the development of flexible frameworks for considering both the kinds of goals that patients might set and the broader purposes of healthcare that current SDT models tend to neglect. In summary, the *work* required to live well with severe asthma needs to consider the complex interplay between the body and self and the associated psychological, physical and emotional impacts.

## **9.5 Practice implications**

The findings of this thesis show that there is a need to reflect on current clinical practices, and follow the aims of policy and theory that emphasise closing the “power” gap between patients and health care providers, by supporting patient autonomy, understanding patient values, capabilities and beliefs, and to more broadly support people to live with their condition. It is

clear that examining the real-world perspective of the individual through a theoretical lens has enabled an in-depth understanding of *how* people with severe asthma live and manage their condition, *what* makes them flourish psychologically and *how* this has influenced their overall well-being. The outcomes of this research should impel healthcare stakeholders to reflect and consider the implications of these perspectives for practice and policy.

To understand the nuances of individual experiences and their interaction with contextual systems the ecological perspective provides an understanding of how complex factors may influence an individual's overall well-being (Figure 14). Focusing solely on attributes and behaviours of the individual is an artificial perspective. The contextual factors include: 1) the changing dynamic aspects of illness and personal needs, 2) the person's interactions with family, health professionals and immediate settings such as health care services/systems (microsystem) and 3) societal influences (macrosystem).

The Ecological System Theory, developed by Bronfenbrenner, proposes that individuals live in an environment with “power settings” (57). According to Bronfenbrenner, the world of an individual is influenced by their social network and interactions, services and systems, and society (57-59). Each interaction has a direct or indirect effect on an individual's well-being. This theory suggests that there are four systems that an individual interacts with, each nested within the other. The first and most immediate layer is the microsystem, this encompasses the individual's interpersonal interactions and immediate surroundings, such as with immediate family and healthcare providers (57). The second layer from the individual is the mesosystem, this encompasses the different *interactions* between the actors of the microsystem (57), for example, the relationship between the individual's partner and their healthcare provider. The third layer is known as the exosystem and consists of elements of the microsystem which do



not affect the individual directly but may do so indirectly (57). For example, if the individual's partner were to lose their job this would affect them in an indirect way such as financial stress. The final layer is known as the macrosystem and this is thought to be all encompassing societal beliefs that influence an individual's wellbeing, such as policy makers.

Using Ecological System Theory, the learnings from patient experiences in this study gives some pointers towards supporting a number of microsystem and macrosystem recommendations. Given that the focus of this thesis is on the individual, the mesosystem and ecosystem recommendations have been excluded as they occur without the presence of the individual.

#### **9.5.1      *Microsystem recommendations (healthcare system)***

9.5.1.1 Supporting psychological needs in clinical practice

9.5.1.2 Use of narratives in an evidence-based world

#### **9.5.2      *Macrosystem recommendations (policy makers)***

9.5.2.1 Patient-centred care and self-management

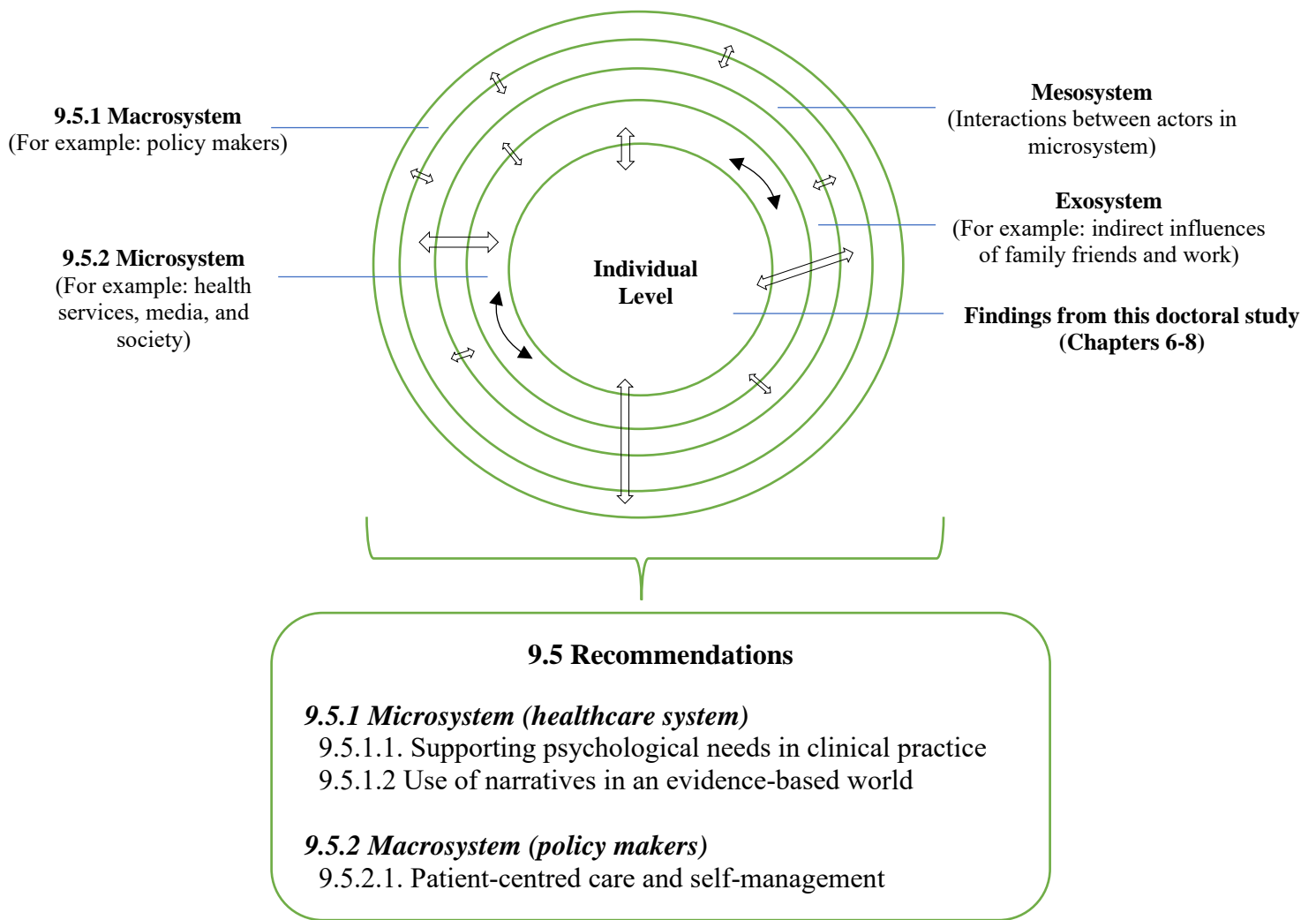


Figure 14 - Conceptual diagram summarising practice implications.

## 9.5 Recommendations

### 9.5.1 *Microsystem recommendations (healthcare system)*

#### 9.5.1.1 Supporting psychological needs in clinical practice

This thesis has potentially added new meaning to how people manage and live with severe asthma. SDT served as a framework to understand *how* people live with severe asthma and foster their sense of wellness. The current literature applying SDT in the context of health has predominantly followed a biomedical approach and has not recognised the psycho-social issues (9). Psycho-social issues are complex and cannot be “fixed” with a biomedical approach. A recommendation from this body of work is to target the dynamic between the individual and the microsystem, such as the relations between the individual and their immediate environment (e.g. during healthcare interactions).

Based on theoretical advances and the current literature drawing on SDT, healthcare providers caring for those living with severe asthma should provide autonomy-supportive care. This would require identifying and implementing the experiences that are relevant and meaningful to patients. Taking an autonomy-supportive approach would, firstly, involve nurturing the need for competence which we suggest would require providing a scaffolding for people living with severe asthma to achieve both asthma and life goals, and for healthcare providers to provide empathetic feedback which is not evaluative. Secondly, supporting their need for autonomy would encompass understanding the patient’s perspective, seeking their input and ideas, offering meaningful choices, empathising with obstacles, minimising the use of controlling language and providing a rationale for recommendations. Finally, nurturing their sense of relatedness would require conveying respect to the patient, making them feel valued and

significant, showing care and concern if they face challenges, and providing them with opportunities to contribute to decisions.

In the context of well-being, this body of work highlights that the stability of the self is influenced by an individual's ability to undertake psychological *work* required to control their social surroundings and transition from focusing on their needs as defined by the illness to learning how to understand their body and integrate the illness into the context of their lives. Thus, patients need to be allowed to legitimise their "suffering" beyond the physical. As Arthur Frank notes, "suffering is the subversive voice in the biomedical discourse; it is central among all the things that do not fit." (60, p.360). Suffering appears to be categorised as valid when spoken about, yet aspects of suffering which remain unspeakable are ignored (60).

#### 9.5.1.2 Incorporating the use of narratives in an evidence-based world

"Storytelling seems to be a natural reaction to illness. People bleed stories, and I've become a blood bank of them." (61, p.21)

(Anatole Broyard, who in his pathography reconstructed the story of living with his illness)

An alternative approach to traditional clinical practice, may be the use of narratives. This approach would include accommodating what matters to people and illuminating the challenges involved in the *work* required in living well with severe asthma. The following section draws on our theoretical advances and proposes incorporating illness narratives in daily medical practice as a tool to interpret information on the patient experience of illness (62, 63).

A pressing recommendation from this study is that healthcare providers should rethink their approach to caring for people living with a chronic illness. The current debate is focused on the

dualism between narrative medicine and evidence based medicine (64), also known as narrative-evidence based medicine (63, 65). This approach is associated with better diagnosis and treatment plans (66). The use of narratives involves taking the patient's subjective role and making sense of the human experience of illness, and arguably a more richly textured way of understanding their realities and representation of living with a debilitating condition, more than medical accounts on their own could ever offer.

This thesis suggests that healthcare providers need to practice and adopt a 'narrative evidence based' practice to their care (63, 65). Narrative-based medicine (NBM) has shown to have a positive effect on daily practice rather than adding already existing pressures such as time constraints (66, 67). According to Kalitzkus et al., (67) physicians who practice both evidence-based and narrative-based medicine are more resilient, empathetic, find greater meaning in their work and results in greater patient satisfaction. NBM has been criticised as being time-consuming (68), however, studies have shown that allowing a narrative flow does not necessarily require a lot of time. Time spent gaining understanding is also time well spent, whereby practicing NBM has shown to be associated with better diagnosis and treatment (66). This approach in daily medical encounters has consisted of being sensitive to the context of the illness experience, establishing a diagnosis in an individual context instead of merely the description of the disease, exploring differences, sharing power and reflection upon active listening (67, 69). In doing this, the use of narratives in medicine have been shown to validate the experience of the patient but also encourage self-reflection in the physician (70).

Patient experiences often collected in interviews have come to play a significant role in health care (71). This body of work proposes that story telling is a powerful tool that has enriched our understanding of the physical, psychological and emotional impact of living with severe

asthma. Through the interpretation of the meaning of living with an illness, it's been reported that healthcare providers could incorporate the patient's journey into their clinical range of skills (72). In recent years, there has been a push to introduce the patient's voice in the education of future healthcare providers. Inclusion of patient narratives in healthcare curricula has the potential to disrupt traditional power hierarchies that have permeated healthcare education for decades. Traditionally, patients are perceived as the passive recipients of instruction from healthcare providers. Patient narratives gives voice to those living with an illness and moves them from being passive to active participants in their healthcare. The HealthTalk website is used across the globe to teach and train future healthcare providers to learn more about patients' perceptions of living with an illness (73-78). Research has shown that students taught using videos from the HealthTalk website performed significantly better on their clinical exams and reported feeling more confidence while interacting with patients (74). There is also evidence to show that the use of these narratives may be used as a tool to develop students' reflexivity in relation to the behaviours associated with compassionate care and practice (76).

Narratives become an opportunity to give voice for people to articulate the illness experience and their suffering, and to provide it within a time framework (64, 79). Arthur Frank argues that the use of narrative is a way for patients not to "surrender their bodies to medicine" but to "try and hold their own story" and "telling stories is the attempt , investigated by the body's disease to give a voice to an experience that medicine cannot describe" (80, p.18). The research findings of this thesis highlight the disruptive experience of living with severe asthma, an experience in which physical and psychological traces shape identity and the Through the use of narratives people living with severe asthma reconstructed their life story and connected past events and present experiences of their illness. Furthermore, these

autobiographical accounts highlighted the importance of considering illness as a disruptive event to life and the psychological and emotional work involved towards re-establishing a “new normal” life. The biomedical model is critiqued to lack attention to the person behind the patient (72, 81). Narratives in particular, have valuable contributions in medical practice to attempt to understand what it is like on an everyday basis to live with an unpredictable condition, the experience of having to make life-changing decisions, and the reality of facing possible death (82). Using illness narratives in practice provides patients with moments of reflection; this research has highlighted that living with severe asthma has subjected patients to moments of separation to their body. Indeed, Foucault states that patients are under the “medical gaze”, and at times this can separate their body to his or her integral identity (83).

Furthermore, narratives offer an alternative definition to enriching clinical practice. Grob et al., (84) suggest that listening closely to what patients’ own words convey may be the most time efficient and meaningful path to truly personalised medicine. It is a recommendation that the field of narrative medicine should be incorporated in practice. This would remind healthcare providers that illness unfolds in stories, that clinical practice emerges in the intimacy between teller and listener, and that healthcare providers are as much witnesses to patients’ suffering as they are of treating the illness. Whether policy makers call this enterprise, patient-centred care or narrative medicine, it is proposed that recognition needs to be made of the challenges of living with a chronic illness on the embodied self.

## 9.5.2 *Macrosystem recommendations*

### 9.5.2.1 Re-framing the concept of self-management and patient-centred care

This doctoral study examined SDT's constructs and the concerns about current approaches to long term condition management. Together with the insights from theoretical framework, this thesis suggests re-conceptualising the way current guidelines articulate self-management of severe asthma. This study proposes re-framing the concept of "self-managing severe asthma" to "living well with severe asthma". The concept of *living well with* a chronic illness resonates with Entwistle and Cribb's work on enabling people with a chronic illness to live well with their illness (53, 85). They emphasise the importance of healthcare interactions that are inclusive of biomedical, psychological and social aspects health and illness, supporting patient autonomy and reducing power hierarchies between patients and healthcare providers (53, 85). Broadening the positivist concept of 'self-management' would be a translation of the theoretical work of Entwistle and Cribb (53), which would include prioritising how to live well with a chronic illness.

Applying patient-centredness to self-management programs and interventions typically consist of providing patients with learning opportunities and resources to gain these skills with the aim of supporting their autonomy and 'empowering' them to become competent partners in their care (20). It is narrowly orientated towards educating and motivating patients to adopt behaviours recommended by their healthcare providers (62, 85, 86). Though certain self-management programs have been effective, this has not been the case overall. Self-management interventions have resulted in smaller than expected improvements in patient outcomes (87-89).



Despite the growing emphasis of self-management, this doctoral work argues for the value in examining the patients' perspective including their values, needs and illness experience.

This thesis has been the first to demonstrate the *work* required for patients to live their own lives on their own terms, and the efforts required in their care. Severe asthma is not curable: people living with this condition are aware that they will live with this condition for the rest of their lives. Living with this condition has complex and dynamic implications which can be significant for many aspects of people's lives. It also has fluctuating symptoms, which may not always be predictable, so at times patients live with uncertainty. The findings of this study have highlighted the psychological, physical and emotional challenges faced daily. It is increasingly clear that current policy makers and service leaders have focused instead on services and approaches to healthcare that were developed to deal with more acute health problems (90, 91); in isolation these approaches are not appropriate for those living with severe asthma.

This study highlights key issues relating to the current approach in providing care for people living with severe asthma and suggests a shift from focusing on supporting patient 'self-management', which often is linked with putting responsibility on the individual, to 'enabling people to live well with their condition'. Findings from this research have challenged the existing assumptions about the current way of suggesting managing severe asthma. In light of these findings, a pressing recommendation is to move away from the current biomedical model currently being used in clinical practice, towards providing more meaning by drawing from the individuals' own biography. The focus should be on enabling people to live well with severe asthma which may be more of an adequate conception for support for self-management.

## 9.6 Strengths and Limitations

The strengths of this doctoral research include its systematic qualitative methodology, and the use of a theoretical frame of reference. Participants from various geographical locations, social and occupational backgrounds, and age were included to represent a range of experiences. The interviews were conducted face to face to build a relationship, and to facilitate openness and in-depth discussions. Using a narrative illness approach, participants controlled the structure, length and content of the interviews. Their stories showed how people living with severe asthma accounted for their individual experiences of illness and health care. This revealed a range of significant psychological, emotional and physical elements of living with a debilitating condition. Previous research has identified the burden of living with severe asthma and the impact it has had on quality of life (92, 93), however these have been described in the absence of a comprehensive theoretical model. SDT was selected to address these shortcomings.

There are several limitations that must be acknowledged. First, our participants did not reflect the ethnic diversity in the Australian population; however, this might reflect access to specialist care, as 85% of patients registered in the Australian Severe Asthma Web-based Database were Caucasian (94). In addition, qualitative researchers do not aim for generalizability but for transferability (95), that is parallel to external validity or the extrapolation of findings to similar situations. Second, participants were invited to take part in the study through their general practitioners or respiratory physicians. This could have influenced patient selection; however, our study criteria included the current international guidelines definition of severe asthma (96), which requires investigation by a clinician to exclude common modifiable causes of uncontrolled asthma. To counter possible influence, prior to the interview, participants were advised that what was said during the interview would not be shared and would have no effect

on their relationship with their health-care providers. Finally, the doctoral candidate conducted all of the interviews and subconscious bias may have been brought to the interviews. To mitigate this, a broader team were included in all aspects of the study from planning, designing and reviewing of the interviews to analysing and interpreting the data. Additionally, after each interview the interviewer wrote field notes and re-read the transcripts.

## **9.7 Concluding remarks**

The current literature examines the impact of living with severe asthma by *describing* experiences rather than *explaining* illness behaviours. This body of work provides new understandings of the lived experience of severe asthma. Using self-determination theory as a lens provided a philosophical insight into what makes people living with severe asthma flourish psychologically and how this has influenced their overall well-being. This thesis offers empirical evidence of how living (well) with severe asthma requires physical, emotional and psychological *work*.

Overall, these findings challenge the current status quo regarding supporting people to live well with severe asthma. It seems that the current system may not meet the needs of these people. This involves greater attention both at the micro and macro levels. To bridge the power gap between the individual and their healthcare environment would require supporting people to live well with their condition beyond medical management. It is clear that there is an urgent need to reflect on current clinical practices and educate healthcare providers about illness experiences. This thesis has demonstrated that to be patient-centred when supporting self-management, would require exploring differences, sharing power, and understanding people's psychological needs by entering the person's world, a world different from traditional medicine.

In a healthcare environment, that is increasingly prioritising understanding patient values and beliefs, the current body of work makes a timely contribution to the field, serving as a useful framework to challenge the current approach in severe asthma care.

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# Appendices



**Appendix 1:**  
**A qualitative meta-synthesis of people's  
experiences of living with asthma**

## **Authorship statement**

The co-authors of the paper “‘This illness diminishes me. What is does is like theft’: A qualitative meta-synthesis of people’s experiences of living with severe asthma” confirm that Daniela Eassey has made the following contributions:

- Collection and extraction of data
- Analysis and interpretation of the findings
- Drafting and revising of the manuscript and critical appraisal of the content

As the primary supervisor for the candidature upon which this thesis is based, I can confirm that the above research attribution statement is correct.


Professor Lorraine Smith

The University of Sydney

11 October 2019

**REVIEW ARTICLE**

# “This illness diminishes me. What it does is like theft”: A qualitative meta-synthesis of people’s experiences of living with asthma

Kristen Pickles MPH<sup>1</sup> | Daniela Eassey B.Pharm (Hons)<sup>2</sup>  | Helen K. Reddel  
MBBS PhD FRACP<sup>3</sup> | Louise Locock MPhil, PhD<sup>4</sup> | Susan Kirkpatrick BSc (Hons), MA<sup>4</sup> |  
Lorraine Smith BA (Hons), PhD<sup>2</sup>

<sup>1</sup>Centre for Values, Ethics & the Law in  
Medicine, University of Sydney, Sydney, NSW,  
Australia

<sup>2</sup>Faculty of Pharmacy, University of Sydney,  
Sydney, NSW, Australia

<sup>3</sup>Woolcock Institute of Medical  
Research, University of Sydney, Sydney, NSW,  
Australia

<sup>4</sup>Nuffield Department of Primary Care Health  
Science, University of Oxford, Oxford, UK

**Correspondence**

Lorraine Smith, Faculty of Pharmacy,  
University of Sydney, Sydney, NSW, Australia.  
Email: lorraine.smith@sydney.edu.au

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**Abstract**

**Background:** What matters to people in their everyday experiences of living with asthma is influenced by a diverse range of personal, social, medical and environmental factors. Previous reviews of the asthma literature have largely focused on medical aspects of asthma or specific population groups with particular needs.

**Objective:** To identify, describe and synthesize from the available qualitative literature the views and experiences of adults living with asthma.

**Method:** We systematically searched for qualitative studies reporting on the personal experience of living with asthma. A meta-synthesis approach was used to analyse and interpret the data. Key themes relating to personal perspectives on asthma were identified and grouped into overarching concepts.

**Results:** We identified 26 studies. There was a paucity of literature on the physical burden of asthma symptoms and the role of social support. Our synthesis generated a central concept of the “work” associated with living with asthma: work was of a personal nature, and at times an intensely emotional experience. Individuals tailored their behaviour in response to demands of the physical and social environment, including interactions with health-care professionals.

**Conclusion:** This is the first systematic review of the qualitative literature reporting on people’s own perspectives of living with asthma. Our findings draw attention to the nuances and sensitivities surrounding patient experiences of self-management. Medical care is a central plank of managing chronic conditions, but our health-care systems are now expected to deliver patient-centred care. Considering the broader aspects of asthma management, beyond that of symptoms and treatment, will help to facilitate comprehensive care.

**KEYWORDS**

adults, asthma, chronic illness, lived experience, qualitative synthesis

## 1 | INTRODUCTION

Asthma is a common chronic lung disease that cannot be cured. It affects as many as 334 million people of all ages in all parts of the world, causing an estimated 346 000 deaths annually.<sup>1</sup> It is well established in the existing literature that asthma has a significant impact on physical, psychological and social well-being, albeit with considerable variation between individuals. In 2010, asthma was ranked 14th in the world in terms of extent and duration of disability.<sup>2,3</sup> Asthma often interferes with daily living,<sup>4</sup> is associated with poorer self-assessed health status and is a substantial burden in terms of time off work.<sup>5</sup> Much of this impact comes from the physical effects of asthma symptoms, but there is also a significant social and emotional impact. Previous studies have reported a high rate of mental health problems among people with asthma,<sup>6-9</sup> including anxiety and panic attacks affecting between 6.5% and 24% of people,<sup>10</sup> a prevalence 3-10 times higher than in the general population.<sup>11,12</sup> Further, the direct and indirect economic burden associated with asthma is one of the highest among chronic disease due to the significant health-care utilization associated with this condition.<sup>13</sup>

Not surprisingly, clinical practice guidelines for the management of asthma mainly focus on medical aspects of treatment. Guidelines provide evidence-based recommendations about diagnosis, assessment and appropriate use of medications and non-pharmacological strategies, to minimize asthma symptoms and the risk of adverse outcomes such as flare-ups and asthma-related death. However, despite advances in medical care, poor outcomes for patients persist. Patient adoption of asthma self-management practices, as recommended by health-care professionals (HCPs), remains low. One factor may be discordance between patient goals for managing their asthma and those of the medical profession: an analysis of patients' personal goals found that 35% of those goals did not map to the medical elements of the 2006 Australian asthma guidelines.<sup>14</sup>

More recently, asthma guidelines have increasingly emphasized the need for patient-centred care, taking into account the patient's perspective, finding out the patient's own goals for their asthma, and using shared decision making to engage the patient in a partnership to manage their asthma. This has shown to improve asthma outcomes and patient engagement.<sup>15</sup> However, the extent to which a patient-centred approach has been implemented in clinical practice is unclear. It is an on-going challenge for both patients and health-care professionals to discuss self-management strategies in everyday consultations.<sup>16</sup>

One explanation could be a lack of research evidence about the patient's experience of living with asthma. The viewpoints of people about their day-to-day personal experiences of living with asthma, including its management, are extremely important. Reviews conducted so far have focussed on specific medical questions or population groups (eg, adolescents) rather than the broader personal experiences of adults living with asthma.<sup>17,18</sup> Currently, there is considerable disparity between research exploring the health priorities of people living with a range of chronic conditions, including asthma, and the management and

treatment priorities of HCPs.<sup>19-25</sup> This body of research reveals that HCPs focus strongly on asthma symptoms, their triggers and taking medicines, whereas people with chronic conditions are concerned with more personally relevant and broader lifestyle issues such as exercise, fatigue, sleep and stress reduction, with a lesser focus on disease-specific problems such as use of medicines.<sup>18,26</sup> Personal and social factors, life goals and choice all appear to play a role in the ways in which people with chronic illnesses manage their condition. Exploring the perspectives of those most closely concerned—the people living with asthma—is an important step in furthering our understanding of the specific needs of those affected.

Published systematic reviews have examined specific aspects of asthma management, such as asthma action plans.<sup>27</sup> However, there is currently no comprehensive systematic review (qualitative or quantitative) of the *personal experiences* of adult patients living with asthma. That is, what matters to people with asthma and how it has affected their lives.

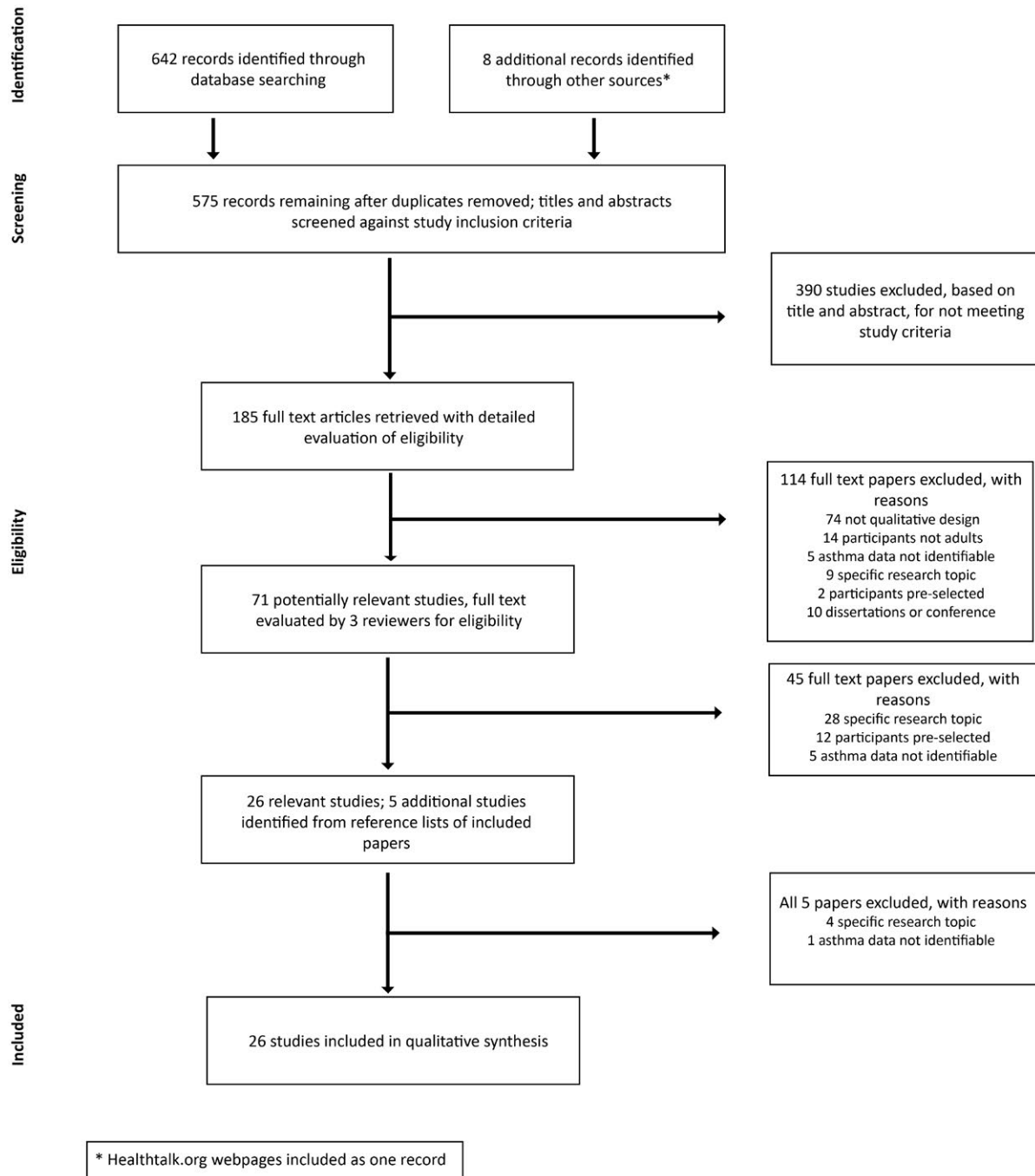
Integrating qualitative research studies into a synthesis will generate new insights and understandings of the existent empirical work in this important area. The objective of this systematic review is to identify, describe and synthesize from the available qualitative literature the views and experiences of adults living with asthma. We ask the question, "How do people living with asthma experience their condition?"

## 2 | METHODS

We conducted a systematic review and synthesis of the qualitative evidence describing adult experiences of asthma. The review was reported using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Figure 1).

### 2.1 | Search strategy

A comprehensive literature search was conducted using the electronic databases: MEDLINE via OvidSP, PsycINFO via OvidSP, PubMed, CINAHL, EMBASE, Sociological Abstracts and Google Scholar for empirical studies reporting on the lived experience of adults with asthma (search strategy available in Appendix A), from inception to December 2015. Databases were selected due to their coverage of medical and allied health information. The journals *Qualitative Health Research* and *Qualitative Research* were searched using keywords relating to asthma. Additional references were sought by searching the reference lists of relevant studies. The review includes a study of experiences of asthma by the Health Experiences Research group, disseminated on the healthtalk.org website;<sup>28</sup> each of its 25 topic-based webpages were referenced separately.<sup>29-53</sup> There is evidence for the appropriateness of including the healthtalk.org website as a reliable source of qualitative data. The website was previously used in a systematic review by the Evidence for Policy and Practice Information and Co-ordinating



**FIGURE 1** Flow of information through the different phases of a systematic review (based on PRISMA reporting flow chart)

Centre (EPPI-Centre) on young people and obesity.<sup>54</sup> The EPPI-Centre review found the healthtalk.org website to be a highly rigorous and relevant source. In addition, it was the only study to cover all themes found in their review.<sup>54</sup>

## 2.2 | Study eligibility

Studies were included if: (i) the article reported on the personal experience of adults living with asthma. We focused on the literature on adult experiences only because the experiences of children with asthma would be reported mainly through their parents, and

adolescents' experiences are distinctly different from those of adults or children;<sup>55</sup> (ii) the data collection and analysis methods were reported as qualitative; (iii) the publication reported original primary data; and (iv) the publication was in English language only, due to lack of resources for translation. This review considered studies that focused on qualitative data or included a qualitative aspect, including, but not limited to, designs such as phenomenology, grounded theory, ethnography, illness narrative and action research. We excluded (i) studies that focused on a specific medical question rather than the personal experience of living with asthma, (ii) studies where participants were preselected by their inclusion in another study,

because of the potential for sampling bias or modification of their experience, and (iii) studies that were specifically about the experiences of living with "severe asthma"; this condition, affecting around 5%-10% of the asthma population, is characterized by failure to respond to optimized conventional asthma treatment, and the diagnosis is established only following specific detailed investigations.<sup>26</sup> For the same reason, data from interviews in healthtalk.org<sup>28</sup> with patients who were clearly identifiable as having severe refractory asthma were also not included.

We identified 575 reports of which 26 met the inclusion criteria for the synthesis (Figure 1). Results were merged using reference management software (Endnote), and duplicates were removed.

### 2.3 | Data extraction and analysis

Two reviewers (KP and HR) extracted the data onto a data extraction form for qualitative analysis. The data extracted from the studies included specific details about study location, date of publication, qualitative method, participants, recruitment (primary or secondary care), study aim(s), methods for data analysis, principal experience(s) explored, diagnosis and definition of asthma, medications and duration of diagnosis.

This study was a meta-synthesis of the qualitative literature. We used this systematic and iterative method to integrate themes and synthesize results across the studies into taxonomies detailing the range of conceptual findings. The synthesis was led by KP and LS. Views reported by participants in the original studies, including the authors' interpretations of those experiences, were extracted verbatim and became the data for the synthesis. We compiled tables summarizing the main themes, and conclusions drawn, about people's experiences of asthma, as reported in the papers. Themes and concepts identified in the original studies were examined in relation to one another and across the studies. The reviewers went back and forth between the original papers, the extracted data and the tables of reported concepts and themes continually during the analysis. We constructed codes and categories iteratively from the text to capture the meaning and content of the participants' perspectives. Preliminary interpretations were presented to the wider team for critical analysis and refinement. By considering the data within the framework of our research question—"How do people living with asthma experience their condition?"—we explored the possibility of more abstract or analytical themes or concepts. The process culminated in the development of a "line of argument,"<sup>56</sup> bringing the range of conceptual findings together and, crucially, going beyond the content of the original studies.

### 2.4 | Quality assessment

Criteria for assessing the quality of published qualitative research are contested.<sup>56</sup> Some authors question the appropriateness of using structured quality appraisal tools to assess qualitative research because of the diversity of approaches in collecting, analysing and interpreting qualitative data.<sup>56,57</sup> There is little empirical evidence in relation to excluding qualitative studies based on quality assessment,

and quality appraisal guidelines and checklists do not necessarily produce greater consistency of judgements about which studies to include in a qualitative synthesis.<sup>58</sup> Concerns have been expressed about less well conducted, but more insightful studies being excluded from qualitative syntheses.<sup>58</sup> Accordingly, and like authors of previous qualitative syntheses,<sup>59-61</sup> we considered the quality of the studies on the basis of their conceptual contribution, that is the relevance and usefulness of their findings to our research question.

## 3 | RESULTS

From 575 potentially relevant studies, 26 satisfied our inclusion criteria (Appendix B). The included papers were published between 1993 and 2014, from the United States (8), Australia (7), United Kingdom (7) and Denmark, Portugal, Turkey, Canada and the Netherlands/Canada (one each).

Participants were mostly recruited from hospitals or hospital emergency departments (number of studies=11) followed by primary care (number of studies=5). The favoured qualitative method was semi-structured interviews, and data analysis was mostly thematic.

The number of participants included in the studies ranged from 4 to 95 people. There was a considerably higher proportion of female participants, consistent with asthma being more prevalent among females than males in the adult population.<sup>3</sup> Participant age varied from 18 to 73 years (not all studies reported patient age). Eight studies specified the inclusion of a minority group, predominantly African American.

The included articles reported on a range of contexts relevant to individual experiences of asthma: thirteen reported on asthma management,<sup>40,41,45,62-70</sup> six articles on patient experiences of emergency care,<sup>42,71-75</sup> eight articles about asthma medication use and treatment,<sup>37-39,44,76-79</sup> four articles about patient and physician communication,<sup>43,53,80,81</sup> two articles on quality of life,<sup>82,83</sup> one on asthma and the workplace,<sup>47</sup> seven on general experiences of asthma,<sup>46,48,50,51,84,85</sup> two articles on asthma and lifestyle issues<sup>49,86</sup> and six on the symptoms and causes of asthma.<sup>30-35</sup>

The included studies varied in design; both study design and content were considered to be of reasonable quality and of direct relevance to this review.

From the 26 studies, 64 experiences were extracted and grouped into 20 categories. Four synthesized concepts were produced from these categories:

1. Individual experiences of asthma are shaped by diverse physical and social environments (Table 1);
2. Individuals tailor their behaviour to their immediate context (Table 2);
3. Living with asthma necessitates on-going periods of cognitive and emotional adjustment (Table 3); and
4. Living with asthma involves both positive and negative interactions with the health-care system (Table 4).

We present the summarized results in Tables 1-4. Each table represents collective observations we derived from looking across all

**TABLE 1** Synthesis 1: Individual experiences of asthma are shaped by diverse physical and social environments<sup>a</sup>

Categories	Findings—the experience
The physical burden of asthma	Physical symptoms can be frightening “panicky,” “choking,” “I was fighting” <sup>65,82</sup> “breathing through a straw,” “suffocating,” “drowning” <sup>34</sup>  Asthma symptoms are unpredictable “...Because some people you can [imitates someone gasping with an asthma attack] but sometimes I don't get that, I just have a very, very, tight, tight chest. And that's all the symptom I can get. So I'm not always, for the medical profession they have a sort of a check list...but not everyone meets that check list criteria every time.” <sup>34</sup>  Diminished capacity “I want to take a deep breath comfortably. I want to run. You suffocate me when you are inside me” <sup>85</sup> “it was terrible. I, I could not walk across a normal living space...I couldn't really live a normal life. I mean, when my asthma was bad it was just so bad I really, I, actually I didn't want to live because I just couldn't do anything.” <sup>32</sup>
Feeling judged by others	Feeling judged by family member “it's all in your head, mum” <sup>70</sup>  Feeling judged by society “I do worry about what other people think about my asthma...I become concerned that they'll think, 'Oh my goodness we've got somebody with asthma, what are we going to do?' And actually I just want to say to them, I'm fine and I can manage this. And I'll let you know if I'm not.” <sup>51</sup>  Feeling judged by employer “You must be on the bitch medicine again” <sup>78</sup> “this guy's going to be sick all the time, so we won't bother” <sup>47</sup>  Feeling judged by health professional “When I was at the hospital...the doctor said 'You're not sick, go home...' I didn't go there because I had a little scratch on my finger” <sup>67</sup>  Experience overruled by medical authority “I tell him it's [medication] not working and he tells me he's the doctor” <sup>80</sup>
Judging oneself	Feeling guilty when wanting space from children due to asthma  Questioning legitimacy of experience “it is illegitimate to call in sick because of asthma. It's just silly, right”; <sup>84</sup> “Am I wasting everybody's time” <sup>63</sup>  Delay seeking help because asthma not a “serious” condition “I call the ambulance... when my lips are blue; You don't feel sick enough if you call one [ambulance] yourself” <sup>64</sup>  Feeling embarrassed about having asthma “I find it embarrassing to even have asthma”; <sup>70</sup> “you think you are sort of decrepit if you're asthmatic” <sup>76</sup>
Age of diagnosis	Childhood diagnosis “it was round when I was about ten, I was playing sport. I used to play a lot of sport when I was younger. I still do now...Initially when I was to go back to it, I found it hard to breathe...and just, just wasn't able to keep up really. And then ...your body does adjust even with the inhaler, you get used to it and you find yourself being able to sort of compete with everyone else, being as fit as everyone else.” <sup>31</sup>  Adulthood diagnosis “I was really shocked [about being diagnosed with asthma], 'cause I just thought 'how can someone as fit as me get asthma?' [laughs].” <sup>32</sup> “I realised that it wasn't just a matter of fitness, it was actually a medical condition that I had then. And that was when I had to, kind of admit to myself that I was a wheezy person...And I was really anti-medicine. So I found it quite hard to take on board that I was an ill person that needed to take medicine...” <sup>32</sup>  Childhood diagnosis “it's [asthma] become second nature...once you get into it...you find yourself being able to sort of compete with everyone else...” <sup>31</sup> “there are going to be anger management issues there and resentment that I don't so much have because... I've not known life without it.” <sup>32</sup>
Learned responses	Conditioning: learning from family experiences “smacked” as a child “for keeping people awake” [with her chronic cough]; <sup>65</sup> “it was always [name] and her cough - we all just got used to it” <sup>69</sup>  Conditioning: learning from personal experiences “Asthma is part of me like my bad temper” <sup>76</sup>

<sup>a</sup>The categories and themes reported in the following tables represent a synthesis of those reported by the authors of the original studies.

studies; they are our interpretation of the evidence. The “categories” were extracted from the data, either in our words or according to how the primary studies categorized the data. The “findings” column

presents the experience of asthma as described in the primary studies. Participant quotations extracted from the original studies illustrate the final four core concepts.

**TABLE 2** Synthesis 2: Individuals tailor their behaviour to their immediate context

Categories	Findings—the experience
Concern about possible judgement from others	<p>Disassociating oneself with “asthmatic” identity</p> <p>Selectively disclosing asthma status “You have to be careful who you tell”<sup>76</sup></p> <p>Choosing not to talk about asthma with others “I would not just talk about my asthma with others...I don't want them to think I am a pussy”<sup>84</sup></p> <p>Not participating in activities likely to trigger symptoms in public or inconvenience others “I usually do not take a walk with others because I don't want to slow them down”<sup>84</sup></p> <p>Concealing taking medication in social situations “If you are with strangers it is embarrassing to take medication in front of them...I do not take my medication in unknown territory”<sup>84</sup></p> <p>“Sure you have to take your inhalers from time to time, and sometimes, I guess when you go to a new place for instance you join a new club or you're with a new group of people there is a factor where you don't want them to see you blowing on the inhaler, because it looks quite geeky. It looks, it doesn't look too, too cool.”<sup>37</sup></p> <p>“I don't know why. It was just like, it's almost an admission of weakness [using a reliever], you know, there's something.... You know, I don't want to be seen as sickly as weak you know, but it's not, you know, you're not really sickly with it, it's just something that's just gone wrong.”<sup>37</sup></p> <p>Concealing taking medication in the presence of employers</p>
Normalizing condition and experience	<p>“Soldiering on”</p> <p>“I come out of hospital and go straight back to work.....if I'm fit enough to be out of there I'm fit enough to be at work”<sup>64</sup></p> <p>Avoiding activities that will compromise employment</p> <p>Asthma is routine As “routine as putting one's watch on in the morning”<sup>76</sup></p> <p>“That's just so important, it's just part of the morning and night routine, before you clean your teeth, you take your inhaler, breathe in, wait for ten seconds breathe out, if you need another dose you take it.”<sup>41</sup></p> <p>“You can always see there's someone with the same symptoms as you or, you know, if not worse than you kind of thing. And that's that is one of the things I think about online forums is that they can be quite reassuring in the sense that you're not the only person that's living with this condition and these symptoms...”<sup>45</sup></p>
Taking proactive measures	<p>Seeking information</p> <p>Planning or anticipatory actions “I used to go to bed with my shoes on, it used to be so bad. Now at least I put a pyjama top on”<sup>71</sup></p> <p>Becoming computer literate to research asthma</p> <p>Obtaining a personal peak flow meter to monitor asthma<sup>72</sup> “I measure my peak flow, that's the volume that you're able to inhale and exhale. I measure that usually three times a day and keep records of it...And if my peak flow shows that I'm sort of 20% below what I ought to be, or below my sort of personal best in terms of peak flow output then I start using prednisolone.”<sup>41</sup></p>

### 3.1 | Synthesized line of argument: “work”

Our synthesis of the findings culminated in a line of argument about the active and passive “work” of living with asthma: “passive” being the more routine aspects of the experience itself, and “active” comprising efforts by the patient to present as living normally or actively defending against asthma. The “work” was at times an intensely emotional experience. A variety of cognitive and behavioural strategies were utilized by people living with asthma to negotiate the demands of their immediate environments, including interactions with health-care professionals (HCPs).

#### 3.1.1 | Individual experiences of asthma are shaped by diverse physical and social environments

As presented in Table 1, some participants judged themselves according to their experience of asthma, and questioned the legitimacy of that

experience. Personal experiences were greatly shaped by everyday interactions with the external environment. Some environments were more physically, socially and emotionally challenging to “work” within than others. For example, some participants described delaying seeking health care because they had been conditioned to feel embarrassed by their asthma, while for others asthma was just another part of their personal make-up.

Of note were the participants who reported experiencing negative interactions, judgement or de-valuing of their personal experience by employers, family and health-care professionals; “when I was at the hospital on the Friday, and the doctor said ‘You're not sick, go home!’ ... Yes [I felt judged]. Very much, and very much lately. Oh yes. We've seen it more and more over the last couple of years. I often wait, I wait until the last minute.”<sup>67</sup> For some, those situations served as concrete cues prompting them to question how they relate to their asthma, and subsequent efforts to work with or against their asthma.



**TABLE 3** Synthesis 3: Living with asthma necessitates on-going periods of emotional and cognitive adjustment

Categories	Findings—the experience
Managing asthma by denying	<p>Denying asthma diagnosis            “I don’t know if I could cope if I really had it”;<sup>76</sup> “Well the doctors say I’ve got asthma but I’ve been hard to convince of that actually”<sup>69</sup></p> <p>Minimizing experience/condition            “I’ve got a bit of a cough but it doesn’t mean I go to an asthma clinic. I wouldn’t belong”;<sup>76</sup> “I’m not sick enough”<sup>84</sup></p> <p>Denying need to take medications            Taking medication every day “it’s really admitting to yourself that you are an asthmatic with a real problem here”<sup>76</sup></p>
Fearing the associated implications of having asthma	<p>Fearing dependency on medications</p> <p>Fearing or experiencing side effects from medication            “...I’m not exactly a slim person in the first place, and that’s very hard to control, not wanting to eat more, and that’s something that I find very hard. But, it’s [taking oral steroids] the lesser of the two evils.”<sup>38</sup>            “I didn’t like it at the start because it’s almost like just, I mean I think in everybody’s head there’s a kind of a, don’t go there factor with taking steroids because it feels like you’re, you know, polluting your body in some way”<sup>38</sup></p> <p>Fearing unpredictability of asthma            “I feel worried about the places I visit, my health, and the possibility of an asthma attack all the time”<sup>85</sup>            “... Asthma is an absolutely awful condition because we all take breathing for granted until you can’t breathe. To not be able to breathe and ...it can also be painful for your chest is terrifying, and you just sometimes think, ‘Well, if the next one doesn’t kill me the next one might...I’m not enjoying life right now’. And my mate died in the holidays ‘I really wish this would end’ because you’re also made aware that there’s no cure.”<sup>31</sup></p>
Feeling disappointed about having asthma	<p>Making sacrifices            “This illness diminishes me. What it does is like theft.” “It means growing away from the pleasures of life”<sup>85</sup></p> <p>Wishing to be “normal”            “I wish I could be normal like everybody else; Why can’t I be like others, just walking normally and nothing happening to me?”;<sup>86</sup> “I hate feeling like I’m different”<sup>68</sup></p> <p>Being significantly restricted and fighting those imposed restrictions, lacking achievements</p>
Finding meaning	<p>Asthma is “horrible,” “gloomy”<sup>85</sup></p> <p>Comparing asthma experience to other chronic conditions            “Asthma is not the worst thing to get”<sup>84</sup></p> <p>Wondering, why me?            “I used to ask myself ‘Why me?’ ...After learning to live with it, as I grew up, I tried adapting it to my life standards instead of seeing it as an obstacle to my moves”<sup>85</sup></p> <p>Having asthma takes time to come to terms with            “You can’t in the beginning, especially before diagnosis, because you haven’t, you might have no idea why you’re ill. Why you feel like you have no energy, why you can’t do certain things, why you can’t do certain jobs. Your career can be affected by it. Your home life is affected by it. Your social life is affected by it. And I think people who are newly diagnosed have got to give themselves time to come to terms with it”<sup>46</sup></p>
Acknowledging loss	<p>Losing particular roles; loved sport or pets</p> <p>Cannot be in some public spaces            “I can’t go to a public place, someone might have perfume or smoke a cigarette and then I become endangered”<sup>86</sup></p> <p>Choosing flexible employment</p> <p>Reluctantly adapting to restrictions and lifestyle change</p>
Becoming expert on asthma—knowing what to do	<p>Experiencing significant pivotal episodes            “I never have carried medication before, and I probably always will from now on...now that I’ve come that close to having to go to the hospital”<sup>71</sup></p> <p>Developing personal disease experience            “I think I understand my asthma now, and it’s like when I was ill on Saturday I knew, you know, how much I could take of that environment before I’d got to remove myself from it.”<sup>41</sup></p> <p>Discovering limits to self-control            “I knew it was beyond my ordinary medication routine...it’s time. You better get the hell out of the house, you know, get to the doctor.”<sup>71</sup></p>

(Continues)

**TABLE 3** (Continued)

Categories	Findings—the experience
Acceptance	<p>Accepting symptoms and dependency on medication</p> <p>Accepting identity            “You just have to find your way with it. And then try and get on with life and accept that you will have bad days.... I work full-time. I’m off sick less than healthy people because I manage it. I travel abroad on my own. It’s not going to stop you from having a life, you just have to... find the life that suits.”<sup>46</sup></p> <p>Accepting inconvenience—“it’s nuisance value” but a small price to pay</p> <p>Never been affected by asthma badly and do not look upon it as an illness            “I am not bothered by my asthma; it’s irrelevant”;<sup>76</sup> “never really thought about asthma. I just had to live with it”<sup>84</sup>            “So I just hope that anybody who is watching this and is worried, it’s worth just beating it. It’s a long term, at the moment a long term and what they call a chronic condition which I hate, I hate the terminology, but it doesn’t mean to say that it must rule your life.”<sup>41</sup></p>

### 3.1.2 | Individuals tailor their behaviour to their immediate context

For some people, living with asthma was an on-going process of monitoring and appraising themselves, others and their environment for relevant cues, and tailoring their behaviours responsively—according to the messages they received from that immediate context and as we observed, in notably self-protective ways (Table 2).

Many of the findings of this review indicated that people felt it important to conceal their condition and/or medication use as a means of self-protection from undesirable consequences, such as negative social judgement, “there’s a certain amount of the public have a certain amount of baggage about asthma.”<sup>83</sup>

### 3.1.3 | Living with asthma necessitates on-going periods of emotional and cognitive adjustment

Our synthesis draws attention to the idea that living with asthma is an on-going “work in progress.” The concept of work was not necessarily readily observable, rather “work” of a personal nature, including emotional adjustment and shifting cognitions (Table 3). For example, finding meaning and acknowledgement of loss represented substantial adjustment to changed and changing circumstances; “I’d love to be able to walk ... go on a holiday. If I go anywhere, I go out in the car, I’ve got to think ... where’s the hospital from there, where’s the doctor from there ... it’s just been horrendous.”<sup>83</sup>

Our data suggest that living with asthma can be a variable emotional journey. Adjusting to asthma appeared to be a process that evolved via learning and responding to varied circumstances through lived experience. As the natural history of asthma is characterized by variability in its symptoms over time (symptoms may be present or absent at any given moment), individual trajectories varied too: coping and adjusting involved harder work at different points in time, including the emotional impact of the adjustment. Denial was a core experience illustrating the personal and often emotional work involved. This was exemplified through people’s belief that they did not actually have asthma, or through efforts to minimize the effect of the condition, or a tension between the need to take medications every day and identification with being a person with asthma.

### 3.1.4 | Living with asthma involves both positive and negative interactions with the health-care system

Dissatisfaction with primary care was a prominent experience, and an interesting finding given the emotional burden described. Unfortunately, for some individuals, their asthma experience was not validated by health-care interactions; “some of them don’t believe that you’re sick;<sup>80</sup> they just placate me ... and act like, ‘what did you waste my time for’.”<sup>71</sup> Some data suggested dismissive and negative judgemental comments from HCPs (Table 4). An inability to afford asthma medications and treatment was also a relatively common concern and in some cases influenced patient interactions with health-care providers; “I got cut off my benefits and I couldn’t afford medication...had an attack and no medication. They [HCPs] just thought it was my neglect, but I just didn’t have any money to buy anything.”<sup>73</sup>

## 4 | DISCUSSION

Asthma is a heterogeneous condition; the individual experience of it inevitably varies from one person to another, and within individuals too as symptoms and personal circumstances fluctuate. Our synthesis captures the multiplicity of the experience of asthma as a chronic condition and highlights the significant contribution of everyday interactions to that individual variation.

The majority of the evidence related in some way to the work of appraising one’s personal situation, adjusting to, and for some patients, acceptance of their experience. This resonates with the wider literature on biographical disruption and repair in chronic illness, as people reflect on what has changed in their sense of self, what remains the same and what can be regained.<sup>87-92</sup> The episodic nature of asthma, particularly in its milder, well-controlled form, may result in little sense of loss of self, and may indeed lead people to reject any on-going illness identity, unlike those with enduring or progressive illness. By contrast, those with severe and perhaps very visible asthma may experience a more lasting sense of disruption and a continuing awareness of vulnerability to a lethal episode.

This review adds considerable depth to what has already been highlighted in quantitative studies. For example, we know that

**TABLE 4** Synthesis 4: Living with asthma involves both positive and negative interactions with the health-care system

Categories	Findings—the experience
Receiving different quality health care	HCP has poor knowledge about asthma and medications “My GP is a good doctor but he does not know much about asthma” <sup>67</sup> Preferring outpatient care [rather than GP]; outpatient staff know what to do Not given choice to participate in health care; no time available “They give you what they want to give you”; <sup>80</sup> “All they do is give you tablets...take that and go away” <sup>72</sup> Experience dependent on HCP “He [His GP] he’s actually an asthma sufferer himself... but he’s also reassuring at the same time... he just explained how it hasn’t hampered his life...He stays fit and healthy; it’s again, positive mindset.” <sup>43</sup>
The importance of communication and understanding	Not being heard “Some of them [HCPs] don’t want to listen”; <sup>80</sup> “the doctor was just kind of oblivious...we never actually sat down and made a plan” <sup>68</sup> Receiving insufficient information and advice “My GP gave me a prescription for an inhaler but didn’t tell me how to use it” <sup>66</sup> “...he prescribed the preventer and the Salbutamol or Ventolin...And the next time I saw the GP, because I asked for an explanation and she said, ‘Oh because you have to’. And she didn’t go into details and I’m the sort of person, I like to understand why I’m taking something. Not just because I have to. I need to understand the reason for it. So it helps me to appreciate the seriousness.” <sup>43</sup> Asthma management explained well in outpatient clinic Disagreeing about medical care “So me and the doctor, we couldn’t agree about it” <sup>67</sup>
Tailoring adherence to recommended prevention and treatment	Being limited by inability to afford medications—tailor to suit or go without “I was short of money...so I went without Seretide [a long-term inflammatory medication] for a week and that was a big mistake because I ended up going back in [to hospital]” <sup>64</sup> Asthma medication can be expensive—purchase but with compromises “I can’t afford it [Flixotide, a long-term anti-inflammatory medication] financially...I’m trying to compensate by using more Ventolin, more Atrovent [both short-term reliever medications], or something like that. So this has an effect on me too” <sup>83</sup> Being limited by inability to access health care
Preferring to manage asthma independently	Preferring to self-manage “I understand my asthma better than anyone else. Someone that lives with it. So if they [doctor] don’t answer me the way I know they should be I won’t go back” <sup>72</sup>
Health care is a necessity	Not wanting to end up in hospital “...I was hospitalised and nebulised and treated with prednisolone for another attack and that was because I misjudged how far down into breathing difficulties I was because I didn’t have a peak flow meter.” <sup>44</sup> Taking medications (reluctantly) to feel in control “I don’t like taking steroids...but here. I need them to breathe properly, so what can you do?” <sup>76</sup>

depression and anxiety are common among people living with asthma, but while standardized psychological measures provide important information about the health and well-being of people with asthma, these quantitative measures often miss the subtle complexities of the actual patient experience. This synthesis highlights a broad range of emotional experiences, including key factors driving those experiences at the individual level. Personal experiences streamed from and were shaped by external influences, such as local contexts and interactions with health care.

Interpersonal relationships and social environments play an important role in shaping people’s life-experiences. Yet in this review, we noted very few studies reporting on the social support systems of people living with asthma; there were few data in relation to family or friend relationships or other social networks and their place in this context. Only one study appears to have directly asked people with asthma about the support they receive from friends, family and other

support groups.<sup>28</sup> In addition, this was also the only study to contribute to all themes synthesized in the review.<sup>28</sup> Given the impact of asthma on daily routines and responsibilities for many people, we presume that emotional support could form an integral part of living with and managing asthma, and when present, could offer benefit to lessening the overall workload of living with asthma, particularly its emotional impact. The extant literature suggests a positive relationship between social support and asthma self-management behaviours,<sup>93</sup> and asthma control and quality of life.<sup>94,95</sup> However, in this review, our findings highlight that when social contacts or networks were reported, it was mostly in the context of exerting *negative* influence and creating social vulnerability.

The relative absence of descriptors of the physical experience of asthma in our review was also notable, except in the Healthtalk resource.<sup>28</sup> Asthma is defined clinically as the combination of variable respiratory symptoms (eg, wheeze, shortness of breath, cough and

chest tightness) and excessive variation in lung function. Its treatment is focused on minimizing symptoms, reducing the risk of flare-ups and asthma-related death and improving quality of life, including the use of various medication regimens, depending on disease severity. We identified only a small number of studies reporting on patient descriptions of the physical experience; these descriptions often encapsulated the fear and panic experienced by some people living with asthma. A 2006 study reported 53% of patients believed they had asthma only when they were experiencing physical symptoms.<sup>96</sup> This begs the question, was the overarching emotional experience of most participants included in the present review a more prominent feature of their condition because physical symptoms were absent at the time of the studies, or because the interviewers did not ask about physical symptoms (or took them for granted), or is the emotional burden as—if not more—relevant to the overall asthma experience?

Asthma has sometimes been discounted as a serious illness, yet patients with even mild asthma can have severe flare-ups that require hospitalization, and for some people, it can be life-threatening.<sup>97</sup> For the past 25 years, asthma has been clearly recognized as an inflammatory medical condition. Prior to this, asthma was often discredited as a “real” illness among health professionals and the community because it was believed to have a psychological basis.<sup>98</sup> This was a particularly prevalent belief in the 1960s, during the childhood of some of the participants in the included studies. This may partly explain the feelings of judgement, either by others or oneself, that were reported in some of the studies in our synthesis.

Anticipating judgement from others was a significant feature influencing people's disease experience. The judgement could be real or perceived, and was of great concern to many participants across the studies. Our synthesis revealed that efforts to work around this involved a variety of cognitive and behavioural strategies, primarily concealment, selective disclosure, normalizing and taking proactive measures. Of note was the overall negative perception of asthma and efforts to hide it, which was of more or less priority depending on the person's context—their social, employment or home environment, alongside the frequency and intensity of their symptoms (requiring more or less effort to conceal). While asthma itself may range from extremely mild to extremely severe, understanding how individuals perceive their environment and respond accordingly is an integral step in addressing and explaining how and why individuals experience asthma differently. This is important because such perceptions could potentially be a barrier to seeking appropriate care, taking medications or seeking help.

Living with a chronic illness can be physically and emotionally challenging. Generally, our findings suggest that these challenges are harder to face when diagnosed as an adult. Those with childhood diagnosed asthma reported not really knowing a life without it and that managing their asthma was a routine experience. In contrast, negative emotions and feelings were typically felt by those who had been diagnosed as adults.<sup>31</sup> Concerns about the future and controlling the condition may have been harder to accept.<sup>31</sup> Thus, our findings suggest that age of diagnosis influences the amount of work involved in living with asthma.

People learn how to live with their asthma and develop personal preferences for management and care. Health-care interactions can play a significant role in a person's illness experience, for example, receiving good quality or conflicting information, or encountering poor health professional knowledge. General practitioners (GPs) are central to the management of asthma in the community, and asthma represents one of the most frequently managed chronic problems by GPs.<sup>99</sup> Our findings suggest that considerable work is invested by people with asthma to manage both the positive and negative interactions they encounter in the health-care system. Unsatisfying health-care experiences may significantly limit the work of individuals in trying to manage their asthma; some studies report associations between regular review with health professionals and medication adherence.<sup>100</sup> Alternatively, some patients might develop low expectations for their asthma care. Patients in Cvetkovski et al.'s<sup>63</sup> study reported being satisfied with their care despite health-care providers perceiving the delivery of asthma care as suboptimal.

Clinical interactions can help people to form, maintain or re-establish self-identities and offer support for emotional load and social stigma. Unfortunately, for some individuals, their asthma experience was not validated by health-care interactions. Some of our data suggested dismissive and negative judgmental comments from health-care providers. These comments risk challenging a person's identity and undermining their self-evaluation.

#### 4.1 | Clinical and policy implications

The topics of the included papers of this review were notably clinically focussed which is indicative of the type of studies that have been conducted in this area. Our higher-order analysis about the work involved in living with asthma is about the psychological, emotional and social experience, particularly the burden of asthma for some. Our findings, with an emphasis on emotional experiences, suggest that what matters most to those with asthma is not necessarily what matters to clinicians. Similar findings have been made in other chronic illnesses.<sup>101</sup> Clearly medical care is a central plank for managing chronic conditions, and it would be extremely detrimental to return to the perception of the 1960s that asthma was a psychological disease, but it is important for HCPs to consider the broader aspects of management, beyond that of symptoms and treatment, if our health-care systems are to deliver patient-centred care. Further in-depth and focused investigation of these aspects is warranted, to gain first-hand insight into the patient experience of asthma in order to direct evidence-based efforts towards improving health-care support systems.

Patients play an instrumental role in managing their own long-term condition(s). Yet their capacity to manage their illness will inevitably depend on individual circumstances and the medical support they receive. Patient understanding of their illness and its treatment is a potentially modifiable mediator of adherence with medications and self-management behaviours.<sup>96</sup> Improved communication with health-care professionals, including detailed understanding of the broader patient experience, is key.

There are implications emerging from this review for health-care planners and policymakers to address, specifically improving supportive care within the health-care system. More attention could be paid to the nuances and sensitivities surrounding self-management which are relevant to the patient experience. HCPs need to be aware of how living with asthma must be accommodated within the context of individuals' life circumstances.

A review by Andrews identified that many self-management programmes focus predominantly on medical management and overlook the social and psychological work of the asthma experience.<sup>102</sup> Our review identified a notable gap in the literature, namely the role of social support in the lives of people who have asthma. Given the strong evidence base regarding the influence of social support on health management and outcomes,<sup>103</sup> this is a key area deserving of further investigation. The findings of this review also highlight the importance of recognizing the complex and variable emotional experiences of those living with asthma—their perspectives and opinions, alongside medically driven considerations and measures.

## 4.2 | Limitations

Some argue that it is difficult to synthesize studies that are carried out in disparate contexts and that attempting to do so ignores the rich detail that characterizes good qualitative research. However, like Britten et al.,<sup>104</sup> we argue that it is important to realize the full contribution of qualitative research by synthesizing individual studies: "it is possible to make generalizations across qualitative research studies that do not supplant the detailed findings of individual studies—but adds to them." This qualitative synthesis provides an in-depth exploration and analysis of the spectrum of the patient's perspective of living with asthma.

These studies were mostly conducted in white populations. However, rates of asthma morbidity, mortality and acute resource utilization are highest among minority, non-white, inner-city populations, and of these groups, our knowledge and understanding of the experience of living with asthma remains poor.

People whose asthma is currently well controlled may be relatively under-represented in existing literature, with 8 of 26 (31%) of the included studies recruiting emergency department attendees or patients admitted to hospital in order to investigate their specific experiences in these settings. However, emergency department visits are surprisingly common even in well-controlled asthma; for example, in a large US survey, one in seven patients with well-controlled asthma reported having an emergency department or urgent care visit in the previous year.<sup>105</sup>

## 5 | CONCLUSION

We explored the existent qualitative empirical evidence reporting on adult experiences of living with asthma. To our knowledge, this is the first systematic review of the qualitative literature in this area. A key strength of this review was the methodology utilized to examine and

interpret the findings from a diverse array of studies. We have brought to the forefront those aspects of the "work" of living with asthma that are important to those who have it, and highlight the unique nature of the personal experience of asthma and diversity in how individuals perceive, manage and relate to their experience. In so doing, we hope this work informs health-care professionals in their care of patients with asthma and facilitates the delivery of a patient-centred care approach to improving patient health and treatment outcomes.

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## Appendix A

ti=title, tw=text word

PsychInfo & Medline (variations made according to database requirements):

exp Asthma/

Asthma\$.ti. or wheez\$.ti.ab.

(asthmatic? or (asthma\$ adj2 (chronic\$ or patient?))).ab.

(lung disease or lung diseases).tw.

or/1-4

exp adult/or exp aged/or middle aged/or young adult/

(patient\* or inpatient\*).tw.

or/6-7

Qualitative Research/

ethnog\*.tw.

phenomenolog\*.tw.

participant observ\*.tw.

constant compar\*.tw.

focus group\*.tw.

action research.tw.

qualitative stud\*.tw.

(focus group\* or interview\*).tw.

(grounded adj (theor\* or study or studies or research)).tw.

9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18

patient experience\*.tw.

lived experience\*.tw.

life experience\*.tw.

patient perspective\*.tw.

experience\*.tw.

health experience\*.tw.

living with asthma.tw.

personal experience\*.tw.

illness experience\*.tw.

quality of life\*.tw.

20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29

5 and 8 and 19 and 30

limit 31 to (english language and humans)

Asthma OR wheez\* (Cinahl, Embase, Medline)

Asthma\* OR ASTHMA-in DE OR wheez\* (PsychINFO)(Embase)

exp \*asthma/

(asthma\$ or wheez\$.ti.

(asthma\$ adj3 (sever\$ or chronic\$ or primary or major)).ab.

or/1-3 [Asthma]

(exp asthma/) and chronic disease? management.ti.ab.

4 and chronic disease? manag\$.ti.ab.

or/5-6 [Focussed Key Terms]



**Appendix B**  
**TABLE B1** Summary of included studies

Study/Country	Aims and Objectives	Method of analysis	Method and setting	Study population
Adams et al., 1997 UK <sup>6</sup>	Explore the perspective of patients with asthma on the use of preventer medications "To generate a hypothesis for the findings and extending concepts already used within the literature on chronic illness." <sup>76</sup>	Thematic	In-depth interviews (an interview guide was devised) carried out at the participant's own home	Sample (N): 30 Age range: 19-57 Gender (% of females): 47 Source: primary care
Al-kalemji et al., 2014 Denmark <sup>84</sup>	Explore the perspectives of people living with asthma and how "coping mechanisms were influenced by health professionals and networks." <sup>84</sup>	Thematic	Semi-structured interviews conducted in either the participant's own home, work place or hospital	N: 10 Age range: 36-52 Gender (% of females): 60 Source: community population
Baptist et al., 2010 USA <sup>62</sup>	Reveal common challenges "older adults face to manage their asthma and provide age-specific information to inform treatment and counselling/education decisions." <sup>62</sup>	Thematic	Focus groups. Setting not stated	N: 46 Age range: 65+ Gender (% of females): 85 Ethnicity: 23 identified as white, 20 as African American and 3 as other Source: primary and/or secondary care
Becker et al., 1993 USA <sup>71</sup>	None stated	Thematic	Three semi-structured monthly interviews in research laboratory or at home	N: 95 Gender (% of females): 62 Source: not stated
Cvetkovski et al., 2009 Australia <sup>63</sup>	"Investigate the perceptions and attitudes of general practitioners, pharmacists and people with asthma, towards management of asthma." <sup>63</sup>	Thematic	Semi-structured interviews conducted in a small rural centre	N: 10 Age: 18+ Source: community pharmacies
Donald et al., 2005 Australia <sup>64</sup>	Why do adults living with "life threatening asthma report delaying treatment, and downplay the seriousness of their symptoms?" <sup>64</sup>	Thematic	Focus groups. Setting not stated but recruited from one of two metropolitan teaching hospitals.	N: 5 Age range: 20-42 Gender (% of females): 60 Source: patients admitted with life-threatening asthma
Douglass et al., 2004 Australia <sup>72</sup>	"What do patients with asthma who seek emergency care look for in a doctor-patient relationship?" <sup>72</sup>	Thematic	Semi-structured interviews conducted in a city, rural and suburban hospital	N: 62 Age range: 18-69 Gender (% of females): 69 Source: ED attendees (same sample as Goeman 2002 and 2004)

(Continues)

TABLE B1 (Continued)

Study/Country	Aims and Objectives	Method of analysis	Method and setting	Study population
Drummond 2000 UK <sup>82</sup>	How does asthma influence a patient's quality of life?	Thematic	Semi-structured interviews in participants' homes	N: 22 Source: primary care
Goeman et al., 2002 Australia <sup>83</sup>	"Explore the burden of asthma on the lives of people presenting to emergency department" <sup>83</sup>	Thematic	Semi-structured interviews. Setting not stated	N: 62 Age range: 18-70 Gender (% of females): 69 Source: ED attendees (same sample as Douglass 2004 and Goeman 2004)
Goeman et al., 2004 Australia <sup>73</sup>	"Explore the reasons why patients recurrently present with asthma to emergency departments" <sup>73</sup>	Thematic	Semi-structured interviews. Setting not stated	N: 62 Age range: 18-70 Gender (% of females): 69 Source: ED attendees (same sample as Douglass 2004 and Goeman 2002)
Goeman et al., 2007 Australia <sup>65</sup>	"Explore the perspectives of older people living with asthma, and the barriers which may exist and prevent optimal asthma care." <sup>65</sup>	Thematic	In-depth interviews. Setting not stated	N: 55 Age range: 40% in their 60s Gender (% of females): 71 Source: community population
Haughney et al., 2004 UK <sup>77</sup>	"Assess patient understanding of their asthma and their preferences regarding the delivery of asthma care and treatment." <sup>77</sup>	Thematic	Semi-structured interviews. Setting not stated.	N: 40 Age range: 14-65 Source: community population
Health Experience Research Group (2015) UK <sup>28</sup>	Improve understanding of people with asthma experiences of health, illness and health care	Thematic	In-depth, open-ended questions followed by semi-structured interviews conducted in participants' homes	N: 37 Age range: 16-73 Gender (% of females): 65 Source: community population
Hussein et al., 2002 UK <sup>66</sup>	"Explore 1) the knowledge, attitudes, perceptions, health beliefs and needs of those originally from India and Pakistan, and 2) their attitudes of self-management plans." <sup>66</sup>	Thematic	Two interviews were conducted: 1) semi-structured and 2) focus groups. Setting not stated.	N: 60 Age range: 16-50 Source: primary care
Janson et al., 1998 USA <sup>78</sup>	Explore how patients respond to acute asthma symptoms and understand why they would delay treatment	Thematic	Three monthly, semi-structured interviews. Setting not stated	N: 95 Gender (% of females): 62 Source: primary and/or secondary care

(Continues)

**TABLE B1** (Continued)

Study/Country	Aims and Objectives	Method of analysis	Method and setting	Study population
Jones et al., 2008 UK <sup>74</sup>	Investigate the relationship between psychosocial factors, perception of life events and managing asthma in those who have been admitted and not admitted to hospital	Framework	Participants in hospital interviewed at the bedside and non-hospital participants interviewed in their practice. Method not stated	N: 50 Age range: 16+ Gender (% of females): 64 Ethnicity: 31 are white British, 22 Afro Caribbean, 8 Asians and 14 "others" Source: hospital and primary care (for comparison)
Lawson et al., 2014 USA <sup>75</sup>	Explore the reasons for "asthma-related emergency department use among adults." <sup>75</sup>	Thematic	Open-ended and semi-structured interviews conducted in a private area in a hospital	N: 26 Age range: 18-65 Gender (% of females): 69 Ethnicity: 21 African Americans Source: ED attendees
Loignon et al., 2009 Canada <sup>67</sup>	Understand how adults deal with their asthma, "perceive self-management and develop self-care strategies." <sup>67</sup>	Interpretative phenomenological	In-depth semi-structured interviews conducted in participants' homes.	N: 24 Age range: 27-76 Gender (% of females): 58 Additional information: Participants were all francophone, Quebec-born individuals Source: ED and primary care (for comparison)
Mancuso et al., 2006 USA <sup>86</sup>	Investigate 1) the patients' views about exercise and lifestyle activities, and 2) whether these views varied depending on asthma characteristics.	Thematic	Open-ended questions. Setting not stated	N: 60 Gender (% of females): 88 Ethnicity: 28 African Americans, 12 Latinos and 20 "white" Source: primary care
Munro et al., 1996 USA <sup>80</sup>	Characterize the experiences of participants with asthma in 1) the care they receive to manage their disease, 2) their confidence in asthma self-management, 3) any barriers they identify in their asthma management and 4) any recommendations they would make in order to improve asthma care in their community	Thematic	Focus groups conducted in a conference room in a hospital	N: 8 Age range: 19-60 Gender (% of females): 63 Ethnicity: 7 African Americans and 1 Native American Source: ED attendees
Nunes et al., 2014 Portugal <sup>81</sup>	Explore 1) patients with asthma experience of engaging with health services and health-care professionals and 2) how patients search for, interpret and act on medical information related to the condition	Narrative	Semi-structured interviews conducted in hospitals.	N: 40 Source: hospital inpatients

(Continues)

TABLE B1 (Continued)

Study/Country	Aims and Objectives	Method of analysis	Method and setting	Study population
Oncel et al., 2012 Turkey <sup>65</sup>	Investigate the perceptions patients with asthma, have of the disease	Thematic	Participants were asked to write a letter. Setting not stated	N: 23 Gender (% of females): 70 Ethnicity: Turkish Source: primary and/or secondary care (all patients "in remission")
Speck et al., 2014 USA <sup>68</sup>	Understand the barriers young African American adults, have with managing their asthma.  Finding strategies that may be used to improve self-management and explore preferences for joining in asthma self-management programme.	Thematic	Focus groups. Setting not stated.	N: 34 Age range: 18-30 Gender (% of females): 68 Ethnicity: young self-identified African Americans Source: registry and community clinics
Steven et al., 2002 UK <sup>79</sup>	Identify factors which motivate patients with asthma self-management and compare these to the British Thoracic Society (BTS) guidelines for asthma.	Thematic	In-depth interviews at a place convenient to participants, such as their homes or the general practice surgery.	N: 23 Age range: 20-47 Gender (% of females): 48 Source: primary care
Taylor et al., 2014 Australia <sup>69</sup>	"Examine the influences of intergenerational relationships on beliefs, knowledge and practices about health and illness." <sup>69</sup>	Thematic	Semi-structured interviews conducted at a place convenient to participants.	N: 27 Age range: 40+ Gender (% of females): 70 Source: community population
Van Mens-Verhulst et al., 2004 Netherlands & Canada <sup>70</sup>	Explore the question: "How do mothers with asthma manage their illness?"	Thematic	Semi-structured interviews conducted in participants' homes.	N: 8 Age range: 31-65 Gender (% of females): 100 Source: outpatient clinics (primary and/or secondary care)

**Appendix 2:**  
**Institutional ethics approval letter and trial  
registry**

**Research Integrity**

Human Research Ethics Committee

Wednesday, 17 February 2016

Dr Lorraine Smith  
Pharmacy; Faculty of Pharmacy  
Email: lorraine.smith@sydney.edu.au

Dear Lorraine

I am pleased to inform you that the University of Sydney Health Low Risk Subcommittee (HREC) has approved your project entitled "**People's experiences of severe asthma**".

Details of the approval are as follows:

**Project No.:** 2015/934**Approval Date:** 17 February 2016**First Annual Report Due:** 17 February 2017**Authorised Personnel:** Smith Lorraine; Eassey, Daniela; Reddel Helen;**Documents Approved:**

Date Uploaded	Type	Document Name
12/01/2016	External Ethics Approval	External ethics approval SAWD study
12/01/2016	Participant Info Statement	PIS version 2 clean copy
12/01/2016	Recruitment Letter/Email	Recruitment letter version 2
12/01/2016	Safety Protocol	Safety protocol
01/10/2015	Participant Consent Form	Consent form
01/10/2015	Other Type	For participants to contact researchers for recruitment
20/10/2015	Interview Questions	Interview questions
04/11/2015	Recruitment Letter/Email	Summary information leaflet
02/10/2015	Other Type	Transfer of copyright form
01/10/2015	Other Instruments/Tools	withdrawal of consent form

HREC approval is valid for four (4) years from the approval date stated in this letter and is granted pending the following conditions being met:

**Condition/s of Approval**

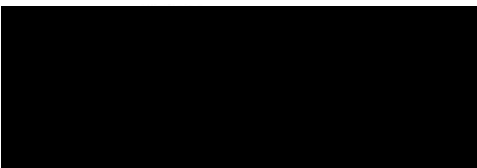
- Continuing compliance with the National Statement on Ethical Conduct in Research Involving Humans.
- Provision of an annual report on this research to the Human Research Ethics Committee from the approval date and at the completion of the study. Failure to submit reports will result in withdrawal of ethics approval for the project.
- All serious and unexpected adverse events should be reported to the HREC within 72 hours.
- All unforeseen events that might affect continued ethical acceptability of the project should be reported to the HREC as soon as possible.
- Any changes to the project including changes to research personnel must be approved by the HREC before the research project can proceed.
- Note that for student research projects, a copy of this letter must be included in the candidate's thesis.

**Chief Investigator / Supervisor's responsibilities:**

1. You must retain copies of all signed Consent Forms (if applicable) and provide these to the HREC on request.
2. It is your responsibility to provide a copy of this letter to any internal/external granting agencies if requested.

Please do not hesitate to contact Research Integrity (Human Ethics) should you require further information or clarification.

Yours sincerely



**Associate Professor Rachel Skinner  
Chair  
Health Low Risk Ethics Subcommittee**

**This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research (2007), NHMRC and Universities Australia Australian Code for the Responsible Conduct of Research (2007) and the CPMP/ICH Note for Guidance on Good Clinical Practice.**



DEFINITIONS



HINTS AND TIPS



FAQs



REGISTER TRIAL



MY TRIALS







## Trial Review

[VIEW TRIAL AT REGISTRATION](#)
[VIEW HISTORY](#)

The safety and scientific validity of this study is the responsibility of the study sponsor and investigators. Listing a study does not mean it has been endorsed by the ANZCTR. Before participating in a study, talk to your health care provider and refer to this [information for consumers](#)

[< BACK](#)

### Trial registered on ANZCTR

<b>Registration number</b>	 ACTRN12616001562460
<b>Ethics application status</b>	 Approved
<b>Date submitted</b>	 31/08/2016
<b>Date registered</b>	 11/11/2016
<b>Date last updated</b>	 11/11/2016
<b>Type of registration</b>	 Prospectively registered

#### Titles & IDs

<b>Public title</b>	People's experiences of severe asthma
<b>Scientific title</b>	Investigating people's personal experiences of living with and managing severe asthma: a qualitative study
<b>Secondary ID [1]</b>	Nil known
<b>Universal Trial Number (UTN)</b>	
<b>Trial acronym</b>	
<b>Linked study record</b>	

#### Health condition

##### Health condition(s) or problem(s) studied:

Severe Asthma

##### Condition category

Respiratory

##### Condition code

Asthma

#### Intervention/exposure

<b>Study type</b>	Interventional
<b>Description of intervention(s) / exposure</b>	This is an exploratory, qualitative study, investigating the personal experiences of people living with severe asthma. Interviews will be performed on a one-off basis. This will involve a video and audio recorded interview that will be conducted in their own home. Each interview would go for approximately 1-2 hours. Using rigorous, systematic qualitative methods we will analyse transcripts from in-depth individual interviews, and use these data to publish in peer reviewed international journals. Also, part of our study will include developing a visual web-based information resource for use by the public (information and support) and health professionals (education/training). We are following the DIPEX methodology, that has been used for thousands of participants in the UK, several other countries, and has been used for six studies within Australia so far (on <a href="http://www.healthtalkaustralia.org">www.healthtalkaustralia.org</a> ).
<b>Intervention code [1]</b>	Other interventions
<b>Comparator / control treatment</b>	No control group
<b>Control group</b>	



Uncontrolled

## Outcomes

<b>Primary outcome [1]</b>	Using transcripts from the interviews, a content and thematic analysis will be undertaken using standard qualitative methods.
<b>Timepoint [1]</b>	One-off interview session
<b>Secondary outcome [1]</b>	Our first secondary outcome is developing a web-based resource, for the Australian version of the website <a href="http://www.healthtalkonline.org">www.healthtalkonline.org</a> as well as the website for the Centre for Research Excellence in Severe Asthma (CRESA). The CRESA website is yet to be developed.
<b>Timepoint [1]</b>	Following completion of all participant interviews and qualitative analysis
<b>Secondary outcome [2]</b>	Our second secondary outcome is Identifying goals important to people with severe asthma using the transcripts from in-depth interviews
<b>Timepoint [2]</b>	during one off interview sessions

## Eligibility

<b>Key inclusion criteria</b>	Participants will be included if they are over 18 years old and must be diagnosed with severe asthma. Severe asthma is defined as asthma for which control can be maintained only with the highest level of recommended treatment or good control is not achieved despite the highest level of recommended treatment.
<b>Minimum age</b>	18 Years
<b>Maximum age</b>	No limit
<b>Gender</b>	Both males and females
<b>Can healthy volunteers participate?</b>	No
<b>Key exclusion criteria</b>	Participants will be excluded if they don't have a confirmed diagnosis of severe asthma.

## Study design

<b>Purpose of the study</b>	Educational / counselling / training
<b>Allocation to intervention</b>	Non-randomised trial
<b>Procedure for enrolling a subject and allocating the treatment (allocation concealment procedures)</b>	
<b>Methods used to generate the sequence in which subjects will be randomised (sequence generation)</b>	
<b>Masking / blinding</b>	
<b>Who is / are masked / blinded?</b>	
<b>Intervention assignment</b>	
<b>Other design features</b>	
<b>Phase</b>	
<b>Type of endpoint(s)</b>	
<b>Statistical methods / analysis</b>	In line with standard qualitative research practice we will use a maximum variation sampling framework, which is a purposive sample of approximately 30-50 people with severe refractory asthma, who will be recruited from different settings across Australia. Therefore, no formal sample calculations were performed. We aim for depth in our interviews and we will keep interviewing participants until no new themes have emerged. The methods used for this project are based on those established by the Health Experiences Research Group (HERG) at the University of Oxford and managed through the DIPEX UK Charity. We will use systematic and rigorous qualitative research methods and analysis, using a narrative illness methodology and thematic analysis.

## Recruitment

**Recruitment status** Not yet recruiting

**Date of first participant enrolment**

**Anticipated** 14/11/2016

**Actual**

**Date of last participant enrolment**

289

**Anticipated** 29/09/2017

**Actual**

**Date of last data collection**

**Anticipated** 30/11/2017

**Actual**

**Sample size**

**Target** 40

**Accrual to date**

**Final**

**Recruitment in Australia**

**Recruitment state(s)** ACT,NSW,QLD,SA,TAS,WA,VIC

**Funding & Sponsors**

**Funding source category [1]**

Other Collaborative groups

**Name [1]**

Centre of Research Excellence in Severe Asthma

**Address [1]**

Hunter Medical Research Institute  
Level 2 West  
Lot 1 Kookaburra Circuit  
New Lambton Heights  
NSW 2305

**Country [1]**

Australia

**Primary sponsor type**

Individual

**Name**

Associate Professor Lorraine Smith, University of Sydney

**Address**

Faculty of Pharmacy  
A15 - Pharmacy And Bank Building  
The University of Sydney  
2006

**Country**

Australia

**Secondary sponsor category [1]**

Individual

**Name [1]**

Associate Professor. Helen Reddel

**Address [1]**

Woolcock Institute of Medical Research  
431 Glebe Point Road  
Glebe NSW Sydney, Australia  
2037

**Country [1]**

Australia

**Ethics approval**

**Ethics application status**

Approved

**Ethics committee name [1]**

Human Research Ethics Committee

**Ethics committee address [1]**

Research Integrity  
Research Portfolio  
Level 6, Jane Foss Russell  
The University of Sydney  
NSW 2006 Australia

**Ethics committee country [1]**

Australia

**Date submitted for ethics approval [1]**

03/12/2015

**Approval date [1]**

17/02/2016

**Ethics approval number [1]**

2015/934

**Summary**

**Brief summary**

Background:

Asthma is a common chronic lung disease and symptoms vary from mild to severe. Within the general population with asthma, approximately 5-10% suffer with severe asthma. People with severe asthma run the highest risk for acute and/or severe exacerbations and mortality, yet there is not much empirical data on how this affects the patients lived experience.

Aim:

Using the Database of Personal Experiences of Health and Illness (DIPEX) methodology we aim to explore the personal experiences of people living with severe asthma.

Methods:

Participants will be included if they are over 18 years old and must be diagnosed with severe asthma. A maximum variation sample of approximately 30-50 participants will be recruited from different settings across Australia. DIPEX methodology involves audio and/or video recording potential participants and encourages them to talk without interruption about all aspects of their experiences that mattered to them. The collected data will be transcribed and coded into 'categories' and 'themes'. These categories and themes will be based on areas that are identified as important to the participants.

**Significance:**

These stories will be used as a reliable source of information to educate students and health care professionals, and as an evidence base to inform person-centered care and future policy improvements to understand the concerns, meaning and priorities of a diverse range of people with severe asthma. The topic summaries, and selected video clips, will also be published on the website <http://healthtalkaustralia.org>

**Trial website**

<http://healthtalkaustralia.org>  
<http://www.severeasthma.org.au>

**Trial related presentations / publications**

**Public notes**

**Contacts**

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**Principal investigator**

**Name** A/Prof Lorraine Smith  
**Address** Pharmacy and Bank Building A15  
The University of Sydney  
NSW  
2066  
**Country** Australia  
**Phone** +61 2 9036 7079  
Fax  
**Email** [lorraine.smith@sydney.edu.au](mailto:lorraine.smith@sydney.edu.au)

**Contact person for public queries**

**Name** Miss Daniela Eassey  
**Address** N372 Pharmacy and Bank Building A15  
The University of Sydney  
NSW  
2006  
**Country** Australia  
**Phone** +61293516471  
Fax  
**Email** [daniela.eassey@sydney.edu.au](mailto:daniela.eassey@sydney.edu.au)

**Contact person for scientific queries**

**Name** Miss Daniela Eassey  
**Address** N372 Pharmacy and Bank Building A15  
The University of Sydney  
NSW  
2006  
**Country** Australia  
**Phone** +61293516471  
Fax  
**Email** [daniela.eassey@sydney.edu.au](mailto:daniela.eassey@sydney.edu.au)

**No information has been provided regarding IPD availability**

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**Summary results**

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No Results

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## **Appendix 3:**

# **Project data collection documents**

- 3.1 Australian College of Rural and Remote Medicine – advertisement
- 3.2 One-page study summary for Physicians
- 3.3 Participant information packs containing:
  - 3.3.1 Summary information leaflet
  - 3.3.2 Participant information sheet
  - 3.3.3 Consent form
  - 3.3.4 Consent to withdraw form
  - 3.3.5 Copyright form
  - 3.3.6 Reply form
- 3.4 Sociodemographic questionnaire
- 3.5 Interview guide
- 3.6 Patient agreement to video/audio recording and transcript amendments



Home / Search / Find News / details



## Does your patient have severe asthma? The Centre of Research Excellence in Severe Asthma want to hear experiences of living and managing the condition

Thursday, 25 January 2018

**This study is part of the program of research being conducted by the Centre of Research Excellence in Severe Asthma, based at University of Newcastle/Hunter Medical Research Institute.**

Danleia Eassey, PhD candidate, will be conducting the study under the supervision of Associate Professor Lorraine Smith (Faculty of Pharmacy, University of Sydney) and Professor Helen Reddel (Woolcock Institute of Medical Research, University of Sydney).

Whilst people with severe asthma often have uncontrolled symptoms, and run a high risk of acute and/or severe exacerbations, there is little empirical data on how this affects the personal lives of those who live with the condition, or about the self-management strategies that they practise. The aim of this research is to conduct a qualitative study into the personal experiences of living with and managing severe asthma. Using audio and/or video recording, participants will be encouraged to talk without interruption about all aspects of their asthma experiences that mattered to them.

Participants will be included if they are over 18 years old and are diagnosed with severe asthma. Researchers have defined severe asthma as asthma for which good control is achieved only with the highest doses of inhaled corticosteroids and a second controlled and/or oral corticosteroids, or good control cannot be maintained despite this therapy.

The findings of the study will be used as a source of information to educate students and health care professionals, and as an evidence base to inform person-centred care and future policy improvements to understand the concerns, meaning and priorities of a diverse range of people with severe asthma. Additionally, the research findings will be used to create topic summaries, which, illustrated using selected video

### Latest news

#### [ACRRM's Rural Procedural Grants Program](#)

Did you know procedural GPs can receive \$2,000 per day, for up to 10 days of training per financial year, and GPs providing hospital based emergency services can receive up to three days of eligible training per financial year? Find out if you're eligible.

#### [ACRRM's first Mental Health Course for 2018](#)

The first Australian College of Rural and Remote Medicine Mental Health Disorders Training for Rural Practitioners course for 2018 will begin on 1 March. Register today for this online course which provides rural GPs with an insightful overview of some of the ...

#### [Free Clinical Placement opportunity in Cancer Survivorship - Victoria](#)

The Clinical Placement Program in Cancer Survivorship is an opportunity for primary care professionals (GPs, practice nurses, and community based allied health practitioners) to gain knowledge in the area of cancer care and ongoing management in a shared care ...

#### [New National Bowel Cancer Screening Program test kit and resources available](#)

A new Immunochemical Faecal Occult Blood Test (iFOBT) kit and associated pathology services were introduced into the National Bowel Cancer Screening Program in the first week of January 2018.

#### [Does your patient have severe asthma? The Centre of Research Excellence in Severe Asthma want to hear experiences of ...](#)

This study is part of the program of research being conducted by the Centre of Research Excellence in Severe Asthma, based at University of Newcastle/Hunter Medical Research Institute.

#### [New arrangements for Medicare-funded urgent after hours attendances to take effect on 1 March 2018](#)

As announced in the 2017-2018 Mid-Year Economic and Fiscal outlook, the new arrangements for Medicare-funded

Article posted in the Australian College of Rural and Remote medicine news feed.

## **PERSONAL EXPERIENCES OF SEVERE ASTHMA STUDY KEY POINTS**

- Patient must have severe asthma, be over 18 years of age and speak English, Arabic or French.
- This research study looks at people's personal experiences of living with severe asthma.
- It will involve an interview, which will be video and/or audio recording according to their preference.
- The interviews will be used to create a resource on two websites ([www.healthtalkaustralia.org](http://www.healthtalkaustralia.org) and [www.severeasthma.org.au](http://www.severeasthma.org.au))
- These websites will be used as a source of information for people with severe asthma and their families, to educate students and health professionals, and as evidence for informing patient care and future policy improvements.
- The interview will be conducted face-to-face in their home or a location of their choice (such as a private room in a community centre or local library) and should take one to one and a half hours.
- They will be asked to talk, uninterrupted, about what it is like to live with severe asthma. Follow up questions will follow focus on:
  - Delays in diagnosis
  - Memories of severe asthma and descriptions of asthma attacks
  - Finding the right medication and treatments
  - Negative experiences
  - Experiences of specialist care
  - How health professionals communicate about asthma
  - Other people's perceptions of people with asthma appearing well when they are not, and
  - Messages for health professionals.
- They can stop the interview at any time, and do so without giving any reason at all.
- They can choose to be identifiable or not

ABN 15 211 513 464

**Professor Lorraine Smith**  
*Associate Dean, Learning and Teaching*

Room N405  
Building A15  
The University of Sydney  
NSW 2006 AUSTRALIA  
Telephone: +61 2 9036 7079  
Facsimile: +61 2 9351 4391  
Email: [lorraine.smith@sydney.edu.au](mailto:lorraine.smith@sydney.edu.au)  
Web: <http://www.sydney.edu.au/>

### **People's experiences of severe asthma**

#### **SUMMARY INFORMATION LEAFLET**

#### **Thank you for taking the time to read these materials.**

You have been given this information pack because we are conducting a study into people's experiences of severe asthma and we are currently recruiting participants for this study. We hope that you may be interested in taking part. Briefly, the study involves an interview with a member of our research team, who will talk to about your experiences of living with and managing your asthma. The interviews from all participants will be used to create a resource on a publicly available website. This website will be used as a source of information for people with severe asthma and their families, to educate students and health professionals, and as evidence for informing patient care and future policy improvements. More detailed information is contained within this pack, which includes:

- A participant information statement
- A consent form
- A withdrawal of consent form
- A reply form; and
- A reply paid envelope for returning the reply form

If you are interested in this study, please take the time to look through these materials. If you wish to participate then you can either return the reply form to us in the reply paid envelope. You can also contact Associate Professor Lorraine Smith on (02) 9036 7079 or [lorraine.smith@sydney.edu.au](mailto:lorraine.smith@sydney.edu.au) if you have any questions.

Thank you again for taking the time to read through these materials,

Associate Professors Lorraine Smith and Helen Reddel



ABN 15 211 513 464

**Professor Lorraine Smith**  
*Associate Dean, Learning and Teaching*

Room N405  
Building A15  
The University of Sydney  
NSW 2006 AUSTRALIA  
Telephone: +61 2 9036 7079  
Facsimile: +61 2 9351 4391  
Email: [lorraine.smith@sydney.edu.au](mailto:lorraine.smith@sydney.edu.au)  
Web: <http://www.sydney.edu.au/>

### People's experiences of severe asthma

#### PARTICIPANT INFORMATION STATEMENT

##### (1) What is this study about?

You are invited to take part in a research study about people's experiences with severe asthma. It will involve an interview, which will be video and/or audio recorded according to your preference. You can choose to be identifiable or not. The interviews from all participants (about 40 people) will be used to create a resource on a publically available website ([www.healthtalkaustralia.org](http://www.healthtalkaustralia.org)). It will have a summary of the findings from these interviews, illustrated by video and audio clips from the interviews. This website can be used as a source of information for people with severe asthma and their families, to educate students and health professionals, and as evidence for informing patient care and future policy improvements.

You have been invited to participate in this study because you have severe asthma. This Participant Information Statement tells you about the research study. Knowing what is involved will help you decide if you want to take part in the study. Please read this sheet carefully and ask questions about anything that you don't understand or want to know more about.

Participation in this research study is voluntary.

By giving consent to take part in this study you are telling us that you:

- ✓ Understand what you have read.
- ✓ Agree to take part in the research study as outlined below.
- ✓ Agree to the use of your personal information as described.

You will be given a copy of this Participant Information Statement to keep.

**(2) Who is running the study?**

The study is being carried out by the following researchers:

- Associate Professor Lorraine Smith, Associate Dean, Teaching and Learning, from the Faculty of Pharmacy at the University of Sydney.
- Associate Professor Helen Reddel, Clinical Associate Professor from the Faculty of Medicine, Central Clinical School at the University of Sydney and the Woolcock Institute of Medical Research.
- Ms Daniela Eassey, PhD Candidate, from the Faculty of Pharmacy at The University of Sydney.

This study is being funded by the Centre for Research Excellence in Severe Asthma (CRESA).

**(3) What will the study involve for me?**

A researcher will conduct an interview with you about your experiences with severe asthma. The interview will be a little like a conversation, in which we will help you talk about yourself in your own words. We will ask you to talk about your experiences of severe asthma. We will ask questions about what happened to you, what your thoughts and feelings have been at different stages, where you have found information, what you have done, and what have been the good and bad parts of the experiences.

The interview will be conducted face-to-face in your home or a location of your choice (such as a private room in a community centre or local library).

You will be able to decide if you will be identifiable from the research results being made available on the website. You have the choice of being audio and/or video recorded for the interview. You will have the option of only having a transcript of an audio interview made publicly available on the website, and you also can have it under a pseudonym of your choosing. The material on the website is protected by copyright, and people are not allowed to copy or record what they find there but it is possible that they could.

Before the interview begins the researcher will ensure you have read and understand the Participant Information Statement (this document) and still have a copy. You will then be shown the [www.healthtalkaustralia.org](http://www.healthtalkaustralia.org) website. You can see how clips from other people's interviews look in video, audio and written formats.

We will ask you if you are willing to have the interview video or audio tape recorded. You will be given the 'consent form'. You only sign this form if you agree to take part in the interview. You will be given a copy of the consent form to keep.

After the interview you will be invited to look at a segment of the film on the camera. You can choose to receive a copy of the transcript or video or both in order to consider whether or not to remove any part of it. You will then be shown the Copyright Form and can choose whether or not to sign then or after you have received a copy of the transcript/video. If you sign this form, you give copyright of the interview to the University of Sydney and [healthtalkaustralia.org](http://healthtalkaustralia.org) for use by the researchers. It is very important that you take time to think about and discuss the copyright transfer form before you sign it. You will be given a copy of this form to keep.

Whether you sign then or later, you will retain the right to remove sections once you look at the transcript/video. Once the audio file has been transcribed, the transcript/video will be sent back to you, along with a draft version of your 'biography' that will appear on the website, for your approval.

**(4) How much of my time will the study take?**

The time it takes for an interview varies, depending on how much you have to say, but most interviews last at least an hour. If you would prefer, we can interview you on two different occasions. Remember, if you want to stop the interview at any time, you can do so without giving any reason at all.

**(5) Do I have to be in the study? Can I withdraw from the study once I've started?**

Being in this study is completely voluntary and you do not have to take part. Your decision whether to participate will not affect your current or future relationship with the researchers or anyone else at the University of Sydney, your doctor, specialist or the person or organisation who passed this information pack on to you.

If you decide to take part in the study and then change your mind later, you are free to do so. We can remove your personal video or audio recording(s) from the website, even after you have signed the copyright form and the website is live on the internet. We can also withdraw your interview recording from inclusion in our data analyses up until the time the website is published live on the internet. However, once the website is live on the internet, the topic summaries (to which analysis of your interview data may have contributed) cannot be withdrawn. You can withdraw from the study by completing the withdrawal of consent form, or contacting the researchers directly.

You are free to stop the interview at any time. Unless you say that you want us to keep them, any video or audio recordings and transcripts will be erased and the information you have provided will not be included in the study results. You may also refuse to answer any questions that you do not wish to answer during the interview.

**(6) Are there any risks or costs associated with being in the study?**

It is unlikely that you will have any risk from being involved in the study. However if, during the interview, topics that you find emotional or difficult to talk about are covered and you become upset we will offer to take a break. You can stop or withdraw from the interview at any time. If necessary, we will encourage you to contact your GP, or, we can contact your GP for you, or our Chief Investigator, Associate Professor Lorraine Smith who is a Registered Psychologist. We will also follow up with you if this situation occurs.

**(7) Are there any benefits associated with being in the study?**

You will be given a \$50 Coles Group Gift Voucher as a token of our appreciation for your involvement in the study.

The outcomes of this research can also provide a benefit to society. The website on which sections of your interview will appear can be used as a source of information for people with severe asthma and their families, to educate students and health professionals, and as evidence for informing patient care and future policy improvements.

**(8) What will happen to information about me that is collected during the study?**

By providing your consent, you are agreeing to us collecting personal information about you for the purposes of this research study. Your information will only be used for the purposes outlined in this Participant Information Statement, unless you consent otherwise.

Your information will be stored securely and will only be disclosed with your permission, except as required by law. Study findings may be published, and you will be identified in these publications if you decide to participate in this study. However, if you wish to participate but remain anonymous, a transcript of your audio interview may be made available on the website, under a pseudonym of your choosing.

The audio and video recordings will be transcribed. They will be analysed by the research team. Approximately 20-25 topic summaries will be written to reflect the most important themes and cover the full range of experiences raised by participants. These summaries will provide the basis for material presented on the website, and each summary will include about 10 video clips which illustrate the major points.

Once your interview has been transcribed, the transcript/video will be sent back to you, along with a draft version of your 'biography' that will appear on the website, for your approval.

Electronic and hard copy data will be stored during the study in a locked cabinet within a locked room in the Faculty of Pharmacy, the University of Sydney. After the study is completed, these data will be stored in a locked storage room within the Faculty of Pharmacy, the University of Sydney. After the study, data will be stored for 5 years, as per the University of Sydney ethics policy. It will then be destroyed. The website will be updated approximately every five years (for which ethics approval will be sought) with new interviews and research findings about personal experiences of severe asthma. Any material considered out of date will be removed. If the removed data are more than 5 years old they will be destroyed.

The results of this study, in the form of the topic summaries and illustrative video and audio clips, will be published on the website [www.healthtalkaustralia.org](http://www.healthtalkaustralia.org) and the website for the organisation from whom our funds are derived, the Centre for Research Excellence in Severe Asthma (CRESA). CRESA has yet to develop their website. The results may also form part of presentations at scientific conferences and be published in scientific journals, where you would not be identified.

The data may be used in the future for comparison with other projects like this one (using the same interview techniques but in different health conditions) both within Australia and internationally. The data would only be used in accordance with the aims of this project – to increase understanding of people's experiences of health and illness conditions. Only researchers who have been trained in and are following the methods used in this study would be given access.

**(9) Can I tell other people about the study?**

Yes, you are welcome to tell other people about the study.

**(10) What if I would like further information about the study?**

When you have read this information, Associate Professor Lorraine Smith will be available to discuss it with you further and answer any questions you may have. If you would like to

know more at any stage during the study, please feel free to contact Associate Professor Lorraine Smith on (02) 9036 7079 or [lorraine.smith@sydney.edu.au](mailto:lorraine.smith@sydney.edu.au)

**(11) Will I be told the results of the study?**

Once your interview has been transcribed, the transcript/video will be sent back to you, along with a draft version of your 'biography' that will appear on the website, for your approval. The overall results of the study will be available on the website ([www.healthtalkaustralia.org](http://www.healthtalkaustralia.org)), which is accessible to anyone from any device with internet capability.

**(12) What if I have a complaint or any concerns about the study?**

Research involving humans in Australia is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this study have been approved by the HREC of the University of Sydney [Project number: 2015/934]. As part of this process, we have agreed to carry out the study according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect people who agree to take part in research studies.

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the university using the details outlined below. Please quote the study title and protocol number.

The Manager, Ethics Administration, University of Sydney:

- **Telephone:** +61 2 8627 8176
- **Email:** [ro.humanethics@sydney.edu.au](mailto:ro.humanethics@sydney.edu.au)
- **Fax:** +61 2 8627 8177 (Facsimile)

*This information sheet is for you to keep*

ABN 15 211 513 464

**Professor Lorraine Smith**  
*Associate Dean, Learning and Teaching*

Room N405  
Building A15  
The University of Sydney  
NSW 2006 AUSTRALIA  
Telephone: +61 2 9036 7079  
Facsimile: +61 2 9351 4391  
Email: [lorraine.smith@sydney.edu.au](mailto:lorraine.smith@sydney.edu.au)  
Web: <http://www.sydney.edu.au/>

People's experiences of severe asthma

### **PARTICIPANT CONSENT FORM**

I, ..... [PRINT NAME], agree to take part in this research study.

In giving my consent I state that:

- ✓ I understand the purpose of the study, what I will be asked to do, and any risks/benefits involved.
- ✓ I have read the Participant Information Statement and have been able to discuss my involvement in the study with the researchers if I wished to do so.
- ✓ The researchers have answered any questions that I had about the study and I am happy with the answers.
- ✓ I understand that being in this study is completely voluntary and I do not have to take part. My decision whether to be in the study will not affect my relationship with the researchers or anyone else at the University of Sydney now or in the future.
- ✓ I understand that I can withdraw from the study at any time.
- ✓ I understand that I may stop the interview at any time if I do not wish to continue, and that unless I indicate otherwise any recordings will then be erased and the information provided will not be included in the study. I also understand that I may refuse to answer any questions I don't wish to answer.
- ✓ I understand that personal information about me that is collected over the course of this project will be stored securely and will only be used for purposes that I have agreed to. I understand that information about me will only be told to others with my permission, except as required by law.

✓ I understand that the results of this study may be published, but these publications will not contain my name or any identifiable information about me unless I consent to being identified using the “Yes” checkbox below.

Yes, I am happy to be identified.

No, I don't want to be identified. Please keep my identity anonymous. I wish to have the transcript of my interview identified under the pseudonym: -

---

I consent to:

- |                                |     |                          |    |                          |
|--------------------------------|-----|--------------------------|----|--------------------------|
| • <b>Audio-recording</b>       | YES | <input type="checkbox"/> | NO | <input type="checkbox"/> |
| • <b>Video-recording</b>       | YES | <input type="checkbox"/> | NO | <input type="checkbox"/> |
| • <b>Reviewing transcripts</b> | YES | <input type="checkbox"/> | NO | <input type="checkbox"/> |

.....  
**Signature**

.....  
**PRINT name**

.....  
**Date**



ABN 15 211 513 464

**Professor Lorraine Smith**  
*Associate Dean, Learning and Teaching*

Room N405  
Building A15  
The University of Sydney  
NSW 2006 AUSTRALIA  
Telephone: +61 2 9036 7079  
Facsimile: +61 2 9351 4391  
Email: [lorraine.smith@sydney.edu.au](mailto:lorraine.smith@sydney.edu.au)  
Web: <http://www.sydney.edu.au/>

**People’s experiences of severe asthma**

**PARTICIPANT CONSENT WITHDRAWAL FORM**

I, ..... [PRINT NAME], no longer wish to participate in the study ‘People’s experiences of severe asthma’.

I wish for the recordings that have been made of me to be deleted:    YES        NO   

.....  
**Signature**

.....  
**PRINT name**

.....  
**Date**



ABN 15 211 513 464

**Professor Lorraine Smith**  
*Associate Dean, Learning and Teaching*

Room N405  
Building A15  
The University of Sydney  
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Telephone: +61 2 9036 7079  
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Web: <http://www.sydney.edu.au/>

### People's experiences of severe asthma

#### COPYRIGHT TRANSFER FORM

##### ***Future use of my interview***

I intend that my interview will be available to [www.healthtalkaustralia.org](http://www.healthtalkaustralia.org), the study investigators at the University of Sydney and other organisations approved by [www.healthtalkaustralia.org](http://www.healthtalkaustralia.org) or the University of Sydney, for use in teaching, broadcasting, research, the making of audio visual resources and other publications. I agree to all such uses including any translation of the material into other languages.

I also intend that my interview will be available to contribute to the collection of 'health and illness experiences' on the websites [www.healthtalkaustralia.org](http://www.healthtalkaustralia.org) and the website for the Centre for Research Excellence in Severe Asthma (CRESA), which is yet to be developed.

I understand that for these purposes the material may be shared with and used by academics, broadcasters, developers of training courses, website developers, information providers and others. It will not be used for advertising or purely commercial purposes.

I understand that by agreeing that my interview and materials relating to it will be available on the internet, it will be accessible to internet users throughout the world including in countries that may have less extensive data protection laws than in Australia. I also understand that the research group may sometimes wish to collaborate with reputable partners in such countries and I consent to my interview and materials relating to it to be shared with and used by such partners.

I consent to my interview being available in the following format(s):

Tick all that apply:

- Video recording of interview
- Audio recording of interview
- Written transcript of interview

To enable the full use of my interview, I assign my copyright in my contribution to www.healthtalkaustralia.org, and the University of Sydney. In return for my copyright assignment my interview will only be used in the manner set out above. If I decide that I no longer want my interview to be used on the website (or for any other purpose) it will be removed, although I accept that it may not be possible to remove all existing copies from circulation.

Name: (block capitals) \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Date of birth: \_\_\_\_\_

Address: \_\_\_\_\_

**THE FOLLOWING TO BE COMPLETED BY THE RESEARCH TEAM**

**Interviewer name:** \_\_\_\_\_

**Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_



ABN 15 211 513 464

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**Professor Lorraine Smith**  
*Associate Dean, Learning and Teaching*

Room N405  
Building A15  
The University of Sydney  
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Telephone: +61 2 9036 7079  
Facsimile: +61 2 9351 4391  
Email: [lorraine.smith@sydney.edu.au](mailto:lorraine.smith@sydney.edu.au)  
Web: <http://www.sydney.edu.au/>

**People's experiences of severe asthma**

**REPLY FORM**

I am interested in participating in the study 'People's experiences of severe asthma'. Please get in contact with me. My preferred method of contact is (you may tick both if you have no preference):

Email: \_\_\_\_\_

Phone: \_\_\_\_\_

Preferred time of day: \_\_\_\_\_

Thank you,

NAME: \_\_\_\_\_

ADDRESS: \_\_\_\_\_

**Participant Details**

Database Reference Number: .....

[Please provide the following information. If you prefer not to answer any questions, please leave them blank.]

**Age:**.....**Postcode:**.....

**Preferred name for website:**.....

**Gender:** female  male  transgender  other .....

**Relationship status:** single  married  divorced/separated  widowed  prefer not to say

**Children:** yes/no (delete as appropriate) Ages of children: .....

**Level of education**.....

**Employment status:** full time  part time  self employed  caring unemployed/not in paid employment  retired

**Occupation** (if retired, please note last employment): .....

If a student, please list your parents' occupations: .....

**Do you live:** a: alone  b: with parent/s  c: with spouse/partner  d: with other

**Ethnicity** (Please circle the number that best describes your ethnic group or background):

**OCEANIAN**

- 1. Australian Peoples
- 2. New Zealand Peoples
- 3. Melanesian and Papuan
- 4. Micronesian
- 5. Polynesian

**NORTH-WEST EUROPEAN**

- 6. British
- 7. Irish
- 8. Western European
- 9. Northern European

**SOUTHERN AND EASTERN EUROPEAN**

- 10. Southern European
- 11. South Eastern European
- 12. Eastern European

**NORTH AFRICAN AND MIDDLE EASTERN**

- 13. Arab
- 14. Jewish
- 15. Peoples of the Sudan
- 16. Other North African and Middle Eastern

**SOUTH-EAST ASIAN**

- 17. Mainland South-East
- 18. Asian
- 19. Maritime South-East Asian



## Interview guide

Preamble: Thank you very much for agreeing to take part in this study, your time and thoughts are much appreciated. I'd like to spend some time hearing about your personal experience of living with and managing severe asthma. Everyone is different, so there are no right or wrong answers. I'm interested in your viewpoints and experiences. So, to begin:

1. Can you take me back to your first memory of having breathing problems?
2. When do you think it went from okay to your doctor saying you have severe asthma (SA)?
3. What kind of asthma would you say you have?
  - Is there a difference to what your doctor calls your asthma and what you call it?
4. How long have you had severe asthma for?
5. Do you remember the early days of living with SA? Tell me about that.
6. What was your reaction to getting a diagnosis of SA?
7. What have your experiences been of telling family/friends/colleagues that you have SA?
  - What was their reaction?
8. To what extent has living with SA impacted on your life?
  - Tell me about a couple of examples of how this impact has affected your life.  
[Probe for social life; work; family; study; geographical location; travel]
  - To what extent has your condition inhibited you from doing the things you want to do?
  - To what extent has this condition affected your relationships?
9. Can you explain the physical experience of having severe asthma?
10. Where or from whom do you get the most support from (for example, friends, family, healthcare providers)
  - What does support mean to you?
11. What has your experience been of the medications you have had to take for SA? [Probe for benefits/disadvantages/ cost]
  - How do you feel taking medications?
  - How have you managed to come to terms with the cost of being able to afford your medicines?

- I am interested in how your medicines have influenced daily routines like work or holidays
  - How do you feel using your inhalers in public?
12. When you have an exacerbation of SA, what happens?
- Have you been hospitalised? Can you tell me what happened?
  - How was the service/support provided to you during your stay in hospital?
  - How did you find the transition from hospital to home?
13. Tell me what happens when you go to see your doctor?
- Would you discuss non-medical issues with your healthcare providers?
  - How is it decided on what medication/treatment you get?
  - To what extent would you say that the healthcare providers you see, see you as an expert on your life with SA?
  - To what extent do you find you have an equal partnership in your relationship with your healthcare providers?
14. How has the distance geographically been a problem in terms of accessing services?
15. How do you manage your asthma?
16. How have things changed over the years for you in terms of living with your SA?
17. What services aren't provided that you would like to see?
18. What do you think HCPs should be trained to do for people living with severe asthma?
19. What are your goals?
- What do you think your doctors' goals are?
20. What are your biggest concerns?
21. What messages do you have for health professionals about caring for patients with SA?
22. What messages do you have for others newly diagnosed with SA?
23. Is there a message you would like to give to HCPs?

Details regarding the number of participants' agreeing to video and/or audio recording and transcripts amendments

<b>Participant agreement</b>	<b>n=</b>
Video recording	34
Audio recording	4
Transcripts sent out	38
<b>Changes made to transcripts:</b>	
None	30
Minimal	8
Substantial	0



## **Appendix 4: Distance travelled**



The doctoral candidate travelled approximately 16,000kms

<b>Participant ID number</b>	<b>Region</b>	<b>State †</b>	<b>Distance from Sydney CBD (kms) ‡</b>
SA01	Newcastle	NSW	168
SA02	Newcastle	NSW	168
SA03	Newcastle	NSW	175.7
SA04	Central Coast	NSW	94
SA05	Grampians	VIC	926.1
SA06	Melbourne	VIC	894.8
SA07	South-western Sydney	NSW	37.8
SA08	Shellharbour	NSW	105
SA09	Hills District - Sydney	NSW	27
SA10	Hunter	NSW	155
SA11	Upper north shore - Sydney	NSW	12
SA12	Blue Mountains	NSW	113
SA13	Newcastle	NSW	151
SA14	Northern Rivers	NSW	740
SA15	Illawarra	NSW	90
SA16	Illawarra	NSW	96
SA17	South East	QLD	906.4
SA18	Brisbane	QLD	914.4
SA19	Gold Coast	QLD	851.9
SA20	Lake Macquarie	NSW	125
SA21	Inner West Sydney	NSW	18
SA22	Newcastle	NSW	168
SA23	Central West	NSW	322
SA24	Mackay	QLD	1722
SA25	Fleurieu and Kangaroo Island	SA	1394
SA26	Murraylands	SA	1303
SA27	North Sydney	NSW	10
SA28	Riverina	NSW	298.9
SA29	Riverina	NSW	298.9
SA30	Flinders Ranges	SA	1601.2
SA31	Riverland	SA	1203.3
SA32	Southern Sydney	NSW	19.6
SA33	Adelaide	SA	1378
SA34	Sorell	TAS	1590.4
SA35	North East	TAS	1561.9
SA36	Launceston	TAS	1416.8
SA37	Wheatbelt	WA	3844.8
SA38	Great Southern	WA	3853.6

† NSW= New South Wales; VIC= Victoria; QLD= Queensland; SA= South Australia; WA= Western Australia; Tas= Tasmania

‡CBD= Central Business District

# **Appendix 5:**

## **Supplementary material for Chapter 5**

5.1 Critical Appraisal Skills Programme (CASP) checklist

5.2 Summary of included tables

**Table 1- CASP checklist results for included studies**

<b>Included Studies</b>	<b>Bingham et al., 2017 (1)</b>	<b>Bingham et al., 2011 (2)</b>	<b>Bhattacharya, 2012 (3)</b>	<b>Murphy et al., 2015 (4)</b>	<b>Knudsen et al., 2018 (5)</b>	<b>Eassey et al., 2018 (6)</b>
<b>CASP questions</b>						
Q1- Was there a clear statement of the aims of the research?	No	Yes	Yes	Yes	Yes	Yes
Q2- Is a qualitative methodology appropriate	Yes	Yes	Yes	Yes	Yes	Yes
Q3- Was the research design appropriate to address the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes
Q4- Was the recruitment strategy appropriate to the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes
Q5- Was the data collected in a way that addressed the research issue?	Yes	Yes	Yes	Yes	Yes	Yes
Q6- Has the relationship between researcher and participants been adequately considered?	No	No	No	Yes	Yes	Yes
Q7- Have ethical issues been taken into consideration?	No	No	Yes	Yes	Yes	Yes
Q8- Was the data analysis sufficiently rigorous?	Yes	Yes	Yes	Yes	Yes	Yes
Q9- Is there a clear statement of findings?	Yes	Yes	Yes	Yes	Yes	Yes
Q10- How valuable is the research?	Yes	Yes	Yes	Yes	Yes	Yes

**Table 2- Summary of included studies**

<b>Authors</b>	<b>Country</b>	<b>Patients (n)</b>	<b>Sex (M/F)</b>	<b>Age Range (y)</b>	<b>Patient population</b>	<b>Data collection</b>	<b>Data analysis</b>	<b>Self-determination theoretical framework</b>	<b>Research topics and scope</b>
<b>Children and adolescents</b>									
Bingham et al., 2011 (1)	USA	17	10/7	8-16	Children living with Cystic Fibrosis (CF)	Structured interviews and SDT survey	Categorisation	BPN part of analytical approach	Barriers to adherence Attitudes about CF Healthcare experience Influences of CF self-management
Bingham et al., 2017 (2)	USA	15	13/2	7-17	Children living with asthma	Semi-structured interviews	Categorisation and deductive analysis from interview questions	Intrinsic and Extrinsic motivation and BPN part of the analytical approach and used to interpret findings	Illness experience Preferred recreational activities (non-digital and digital) Motivation to improve asthma symptoms
<b>Adults</b>									
Bhattacharya, 2012 (3)	USA	31	15/16	Age group % reported: 25 to >65 years	Rural African Americans living with Type 2 Diabetes (T2D)	Narrative approach Semi-structured interview	Thematic analysis (selective coding)	BPN used to interpret findings	Intrinsic and extrinsic motivation Influences upon T2D self-management

Murphy et al., 2015 (4)	Africa (South)	22	6/16	35-75	People living with diabetes and hypertension	In-depth interviews	Inductive and Deductive analysis Categorisation	BPN part of analytical approach	Patient perceived motivation and capacity for self-management and lifestyle change
Knudsen et al., 2018 (5)	Netherlands	14	4/10	18-30	Young adults living with Cystic Fibrosis	Semi-structured interviews	Thematic analysis	BPN used to interpret findings but not part of analytic approach	Experiences of life coaching intervention for those living with Cystic Fibrosis** Illness experience
Eassey et al., 2019 (6)	Australia	29	14/15	19-74	People living with severe asthma	Narrative approach Semi-structured interviews Follow-up open-ended questions	Inductive and deductive analysis Thematic analysis	BPN- in depth exploration on the role of autonomy	Illness experience Role of autonomy

NS= Not Stated

BPN= Basic Psychological Needs

OIT= Organismic Integration Theory

\*\* Although this study was exploring the experiences of life coaching for patients living with CF there were sections in the analysis which noted their illness experience. Thus, this review included the sections on people's views and experiences of living with CF and excluded sections on perceptions of the life coaching.

## **Appendix 6:**

### **Supplementary material for Chapter 7**

- 6.1 Confirmation of acceptance for publication in Chronic Illness
- 6.2 Additional quotes for Theme 1: Self-care is important
- 6.3 Additional quotes for Theme 2: Being at one with the illness



**From:** [Chronic Illness](#)  
**To:** [Daniela Eassey](#)  
**Subject:** Chronic Illness - Decision on Manuscript ID CHI-19-0037.R1  
**Date:** Thursday, 19 September 2019 8:39:20 AM

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18-Sep-2019

Dear Miss Eassey:

It is my great pleasure to accept your manuscript entitled "Living with severe asthma: the role of perceived competence and goal achievement" in its resubmitted form for publication in Chronic Illness. We look forward to seeing your paper in press soon, and to your continued contributions to Chronic Illness.

If you would like your article to be freely available online immediately upon publication (as some funding bodies now require), you can opt for it to be published under the SAGE Choice Scheme on payment of a publication fee. Please simply follow the link to the Contributor Agreement form in the next email and you will be able to access instructions and further information about this option within the online form.

Kind regards,  
Professor Sharon Lawn  
Associate Editor, Chronic Illness  
Flinders Human Behaviour and Health Research Unit  
Department of Psychiatry  
Flinders University  
PO Box 2100, Adelaide, South Australia, 5001

**Table 2- Additional quotes for “learning how to look after yourself”: self-care is important**

Self-care	Experiences
<p><b>Taking medication</b></p>	<p><i>I've always been medicated... I kind of self-medicated a bit too, and I think I did there's a bit more of that...possibly not the right way to go about it...you're a bit of a self-manager... (Erica, 39-year-old female)</i></p> <p><i>I can rattle them off, I can tell you exactly what they are and what they do. Because when I was in hospital, they actually get me signed off so I can actually do my own meds. Because I'm faster at it, because I take so many, and I'm better at it cause the nurses used to kind of go, what is the Theophylline and, I'd go Theophylline, Nuelin...it's like it works on the smooth muscle in my lungs, so... (Jane, 55-year old female)</i></p> <p><i>That's the big advantage [of taking medication] is being able to do anything, well to do what I can do. Go and swim, play golf, socialise, and being able to do it. Where before you probably wouldn't be able to do those if you didn't have those.... Being able to get yourself better and live. (Ben, 60-year-old male)</i></p> <p><i>no longer have my [reliever puffer] constantly attached with me [due to being on omalizumab]. I used to always have a [reliever puffer] with me...it has literally changed my life. I sat there on that last day not having had [reliever puffer], and I just burst into tears talking to a friend, and I'm like, I can have a normal life, I am going to be able to go and take my kids to the park. I'm going to be able to maybe go and work again one day. (Donna, 39-year old female)</i></p>
<p><b>Use of asthma action plans</b></p>	<p><i>I think having an asthma plan is crucial and that's what I found coming back to [HOSPITAL] every 12 months, my asthma plan is monitored, the Doctors take into account um the previous 12 months experience. (Lachlan, 64-year-old male)</i></p> <p><i>I've always got puffers at hand, always, yes, and my Asthma Plan goes in the car with me everywhere... (Grace, 41-year-old female)</i></p>
<p><b>Avoiding triggers</b></p>	<p><i>... knowing what the triggers were and making sure I didn't place myself in situations where a trigger would set me off...my main triggers these days are dust, animal hair, pollen, grasses, grass seeds, all the different types of grasses. I can't think of one I'm not really allergic to, but smells, some perfumes will trigger you as I mentioned earlier, spices, cooking for a lovely Indian curry oh, disaster! I learned that the hard way. (Lachlan, 64-year-old)</i></p>

*When I'm walking in the... in the spring... spring time I have to try and walk different ways if I know there's things around because they can trigger the hay fever... and within a couple of days I will have asthma (Jennifer, 74-year-old female)*

*Yea and then I learnt how to try and stay away from most of them [triggers]. Easier said than done with some things...If I stay away from paint fumes, and cats and then wood fire smoke, everyone's got people got wood heaters around here so come in the afternoon I shut the house up until they're well-lit and the smoke's gone warm. And then when it rains, I've got to be careful when it rains. And when it's too windy outside. Yea. As long as I keep an eye out on all of that I'm fine. (Grace, 41-year-old female)*

**Table 3- Additional quotes for “reaching an agreement with severe asthma”: being at one with the illness.**

<b>Being at one with the illness</b>	<b>Experiences</b>
<b>More than being able to self-care</b>	<p><i>So, I'm my own best friend when it comes to asthma because if I don't know how to look after myself then it's no good, and that goes for any severe asthmatic, you have to know how to look after yourself. It's no good having everybody else do it for you, it doesn't work that way. You have to understand your asthma, you have to know when it's getting bad and when you have to go to the doctor... (Phil, 67-year-old male)</i></p> <p><i>I think the big thing is, you get to know your own body after a while with asthma...it takes more time to recover from the incident or issue, so you can monitor yourself... as I said, you get to know your body after a while. (Lachlan, 64-year-old male)</i></p> <p><i>I could read it very well before hey but I can't now. I just and I'm as horrible as this is, I probably need to see what happens next time now to see whether I'm going to panic or I'm going to be responsible and look at my dot and try and get myself through it... (Jane, 51-year-old female)</i></p> <p><i>I hate being out of control there. Nothing worse than not being in control of your body, not being able to breathe there. So you do anything to- to-to try to fight it off, to-to avert it if you can. (Chris, 66-year old male)</i></p> <p><i>You have to be able... you have to be able to treat yourself, you have to be able to understand your asthma; if you don't then you're not going to be able to treat it properly. You have to treat it, the doctors can only give you the gear, you have to treat it. It's not about them it's about you and that's my strong feeling on the fact anyway (Phil, 67-year-old male)</i></p>
<b>Being able to control their emotions</b>	<p><i>Don't panic and fight it... don't give up. If I can overcome certain hurdles a lot of other people can. I think but you need to be, and don't accept the first thing that's told to you...but don't panic, don't despair because there is something right for you out there. So you need to be need to keep your cool. Panic is the terrible thing. (Dylan, 65-year-old)</i></p> <p><i>Yeah, very disappointed. It [severe asthma] presents to me as physical weakness, uh, because of that it's, uh, it's less easy to do things that you plan to do and commit to do...there's a need to address that negative, effect on your mind because if you fully accept it...These things are needed though the-these mind shift to take you away from talking yourself from becoming bedridden and not enjoying life. (Freddy, 64-year-old male)</i></p>

<p><b>Constant self-negotiation of their own personal capacity to perform tasks</b></p>	<p><i>If it's well controlled and you don't put yourself in a situation where you're going to be at risk, that you can manage to get along with reasonably normal lifestyle I would imagine...you have to make conscious effort to think of the things that you can do. (Joseph, 70-year-old male)</i></p> <p><i>Severe asthma means you can't perform at what your usual level would be like, if I did a gym workout, which I haven't done today, which I only do when I'm finished here...it sort of impacts on the duration of the session and how much I can do and how quickly I can achieve my goals too which is very frustrating, because I know I'm physically capable of doing it, it's just the asthma. (Jeff, 35-year-old male)</i></p> <p><i>But it was like six years apart and then the last six years have been really nasty. because I had... six years ago I had to retire because of illness... I can't earn a wage. it means that we can't do things I'd like to do. (Sarah, 59-year-old female)</i></p> <p><i>I learned the hard way that I couldn't do all the things I wanted to do, particularly socialising, partying. You just learn what your limitations are and you work around it and it's quite OK, you don't miss out on much. (Lachlan, 64-year-old male)</i></p>
<p><b>Coping mechanisms</b></p>	<p><i>Well I sing in a choir when I can and that certainly helps, you know just a bit of breath control, certainly gets stuff moving if there's stuff there. And generally, it makes you feel a lot better... You know, you're breathing and it just makes you feel much better... (Lisa, 60-year-old female)</i></p> <p><i>Yeah, it's important [to meditate]. Because the mindset, the mind's much more powerful than the body. It'll tell you to do things you might not even be consciously aware but you've got to get the right mindset. (Freddy, 64-year-old male)</i></p>

# **Appendix 7:**

## **Project and translation into practice**

**National Health and Medical Research Council Centre of Excellence in Severe Asthma objectives**

