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Determinants of Quality of Life in Adults with Asthma, and their Relevance in Intervention Development

by

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Thesis for the degree of PhD in Health Psychology Research and Professional Practice

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Abstract

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Asthma is a chronic condition requiring long-term management, negatively impacting quality of life (QoL). The present thesis includes three main papers and considers existing literature aiming to explore psychosocial factors which impact QoL in people with asthma and suggest guiding principles to improve QoL in people with severe asthma.

Firstly, a systematic review was conducted aiming to identify psychosocial factors impacting QoL in asthma. Findings included psychological factors, health factors and multifactorial aspects, including the interplay of health and psychological factors and asthma. It was noted that outcomes were notably worse for those with poorly controlled asthma (difficult or severe) compared to people with mild or moderate asthma.

Secondly, a mixed-methods study was conducted aiming to further understand the relationships between psychological factors and QoL and explore the acceptability of a mindfulness intervention. This included integration of a longitudinal questionnaire and qualitative interviews. Findings showed a dynamic concept of QoL, general positive attitude towards living with asthma and a mindfulness intervention, and the need for relevant asthma-specific interventions. These findings contribute to the development of guiding principles for an intervention to support QoL in asthma.

Finally, an interpretative phenomenological study was conducted, aiming to better understand the experience of people living with difficult or severe asthma alongside other physical and psychological conditions. This study found a different experience from that of people with asthma managed in primary care, significant multimorbidity which affected illness perceptions, and QoL described through activity limitation and anxiety.

Overall, this thesis proposes guiding principles for future intervention development. These are: consideration of multimorbidity as an important contextual factor for people with asthma, which affects outcomes; QoL is a dynamic concept for people with asthma, not always asthma-specific but often overlapping with activity limitation and anxiety; and finally, there is a need for relevant severe asthma-specific interventions.

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Research Thesis: Declaration of Authorship

Print name: Sabina-Claudia Stanescu

Title of thesis: Determinants of Quality of Life in Adults with Asthma, and their Relevance in Intervention Development

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. Parts of this work have been published as:

    - Stanescu, S., Kirby, S. E., Thomas, M., Yardley, L., & Ainsworth, B. (2019). A systematic review of psychological, physical health factors, and quality of life in adult asthma. *NPJ primary care respiratory medicine*, *29*(1), 1-11.
    - Stanescu, S., Kirby, S., Liddiard, M., Stuart, B., Djukanovic, R., Russell, D., ... & Ainsworth, B. (2021). “Breathing is the absolute key”: using mixed-methods to understand how a digital mindfulness intervention can improve quality of life for adults with asthma (pre-print).

Signature: Date:

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Chapter 1 An introduction to asthma, the determinants of Quality of Life in adults with Asthma, and non-pharmacological interventions

This chapter will introduce the main concepts relevant to this thesis. Firstly, it will discuss the context this thesis is placed under, by defining asthma, quality of life, co-morbidities and multimorbidity. It will then introduce theoretical frameworks relevant to this thesis, comprising the biopsychosocial model and the health belief model, then discuss the particular relevance of illness perceptions to improving outcomes in asthma. The chapter will then consider existing literature on non-pharmacological interventions for people with asthma. Finally, this chapter will outline the research question of the overall thesis, the aims and objectives, and present the outline of this thesis.

1.1 Context of the thesis

1.1.1 Asthma

According to the latest report by the Global Initiative for Asthma (GINA, 2022) asthma is defined as a heterogeneous disease, usually characterized by chronic airway inflammation. People with asthma report a 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' (Levy et al., 2023). Asthma is described by the World Health Organization (World Health Organisation, 2023) as one of the leading non-communicable diseases worldwide in adults and the most common non-communicable disease in children, estimating that over 262 million people are living with asthma, with 455 000 deaths occurring due to asthma in 2019 alone (World Health Organisation, 2023). In the UK, 8 million people have an asthma diagnosis, with 5.4 million are estimated to receive treatment (making up 12% of the UK population; Asthma + Lung UK, 2023). Asthma is more prevalent in people from lower socio-economic status, or living in areas of higher deprivation (Asthma + Lung UK, 2023), and those living in more deprived areas are more likely to be hospitalised due to asthma. Recently (in 2022), the National Health Service (NHS) has included respiratory illness as one of their priorities for the CORE20PLUS5 project, an initiative to reduce health inequalities (NHS England, 2022).

Asthma is a common respiratory condition comprised of several types described in clinical medicine. For instance, Asthma and Lung UK (the leading UK charity for asthma and lung disease) describe allergic asthma, seasonal asthma, occupational asthma, non-allergic asthma, 'exercise-induced' asthma, difficult asthma, severe asthma (both of which will be described in more detail in this thesis), 'brittle' asthma, as well as differentiate between adult-onset and childhood-onset asthma (Asthma + Lung UK, 2023). Regardless of the type, people report variable symptoms including difficulty breathing, wheezing, chest tightness or cough which vary in intensity over time. These variations are determined by different environmental and personal factors, including triggers (irritant exposure), change in weather, exercise or other illness (Levy et al., 2023). Symptoms may respond to medication and so people with asthma can become non-symptomatic – leading people to believe that if they no longer have symptoms then they no longer have asthma. This is relevant to health psychology and this thesis, The 'no symptoms, no asthma' illness perception will be discussed later in the thesis, in Chapter 4. People with asthma may experience 'exacerbations' in which symptoms unexpectedly symptoms worsen for a short-term period of time, thus posing a significant burden to patients, increasing anxiety and occasionally becoming life-threatening (Levy et al., 2023).

Qualitative explorations of the experience of living with asthma show negative impacts of asthma on social life, relationships, employment and finance, which are shaped by the physical and social environment (Douglass et al., 2002). A synthesis of 26 qualitative studies described that the 'work of living with asthma' was considered a central point by participants (Pickles et al., 2018). They discussed 'work' in terms of the effort that was needed in order to meet the demands of the environment which took personal, social and emotional tolls and compromises. People with asthma focus on the immediate context to make decisions about activities or healthcare (Pickles et al., 2018). A more recent review of 21 papers was concerned with treatment adherence (Amin et al., 2020). Illness perceptions (which are discussed more in depth later in this chapter) played a crucial role, for instance in appraising the need for treatment due to the episodic nature of asthma symptoms. Interactions with health care practitioners play a central role to managing asthma, and thus featuring in several conversations as part of qualitative studies. While interactions are described in both positive and negative terms, negative interactions and poor communication could pose a problem as they could contribute to poor literacy and a perception of low need for treatment (Amin et al., 2020).

The long-term goal of asthma is to achieve good symptom control and minimize the risk of asthma exacerbations, with the aid of medication which is prescribed in a 'step-wise' manner (Levy et al., 2023). As is common for chronic conditions, this requires, adherence to long-term treatment. Treatment is based on severity, starting with an as-needed short-acting inhaled beta$_2$-antagonist (often referred to as "reliever" or "blue" inhaler), and then stepping up to low daily dose of inhaled corticosteroids (such as Fluticasone or Beclomethasone; referred to as "controller" or "brown" inhaler). In the case of persistent symptoms or exacerbations, after checking adherence and inhaler techniques, a combination of inhaled corticosteroids and long-acting beta$_2$-antagonists is recommended. Higher doses and various combinations can be prescribed, including oral tablets (corticosteroids or immunosuppressors) and muscarinic antagonists (such as atropine, which produces bronchodilation) for more severe cases (NICE, 2021). Treatments are constantly reviewed and personalised based on severity and effectiveness for each person. The NHS invites patients for yearly reviews with an asthma nurse.

Self-management is central to achieving the long-term goals of asthma management, and comprises a good control of symptoms, normal day to day activity levels and a minimal risk of exacerbations (Levy et al., 2023). Asthma control refers to the extent to which symptoms are clinically observable in a patient, or whether they have reduced with treatment. Asthma control guidance (Levy et al., 2023) has recently been updated to clarify the presence of two domains: symptom control and risk of adverse outcomes. This guidance states that that poor symptom control has a negative effect on people and is associated with an increased risk of exacerbations but acknowledges that people with good symptom control could still have threatening exacerbations. Asthma control as an outcome is beyond the scope of this thesis, however, it is important to consider since poor asthma control has been systematically associated with decreased quality of life in people with asthma (Oh et al., 2022) as well as other outcomes such as increased hospitalisations (Lundback & Dahl, 2007). To operationalise and quantify asthma control, several measures of asthma control have been developed and validated; these have been systematically associated with guidelines and health outcomes, such as lung function or quality of life (Juniper, O'Byrne, et al., 1999; Nathan et al., 2004)

Despite this, it is estimated that more than half of all people with asthma don't achieve 'optimal' control, defined as minimal daytime and night-time symptoms, no need for emergency services, and minimal use of 'reliever' inhaler (Beasley et al., 2020). Furthermore, both primary care clinicians and people with asthma overestimate how well controlled a person's asthma is (Chapman et al., 2008; Demoly et al., 2010). One of the main reasons suggested for less than optimal asthma control was patients' different understanding of the concept of asthma control from health professionals, leading to misinterpretations or overestimations of asthma control (Beasley et al., 2020). For instance, qualitative findings showed patients referred to issues such as symptoms, activity limitation, attacks, fatigue, panic caused by symptoms, sleep problems and use of reliever inhalers when describing their asthma control (Bidad et al., 2018).

Asthma severity is currently assessed based on patient history over at least 2-3 months of controller inhaler treatment. Often there appears to be a lack of clarity around patient understanding of the terms ‘control’ and ‘severity’, with patients seeing the two concepts as interchangeable (Reddel et al., 2009). For instance, in terms of severity, patients in the emergency department had personalised terminology for symptom exacerbations (Douglass et al., 2004; Goeman et al., 2004). While asthma control and asthma severity are related (with people with more severe illness being also more likely to be poorly controlled), they are not interchangeable. Difficult asthma (or ‘difficult to control’ or ‘poorly controlled’) refers to uncontrolled symptoms or exacerbations, frequent use of reliever inhalers or night-time symptoms, where these occur due to poor adherence to treatment, psychosocial factors, comorbidities or exposure to allergens or toxic substances (Asthma + Lung UK, 2023; Chung et al., 2014). Conversely, severe asthma describes a separate diagnosis (from mild and moderate asthma) which doesn’t respond to usual treatment; it often covers the presence of uncontrolled symptoms despite all the factors mentioned above being addressed and despite treatment with the highest possible dose of inhaled corticosteroids for an individual (Schatz & Zeiger, 2022).

It is estimated that around 6.1% of people with asthma have severe asthma (Backman et al., 2018), and around 200 000 people in the UK live with severe asthma (Asthma + Lung UK, 2023). People with severe asthma live with daily symptoms and overall poor control, despite medication, and often experience side effects and comorbidities (O’Neil et al., 2015). Having severe asthma is estimated to cost 50 times more than having controlled mild asthma (Gibeon et al., 2010).

Whether their type falls under “difficult to control” or “severe”, it is recognised that people with poorly controlled asthma are more likely to have comorbidities, in particular psychological problems, and would benefit from a systematic assessment and complex approaches to treatment and therapy (Hew et al., 2020). Having a systematic assessment and determining therapy options according to its results was found to have positive impacts on quality of life (Gibeon et al., 2015).

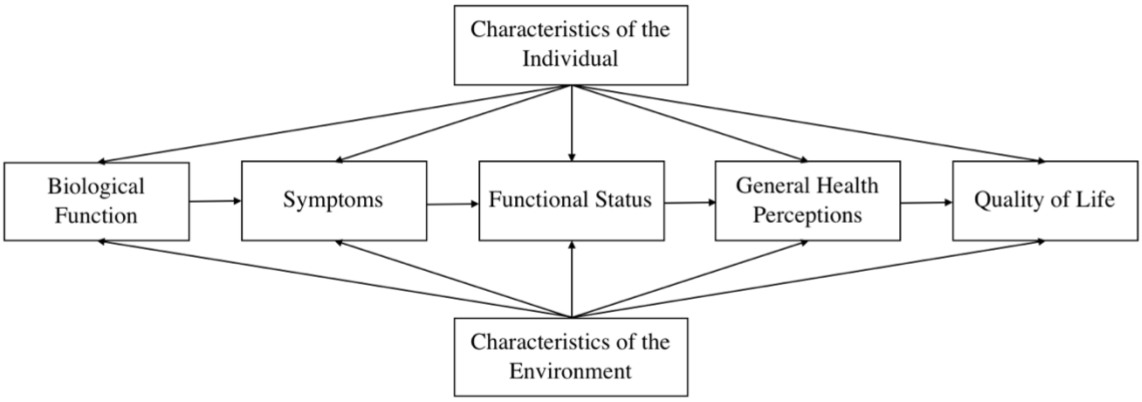
1.1.2 Quality of Life

Quality of life (QoL), is defined by WHO as "individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns." (Whoqol Group, 1995, p. 1403). To better understand the impact of chronic illness, health-related quality of life (HRQOL) is more widely used in health research. Health-related QoL is a multi-dimensional concept that includes domains related to physical, mental, emotional and social functioning (Whoqol Group, 1995). It is concerned with the impact of health status on standard of health, comfort and happiness, going beyond direct measures of population health, life expectancy and causes of death (Karimi & Brazier, 2016).

The widely used conceptual model of HRQOL (Wilson & Cleary, 1995) was more recently revised (Ferrans et al., 2005) and is shown in Figure 1.

Figure 1.

Conceptual QoL model adapted from Ferrans et al. (2005)



In this model, biological function refers to cellular and visceral processes, ranging from ideal function to pathology; symptoms are perceptions of changes from normal physiology; functional status describes the ability to perform tasks in multiple domains; health perceptions are influenced by the aforementioned components, and are subjective, referring to an individual evaluation of health. Finally, QoL is described as a subjective rating of levels of satisfaction or happiness with life, in the context of the mentioned components. Individual factors and elements of the environment influence each of these components, both physiological processes and subjective appraisals (Ferrans et al., 2005).

QoL is an especially important outcome measure for incurable chronic conditions such as asthma (Edwards et al., 2017a), where focus is recommended to be placed on functional individual, patient-focused outcomes. The negative experience often reported by people with asthma has prompted previous research (Juniper et al., 1993; Marks et al., 1992), which found that people with asthma have a poor overall QoL. Days lost of employment and hospital/emergency appointments were also correlated with asthma severity and with poor quality of life, with these effects being stronger in people with co-morbidities or multimorbidity (Accordini et al., 2008). Negative affect and impulsivity are negatively correlated with poor asthma control, which is in turn, correlated with decreased health-related quality of life (on both physical and mental dimensions, (Axelsson et al., 2009). Several studies have explored the factors impacting QoL in asthma, with findings pointing towards a wide range of factors, from sociodemographic factors, asthma control, severity, psychological factors, comorbid anxiety or depression, illness perceptions, and additional chronic conditions (Apter et al., 1999; Barton et al., 2003; Fortin et al., 2004; Juniper et al., 1993; Lavoie, Cartier, Labrecque, Bacon, Lemière, et al., 2005).

To better understand the specific QoL of people with asthma and make it easier to detect small changes relevant specifically to asthma, illness-specific QoL measures have been developed for asthma. The most prominent of these is the Asthma Quality of Life Questionnaire (AQLQ) , which assesses the most important components in asthma, according to the views of the patients: activity limitation, emotions, symptoms, and environment (Juniper, Buist, et al., 1999). Additionally, people with asthma can choose to describe individual activities of their choice, as well as the associated level of impairment they experience.

1.1.3 Co-morbidities and multimorbidity in asthma

Multimorbidity has been defined, following significant research, as the combination of at least one long-term (chronic) condition and one other acute or chronic condition, or a somatic risk factor (for instance obesity or vocal cord dysfunction; Le Reste et al., 2013). Further to this co-existence of conditions, biopsychosocial factors, and wider determinants of health may affect health outcomes such healthcare utilization or QoL (Le Reste et al., 2013). This definition is proposed as a slightly separate concept from ‘co-morbidity’, where the two (or more) co-existing long-term conditions are related and one of which is considered central (or index) by both the patient and the health care professional.

This difference in definitions has an implication in particular when discussing impact, management, and burden. For instance, in discussing a person’s co-morbidities, every additional illness impacts on the index condition which is then managed accordingly. Conversely, multimorbidity deals with the cumulative impact of all conditions on the individual, encouraging an integrated or patient-centered approach to management. Health care professionals recognize this as the future of health care practice, using the term “patient-centered approach” to describe a type of intervention that targets the overall effect on the individual rather than individual effects of particular illnesses (Dwamena et al., 2012). Even though this difference between comorbidity and multimorbidity is clear, both health care professionals and patients use them interchangeably, particularly because there is no formal system of guidelines which measures the cumulative impact of people with MCCs (Hughes et al., 2013). More recent research is starting to acknowledge the importance of looking beyond the co-existence of chronic conditions. A review of papers on multimorbidity (Willadsen et al., 2016) found that 85% of 163 papers included risk factors, and 62% included additional symptoms as multimorbid factors. Further to this, multimorbidity is a public health problem since it's highly linked with socio-economic status or deprivation, with people living in poorer areas developing multimorbidity at younger ages and experiencing poorer outcomes (Whitty et al., 2020).

Arguably, people with asthma can have several co-morbidities as well as live with multimorbidity, making the experience of living with asthma and the impact all the more significant. Asthma tends to be associated with low quality of life, and co-morbid psychological conditions, such as anxiety or depression, are often present in people with asthma. A meta-analysis (Su et al., 2016) revealed that patients with asthma were at significantly higher risk of multimorbid health and psychological conditions, such as cardiovascular, cerebrovascular conditions, obesity, hypertension, diabetes, psychiatric and neurological, metabolic and endocrine, gut and urinary, cancer and other respiratory conditions (only the prevalence of rheumatoid arthritis was not significantly different between asthmatic and non-asthmatic patients).

Additionally, participants experiencing severe and recurrent attacks showed greater co-morbidity and maladaptive coping (e.g. denial or avoidance; Miles et al., 1997). This points towards a link between the presence of uncontrolled asthma symptoms and poor outcomes, however, research is needed to explore underlying mechanisms. Anxiety and depression are very common in people with asthma and could be up to 6 times more likely to have anxiety (Thomas, Bruton, Moffat, et al., 2011). The issue raised by the authors is that such issues are often unrecognized in primary care, and are consistently associated with poor asthma outcomes, including asthma control and QoL. More recent research has investigated the concept of ‘treatable traits’ (Tay & Hew, 2018) in order to explain and understand factors which contribute to poor outcomes in people with asthma, which are not explained by the clinical presentation of asthma only. For example, the authors propose that 'extra-pulmonary' factors (for instance anxiety, depression or other long-term conditions) significantly contribute to asthma control and treatment outcomes. It is suggested they should be addressed in future research and interventions, however the mechanism of how they might interact with asthma is still unclear.

1.2 Theoretical frameworks relevant to this thesis

Health outcomes in asthma have been previously linked to clinical factors, wider determinants such as the environment or access to healthcare, (Sinha et al., 2019) as well as individual contextual factors. For instance, adherence to treatment for asthma is linked to perceptions about the severity of asthma (Kaptein et al., 2008) and the social acceptability of inhalers (Cross, 2001). In exploring this context for people with asthma, the theories outlined below in sections 1.2.1-1.2.3 (the biopsychosocial model, the health belief model, and the common-sense model of self-regulation), were used to guide thinking when planning the papers comprising this thesis.

1.2.1 The Biopsychosocial Model

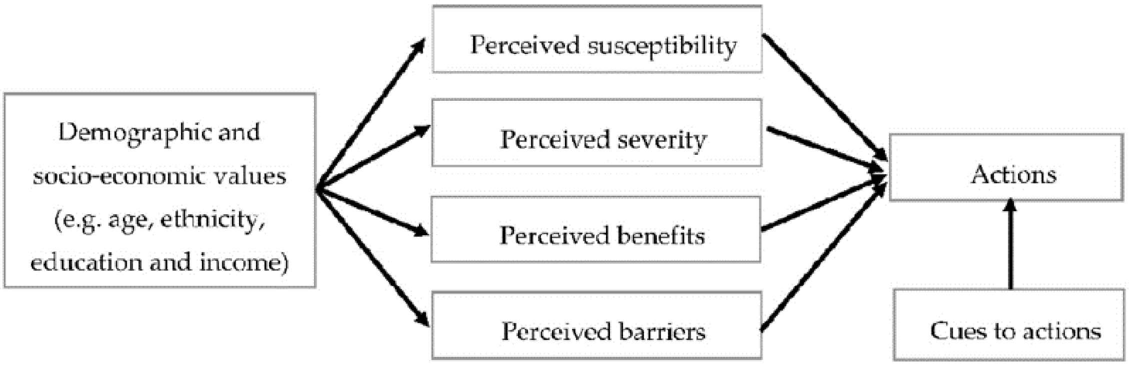
Historically, long-term conditions such as asthma has been seen through the lens of the medical model, suggesting that illness has biological causes only and the only outcome for a disease was cure (or death). However, it has long been acknowledged that psychological factors (like emotions or cognitions), as well as lifestyles or environmental factors (such as social support or socio-economic status) play a part in health outcomes (Dahlgren & Whitehead, 2021). In addition, the leading causes of mortality and disability are attributable to modifiable behaviours (World Health Organization, 2020b). A traditional bio-medical approach to this would not take into account social inequalities, 'lifestyle' choices or the high prevalence or multimorbidity which leads to decreased adherence to treatment, to only name a few (Pilgrim, 2015). As a response to the limitations to the traditional bio-medical model of chronic illness, George and Engel (1980) formulated the biopsychosocial model, a perspective suggesting that psychological and social factors inform the progression of illness alongside biological ones. According to the biopsychosocial model, illness perceptions, coping styles or relationships with close ones have a significant impact on illness outcomes, as well as people's behaviours, such as treatment adherence or healthcare utilisation. Furthermore, it supports the idea that subjective experiences are crucial to understanding illness progression and outcomes (Borrell-Carrió et al., 2004; Wade & Halligan, 2017). As a paradigm, it invites a shift towards patient subjective experience being equally important as clinical markers in driving health care and treatments. Biopsychosocial factors such as illness perceptions (Dempster et al., 2015), coping (Richardson et al., 2017), or social support (Wang et al., 2003) have been systematically proven to be linked with decreased quality of life across several long-term conditions. The biopsychosocial nature of asthma, a long-term condition where people frequently experience anxiety, depression and problems with relationships (e.g. Ritz et al., 2013) has been discussed for decades (e.g. Wright et al., 1998), however, the impact of psycho-social factors on quality of life in asthma is yet to be addressed in a systematic manner. This thesis was informed by the principles of the biopsychosocial model by acknowledging the importance of lived, subjective experience, illness perceptions and individual coping mechanisms in asthma outcomes.

1.2.2 The Health Belief Model

The Health Belief Model (HBM) provides a framework for trying to understand the subjective experience, beliefs and their impact on illness outcomes (Rosenstock, 1974). It suggests that several beliefs about health will determine people's health behaviours. These are: perceived susceptibility to the illness, perceived severity of the illness, perceived costs and benefits as well as any barriers to performing the health behaviours. Health beliefs are embedded within our socio-demographic factors (or wider determinants or health, which are by nature non-modifiable). If met with 'cues to action', such as a change in circumstance or a conversation with a health care provider, the appropriate combination of health beliefs will lead to behaviour change.

Figure 2.

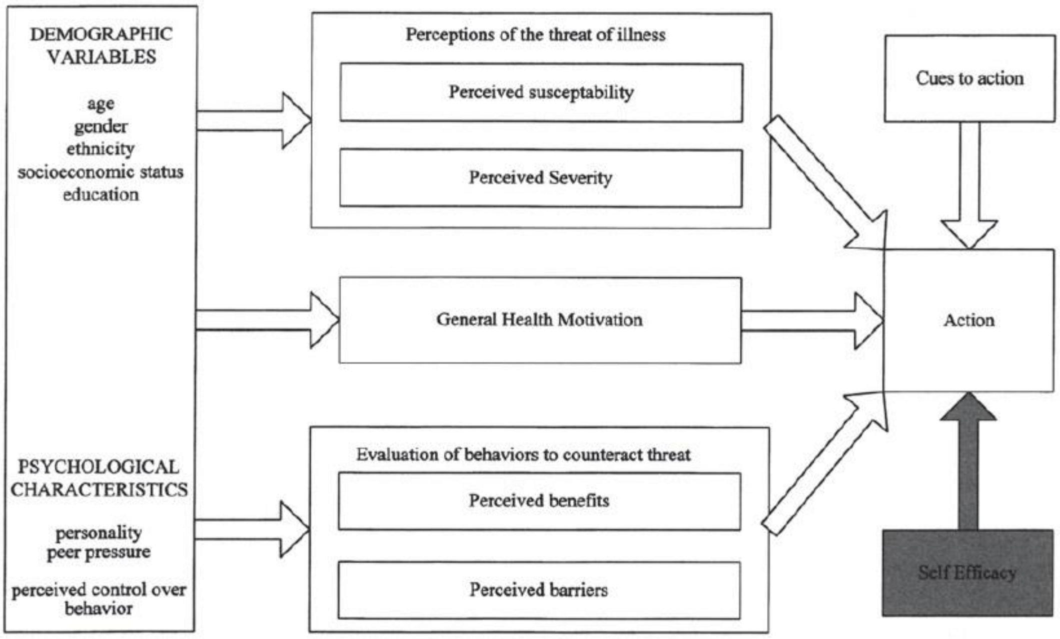
Diagram of the Health Belief Model adapted from Rosenstock (1974)



More recently, self-efficacy has been incorporated to the model as an independent variable, working alongside the original health beliefs in determining health behaviours, the new diagram presented in Figure 3 (Rosenstock et al., 1988).

Figure 3.

Diagram of updated Health Belief Model including self-efficacy, adapted from Rosenstock et al. (1988)



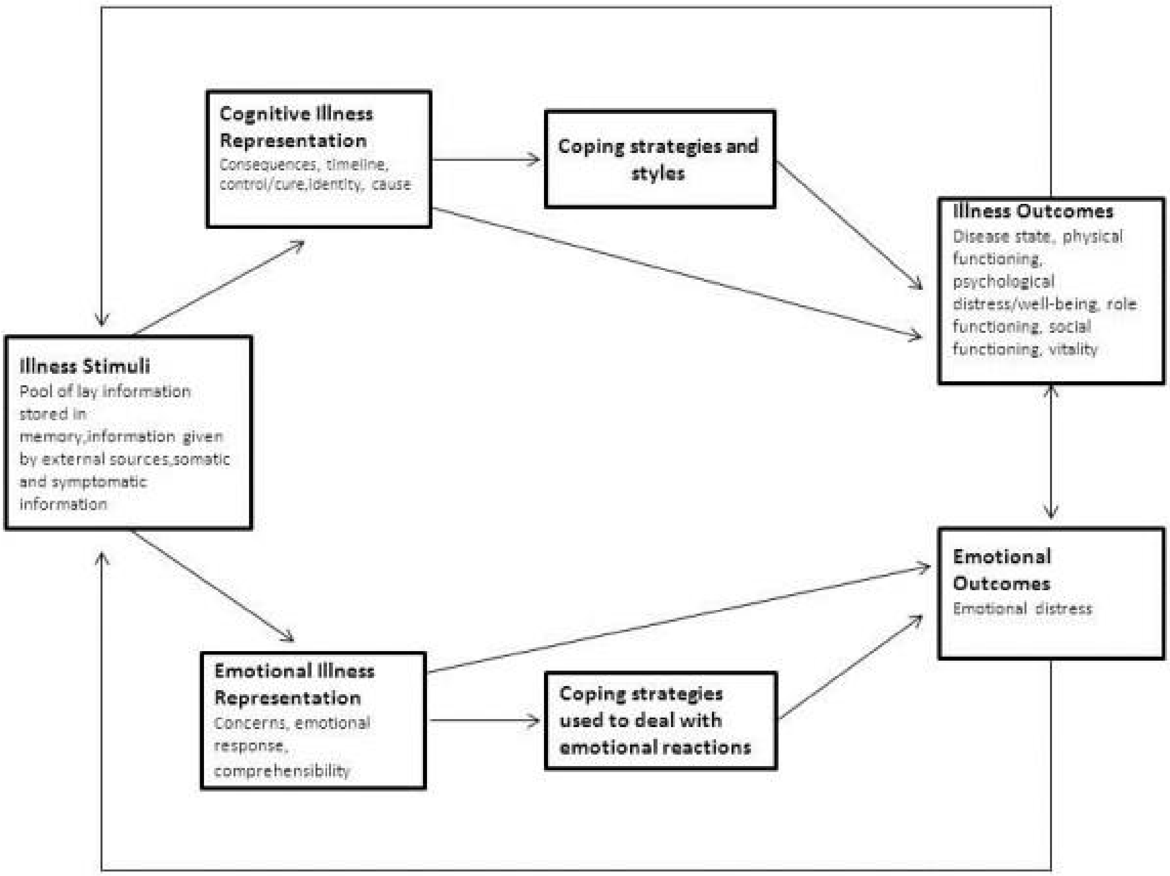
The HBM has been widely used to develop behaviour change interventions, such as treatment adherence or preventative behaviours including cancer screening, vaccination or smoking cessation (Carpenter, 2010). When synthesised together, these studies show limited effectiveness of using the HBM, which acknowledges that human behaviour is more complex and perceptions play a part alongside other factors. In terms of asthma research, several studies aimed to develop and implement interventions informed by the HBM, particularly education-based interventions (Quaranta & Spencer, 2015; Sukartini et al., 2020). While these have been successful, their longer-term impact is unknown.

1.2.3 Common Sense Model (CSM) of self-regulation

The current and most widely used model of self-regulation in the context of chronic conditions is the Common Sense Model (CSM) of self-regulation (Leventhal et al., 1980). This is a dynamic model that describes how individuals' cognitive representations of illness and treatments creates a system for action plans and implementing action. Illness perceptions or cognitions are often initiated by deviations from normal function (i.e. symptoms), as well the discussion with others (such as clinicians to discuss diagnoses). According to the CSM, the representations of illness have 5 dimensions: *identity* (a label and perceptions associated with symptoms), *timeline* (chronicity or prognosis), *causes* (e.g. environmental, psychological, genetic), *consequences* (anticipated physical, psychological or social decline), and *control* (either self-control or controlled by medical providers. Similarly, perceptions or cognitions about treatment can be operationalised using the same five dimensions. The same variables determine representations of treatment. This model has been validated across a number of chronic conditions and outcomes, a meta-analysis finding that the theoretical model of illness perceptions predicted coping and outcomes (Hagger & Orbell, 2003). A more recent conceptualization of the model includes emotional representation and self-efficacy (Leventhal et al., 2016). A diagram of the updated model, adapted from the current model (Weldam et al., 2014) is presented in the figure below.

Figure 4.

Common Sense Model of Illness Perceptions, adapted from Weldam et al. (2014)



Despite evidence consistently showing treatment for asthma to be beneficial in achieving asthma control, adherence to daily preventative treatment is still poor, estimated around between 30% and 70% in adults (e.g. Corsico et al., 2007; Horne, 2006). This makes treatment one of the most important barriers to optimal control and could increase the risk of difficult or poorly-controlled asthma. Regular asthma consultations were a significant predictor of treatment adherence (Corsico et al., 2007) and people who thought that the absence of symptoms meant their asthma was cured were more likely to have poor adherence (Sofianou et al., 2013), suggesting targeting attitudes towards their asthma could improve adherence. Concurrent with this, it is suggested that doctors should be aware that patients' views towards medication (in terms of benefits and side effects) as could have a substantial impact on adherence (Goeman et al., 2002). Research has consistently shown that beliefs about life and chronic conditions are associated with illness outcomes and treatment adherence. For instance, beliefs that life events are out of control was associated with people having difficult to control asthma (Halimi et al., 2007).

In order to better understand barriers and improve treatment adherence, one must first take a step back and explore perceptions about illness and treatment. Previous literature investigating illness perceptions in asthma in relationship with medication adherence (Kaptein et al., 2008) identified beliefs about the benefits of treatment and fear of side-effects as the main barriers to treatment adherence.

Illness perceptions have a significant impact on people's asthma, leading to poor QoL. QoL is defined differently by different people, and in particular people with severe asthma or multimorbidity. They have more of an identity of someone with asthma than those with moderate asthma. For them, quality of life revolves around activity limitation, with good QoL meaning 'being able to do things' and poor QoL referring to restriction of activity. This perception of activity and activity limitation also plays into their concept of identity. People with asthma have significant co-morbidity and multimorbidity which further negatively impacts their QoL but also their perception of how severe their asthma is. This in turn has an impact on prioritisation, adherence to treatment or seeking health care.

Extending from research in treatment adherence, self-management in the context of asthma is often thought to go beyond an action plan and inhaler techniques, instead encompassing the psychosocial management of living with a long-term condition (Barlow et al., 2002; McDonald & Gibson, 2006). Using this broader model to develop interventions was associated with improved quality of life and asthma outcomes (Newman et al., 2004). Overall, the model provided a good basis to support self-regulation-based interventions, suggesting that future interventions should take into account illness perceptions. In line with the idea of including illness and treatment perceptions in self-management intervention and guidance, the current pathway for asthma (GINA, 2022) recommends reviews at intervals between 3-12 months and reducing treatment when possible.

1.3 Non-pharmacological Interventions to improve QoL in asthma

Evidence presented in the sections above suggests that people with asthma have a complex experience and have to rely on self-management and treatment adherence. These, as well as quality of life, asthma control and other asthma outcomes are linked to psychological and wider social factors. Despite advances in pharmacotherapy for people with asthma, a significant proportion of people are not achieving optimal control (and has poor quality of life; Mortimer et al., 2022). Several non-pharmacological interventions for asthma have been trialled with limited success, in particular aiming to improve asthma control and asthma quality of life. For instance, a systematic review was conducted of all non-pharmacological interventions for adults with asthma (Yorke et al., 2015), an update of a Cochrane review conducted by the same authors (Yorke et al., 2006). The critical (systematic) review included 23 studies broadly organised in five categories: relaxation-based therapies; mindfulness; biofeedback; cognitive-behavioural therapies; and multicomponent interventions. Relaxation-based interventions and mindfulness (Pbert et al., 2012) had consistently positive effects, particularly on quality of life and reducing stress, however, more clear-cut conclusions cannot be drawn as such (similar to the Cochrane review) due to the heterogeneity of outcome measures. Cognitive-behavioural therapy (CBT) showed some benefits in particular in improving psychological measures such as anxiety in people with asthma, but authors found significant issues around uptake and retention (Yorke et al., 2015). Other studies, for instance looking into the efficacy of tele-healthcare, showed that mobile phone self-monitoring was met with some success by both patients and GPs, especially in the early phases of diagnosis, when people struggle to understand and adapt to their condition (Pinnock et al., 2007). Recent research has shown support for person-based interventions for asthma, however these mainly focused on self-management and adherence, as well as breathing (Ainsworth et al., 2022; Greenwell et al., 2021). Finally, recent findings from a systematic review of randomized controlled trials show support for digital interventions (Morrison et al., 2014). They were found to have positive effects on activity limitation, quality of life, and asthma control, among others. Further from this, a systematic review and meta-analysis found promising results, particularly for asthma control, but no significant differences on asthma quality of life (McLean et al., 2016). However, authors report poor methodological quality and encourage rigorous development and evaluation of digital interventions.

1.4 Research Question and Thesis Aims and Outline

This thesis will explore the experiences, illness perceptions, and beliefs of people with asthma, and aims to understand how these factors impact quality of life and how they might be targeted by specific elements of a non-pharmacological intervention. The following research question is proposed as overarching across the three papers of this thesis: “*What are the main factors impacting quality of life in asthma, and what is their relevance in developing relevant and effective interventions to improve quality of life in adults with asthma?*”

To answer the research question mentioned above, the following overarching objectives have been set for the present thesis:

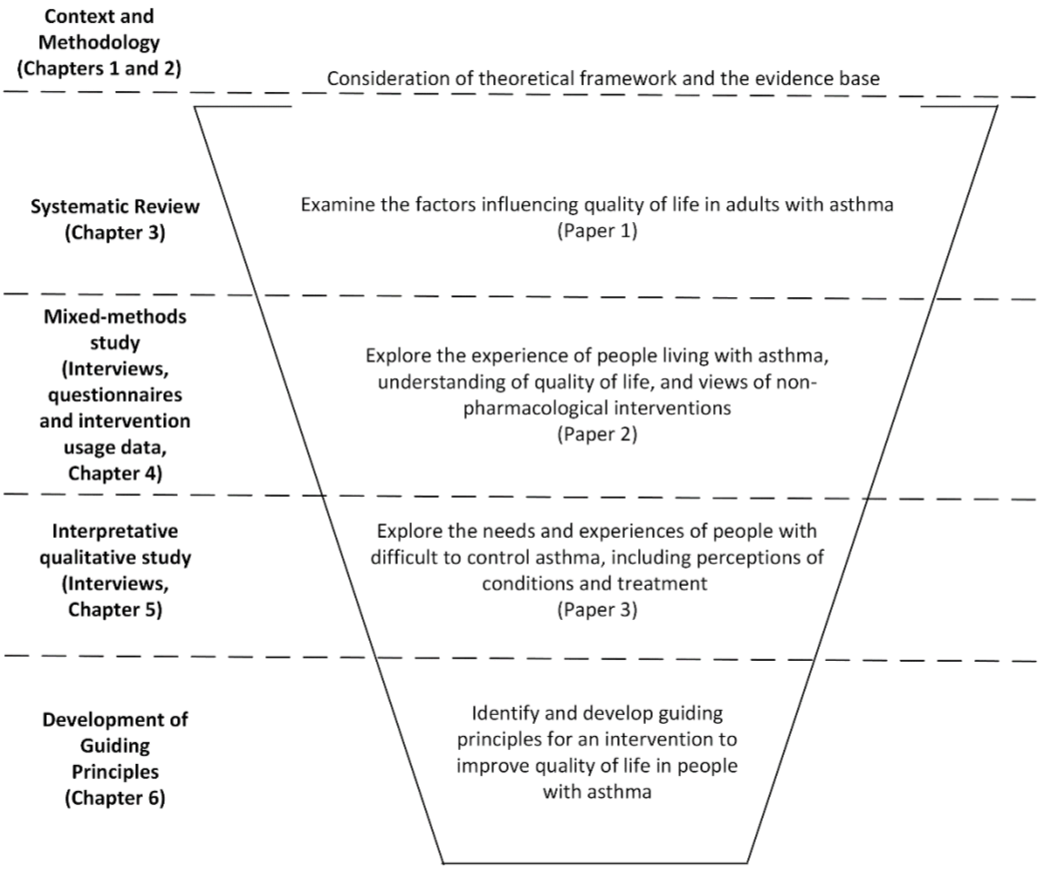
- To identify the potential factors influencing QoL in adults with asthma and to explore the relationships between health and psychological factors and asthma, and their impact on QoL (Systematic review, Paper 1 reported in Chapter 3);
- To understand the experience of people living with asthma, their understanding of QoL and associated psychological factors, and how non-pharmacological interventions can support these factors (Mixed methods study, Paper 2 reported in Chapter 4);
- To explore the needs and experiences of people with difficult to control asthma, their perceptions and representations of their conditions and treatment, their psychological and physical co-morbidities, and to understand how these experiences can inform future therapies (Qualitative IPA study, Paper 3, reported in Chapter 5)
- To highlight gaps in the literature and suggest further lines of inquiry to be addressed by future research, to inform guiding principles of a non-pharmacological intervention to improve quality of life in asthma; this refers to the overarching-chapters (Introduction – Chapter 1; Methodology – Chapter 2; and Discussion – Chapter 6).

1.4.1 Thesis outline

The present thesis consists of three empirical studies, written up in three-paper format. In Chapter 1, the main concepts are introduced and explained. Chapter 2 contains a reflection on philosophical underpinning and methodological aspects involved in this thesis, including using the person-based approach and mixed methods. Chapters 3, 4 and 5 are the three empirical papers. These are: a systematic review of the literature, a mixed-methods empirical study, and a qualitative interpretative study. Finally, Chapter 6 will conclude this thesis by discussing the main findings of this thesis and its contribution to the literature Figure 4 shows a diagram of the components of this thesis and their relationship.

Figure 5.

Visual summary of thesis components



Further from the previous section, where the overarching aims of the thesis were set, the research question of this thesis will be answered by the individual aims and objectives of the three component papers. These are:

Paper 1: A systematic review and narrative synthesis of the literature. It aimed to systematically identify psychological and health factors that influence quality of life in adults with asthma. The objectives of the review are:

- To identify psychological and health factors (or combination of factors) that influence quality of life in people with asthma;
- To synthesise and evaluate the literature exploring psychological and health factors in asthma, and to develop conclusions and suggestions for future research and clinical practice.

Full reference: Stanescu, S., Kirby, S. E., Thomas, M., Yardley, L., & Ainsworth, B. (2019). A systematic review of psychological, physical health factors, and quality of life in adult asthma. *NPJ primary care respiratory medicine*, *29*(1), 37. DOI: https://doi.org/10.1038/s41533-019-0149-3

Paper 2: A mixed-methods study, including questionnaire data, usage data and qualitative in-depth interviews. Its aim was to use mixed methods to explore participants' experiences and perceptions of their asthma and quality of life and evaluate the usage and acceptability of a digital mindfulness intervention in people with asthma. This aim was broken down into two qualitative research questions:

- Research Question 1: What are participants' experiences and perceptions of living with asthma and how do they perceive its impact on quality of life?
- Research Question 2: What are participant's perceptions and experiences (including usage and acceptability) of using a digital mindfulness intervention?

Full reference: Full reference: Stanescu, S., Kirby, S., Liddiard, M., Stuart, B., Djukanovic, R., Russell, D., Thomas, M., & Ainsworth, B. (2021). "Breathing is the absolute key": using mixed methods to understand how a digital mindfulness intervention can improve quality of life for adults with asthma. Psyrxiv. https://doi.org/10.31234/osf.io/axh3s This paper is currently under submission at NPJ Primary Care Respiratory Medicine.

Paper 3: An in-depth interview study, which was analysed using interpretative phenomenological analysis (this is further described in Chapters 2 and 5). Its aim was to explore the experience of people with severe or difficult to control asthma, their self-management strategies, their perceptions of co-morbidities and multimorbidity, activity limitation and quality of life. The research question this paper set out to answer was:

- What are the experiences and shared beliefs of people with difficult to control asthma about living with and managing their condition, in the context of any other co-existing long-term conditions?

This paper is currently under submission for Qualitative Research.

Chapter 2 Methodological Approaches to Explore Determinants of Quality of Life in Asthma

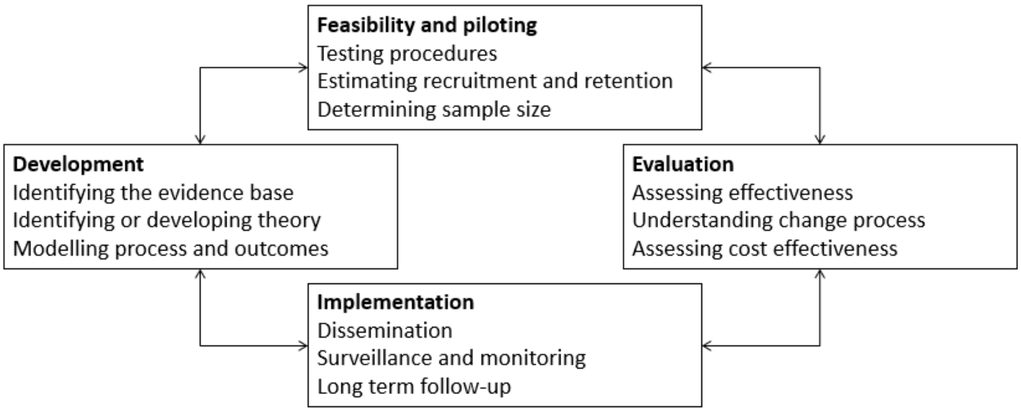
Chapter 2 will build on the context and theoretical concepts presented in Chapter 1 by discussing the methodological approaches used in this thesis. It will first discuss intervention development, firstly by introducing the overarching theoretical framework that underpins this thesis (the person-based approach PBA; Yardley, Ainsworth, et al., 2015). The PBA shapes the understanding of the findings and offers a framework to informing future intervention development and refinement. This chapter will then explore other elements relevant to intervention development, such as public and patient involvement, and other key interventions which informed various stages of this thesis. It will then discuss research paradigms and consider psychological underpinnings influencing the thesis and the three papers comprising it, before offering a critical description of mixed methods research. This latter section will include a discussion of qualitative, quantitative and mixed methods paradigms. Finally, the chapter will describe the methods used within this thesis, their strengths and limitations and a reflection of the role of the researchers in relation to these methods.

2.1 Intervention development

The aim of this thesis is not to create or trial an intervention. The papers of this thesis work towards this aim of developing an intervention in the sense that they are concerned with the early stages of development, by offering an in-depth description of the key elements that would benefit people with asthma in a non-pharmacological intervention. The previous literature presented in Chapter 1 suggests that people with asthma could benefit from a complex intervention. The Medical Research Council (MRC) provide a clear framework for designing and evaluating such complex interventions (Craig et al., 2008). They describe interventions as ‘complex’ if they have more than one element but warn readers about there not being a clear line between ‘simple’ and ‘complex’ interventions, with interventions widely varying in complexity, for example by having different number of interacting elements or varying behaviours required by those delivering or receiving the intervention. Another key element of complexity is the degree to which an intervention is flexible or permits tailoring to individuals’, groups or populations (Craig et al., 2008). Although this guidance has recently been updated (Skivington et al., 2021), at the conception of this thesis, the MRC guidance highlighted four key stages: development, feasibility and piloting, evaluation, and implementation. Figure 6 shows a summary of the four stages.

Figure 6.

Key elements of developing complex interventions, according to 2006 MRC guidance (Craig et al., 2008)



The guidance suggests several overarching principles: interventions require a sound theoretical underpinning; a process evaluation is needed to understand implementation problems; a single outcome might not be enough; and standardisation may not be appropriate, the intervention might be more effective if it allows for adaptation or tailoring. This thesis is concerned with the development phase only. This involves three steps: identifying existing evidence, identifying (or developing) theory, and modelling process and outcomes. Much of the evidence is described in Chapter 1, in particular relevant literature on other non-pharmacological interventions, as well as Chapter 3, which describes a systematic review aiming to identify key elements that impact QoL in people with asthma. In terms of theoretical underpinning, this thesis used the person-based approach (Yardley, Ainsworth, et al., 2015). The goal of this thesis, from a person-based approach point of view is to identify and present guiding principles for a theory-, evidence-, and person-based intervention. Finally, Chapter 6 discusses the ‘guiding principles’ for a proposed future intervention, which are consistent with both the PBA and the MRC guidance, as they suggest processes and outcomes. More recent guidance on intervention development (O'Cathain et al., 2019) supports the complementarity between the development phase of complex interventions guidance (Craig et al., 2008) and the person-based approach (Yardley, Ainsworth, et al., 2015) by affirming the need for an iterative process to development, involvement of stakeholders, a theoretical background, as well as using primary sources of data and taking into account the context the intervention would be placed in.

2.1.1 The Person-Based Approach

The person-based approach (PBA) is a theoretical framework guiding intervention development (Yardley, Ainsworth, et al., 2015). The core of the PBA involves using an in-depth understanding of the viewpoint and context of the target population to inform principles and elements of the intervention. The authors propose this understanding can occur through mixed methods research, as well as necessary iterative qualitative explorations of the main issue with members of the target population (Yardley, Ainsworth, et al., 2015). PBA suggests that in the development of interventions, a focus be placed on understanding and attempting to accommodate the ideas and preferences of the target audience, as well as incorporating the users' perspectives with theory-based and evidence-based methods of behaviour change. PBA is used to enhance the acceptability and relevance of interventions and uses mixed methods to systematically investigate the beliefs, attitudes and contexts relevant to people who might use the intervention (Yardley, Ainsworth, et al., 2015; Yardley, Morrison, et al., 2015).

According to the authors, intervention development is accomplished in three steps: intervention planning, intervention design, and finally development and evaluation of acceptability and feasibility. In terms of methodology, the PBA recommends that, at the planning stage a scoping (systematic) review of the literature is conducted, as well the use of qualitative and mixed-methods designs to aid in the formulation of guiding principles. Firstly, qualitative research is conducted with members of the target population, identifying beliefs, attitudes, contexts, situations, to anticipate not only accessibility, but also future usage and uptake in the context of the users. This is triangulated with findings from the systematic review. This leads to the second stage, intervention design, which is concerned with the development of "guiding principles", which can address behavioural change in a context relevant to future users (Yardley, Ainsworth, et al., 2015). Guiding principles consist of two elements: intervention design objectives (context-specific behavioural needs) and key features (characteristics of the intervention that can achieve these objectives). The guiding principles, together with existing literature and evidence, as well as continuous participant involvement are used to build a prototype intervention, which is then tested for feasibility, using

MRC guidance (the 2006 guidance was still in effect at the time of publication of the PBA guidance paper, however, the process remains relevant under the new, 2021, guidance).

Previous research found interventions informed by the PBA to be feasible, acceptable and effective, for instance those looking at improving self-management for people with hypertension (Band et al., 2017; Bradbury et al., 2018), those aiming to improve adherence in adolescents with asthma by identifying behavioural issues (Easton et al., 2022), or a complex intervention for cancer survivors (Bradbury et al., 2019). Specific to adults with asthma, one such intervention has been developed and proven feasible to people with asthma, as well as showing positive impacts on asthma-specific QoL (My Breathing Matters; Ainsworth et al., 2019). This intervention recruited people with asthma from primary care and focused on self-management and medication adherence in a feasibility study and process analysis (Greenwell et al., 2021).

This thesis was informed by the PBA (Yardley, Ainsworth, et al., 2015). The aim of the thesis was to conduct the first two steps of the PBA, planning and development. To achieve this, a systematic review was conducted, alongside in-depth qualitative and mixed-methods exploration of the perspectives of people with asthma (described in Chapters 3, 4, and 5). The second step, development of guiding principles, is described in Chapter 6, alongside suggestions for future research and next steps for intervention development.

2.1.2 Patient and Public Involvement

Patient and Public Involvement (PPI) refers to carrying out research with (or by, in certain cases) members of the public (Greenhalgh, 2009). In the case of this thesis, it refers to involving people with asthma with an interest in research in the design of the studies in particular. Other terms such as lay members, service users, people with lived experience among others, might be used in research and service improvement. Members of the public are invaluable in giving researchers a steer on how to conduct a study, whether the questions are relevant, whether the length is acceptable etc.

The PBA recommends the use of PPI alongside qualitative research at all stages of intervention planning, development and evaluation (Muller et al., 2019). In the case of the present thesis, each of the main primary research studies (Paper 2 and paper 3) had lay members on their steering groups (Ainsworth et al., 2022; Azim et al., 2019), which meant these members were involved in the planning and conducting these two studies. For paper 2, people with asthma advised on the development of the study from the early stages, they commented on the length of the surveys, and the content and length of the interview script. Before approaching participants for the qualitative interviews, I trialled the script by conducting an interview with an acquaintance who was someone with asthma who was familiar of Headspace. They offered feedback on the experience of taking part in the interview. Following a similar process for the study presented in Paper 3, as part of the approval process to recruit through the WATCH cohort, I consulted one of their lay members on the steering group. They offered invaluable advice in particular about the language used in some of the questions, the length of the interview, and they commented on the merit of the study as a whole.

2.1.3 The interventions informing this thesis

Both papers 2 and 3 (described in Chapters 4 and 5 respectively) were each nested within larger trials. This offered certain advantages in terms of recruitment, as well as support in terms of the rigour of a large trial. Neither of the two trials form part of the thesis, but for context, they are both described below.

2.1.3.1 Mobile Mindfulness for Asthma

The Mobile Mindfulness for Asthma study or MOMA (Ainsworth et al., 2022) was a feasibility trial, aiming to explore the acceptability and relevance of a digital mindfulness intervention (Meditation and Sleep Made Simple - Headspace) for adults with asthma, recruited from primary care. Headspace is a widely available paid-for mindfulness app. At the time of the study, Headspace did not have any asthma-specific meditations or ‘blocks’ but has been found effective in improving wellbeing in the general population. Further evidence on the effectiveness of Headspace is presented in more detail in Chapter 4 (which reports the second paper), as well as in the paper describing the feasibility trial . For the MOMA trial, participants (N=145) were recruited from primary care and randomised to an intervention (N=94) or control (N=51). They completed questionnaires (QoL, asthma control, and psychological measures such as anxiety, depression or mindfulness) at baseline, six weeks and three months. Results showed improved QoL but not asthma control (Ainsworth et al., 2022).

The research presented in this thesis (chapter 2, mixed-methods study) was nested within this feasibility trial. This meant participants had given consent to be approached for a qualitative interview. In addition, participants received illness perceptions questionnaires at the same time as they received all other questionnaires for the trial. In terms of the interviews specifically, the study relied on the added context of participants using the Headspace to explore their experience of asthma, quality of life, and their experiences, views, preferences of non-pharmacological interventions for asthma using a mixed-methods design. Qualitative data was collected and analysed at the same time as quantitative data was being collected. Since this was a longitudinal study, participants completed a battery of surveys when they enrolled. At the same time, they were given an access code to Headspace, which meant that their usage data started being collected. Participants were approached for interviews at around 6 weeks after enrolment (but this varied for some participants, from 1-2 weeks after enrolment to 3 months). This was to allow them time to start using Headspace. Baseline data was used for purposive sampling, to ensure a spread of demographic characteristics, as well as target people with both high and low QoL scores.

2.1.3.2 The Wessex Asthma Cohort of Difficult Asthma (WATCH)

WATCH is described as a 'real-life', prospective study of participants with difficult asthma attending a difficult asthma clinic. Data collection includes an abundance of demographic and clinical measures of people's asthma, as well as quality of life, anxiety, depression and comorbidities. People attend clinic consultations as well as take part in research studies. In this respect, participants experience it as their 'usual treatment' clinic, but with the added familiarity of completing questionnaires. More information about the WATCH cohort and wider measures collected from their participants has been published elsewhere (Azim et al., 2019). The third paper of this thesis (presented in Chapter 5) is a qualitative interview study, with participants recruited from the WATCH clinic. Participants had given consent to have their data shared with other researchers and to be contacted about other studies. They were contacted with the support of the trial manager. Following a rigorous internal approval process, it was agreed that the database of WATCH participants (or patients) could be used for purposive sampling, including some psychosocial measures and contact details. Participation in the interview study did not interact with their participation in the WATCH trial or their attendance to appointments. Further detail on recruitment is presented in Chapter 5.

2.2 Research paradigms

Research paradigms encompass values, practices, beliefs and assumptions (Mertens, 2012) and are what guides the development of research (Clarke & Braun, 2013). Researchers choose paradigms in line with their philosophical outlook. There are four main aspects which determine beliefs and assumptions, and in turn paradigms. These are *ontology* (the view on reality); *epistemology* (view on knowledge); *axiology* (view on the researchers' values and how they impact research) and finally *methodology* (view on how knowledge is acquired). Choosing a paradigm using these four aspects will then guide all aspects of the research process (Teddlie & Tashakkori, 2011). Historically, opposing paradigms have been proposed, arguing for the merits of 'objective' versus 'subjective', 'experiment' versus 'experience', 'qualitative' versus 'quantitative'. On the one hand, positivism argues for the existence of an objective truth, discovered through rigorous experimental design. Further developing on this paradigm, post-positivism acknowledges that truth is objective, however, the researcher can influence observations through the interplay of their own knowledge, values or experience (Panhwar et al., 2017). On the other hand, constructionist argue for the value of a subjective truth explored through individual experiences. Evidence-based healthcare often has a strong focus on experimental designs, clinical randomised trials and attempts at objectivity. It is proposed that such methods, embedded in the objective positivism, might keep health care professionals from understanding their patients' lived experience and how this might shape outcomes (Biggerstaff & Thompson, 2008).

Quantitative methodologies have dominated healthcare and psychology research as they both strived for the nomothetic approach of finding generalisable patterns and infer cause from existing findings (Yardley & Bishop, 2017). It has been particularly prevalent in health psychology due to its similarity to medical or clinical science (Dures et al., 2011). Quantitative methods are characterised by standardised, validated, and discrete measures, where researchers are concerned with rigour, reliability, and generalisability. Sample size and characteristics are crucial, and experimental and randomised studies are the gold standard.

Conversely, qualitative methods, challenge the notion of objectivity in truth or knowledge. It fundamentally asserts that our reality and view of the world is shaped through subjective experiences and social interactions (Yardley & Bishop, 2017). Qualitative methods include data collection such as interviews or focus groups employing open ended questions, that avoids restricting participant response. These methods focus on detail and depth, while not being concerned with 'numbers', be that sample size or similarities in responses.

Both methods have been found to have advantages and disadvantages. Positivist paradigms criticise qualitative research for its lack of rigour, subjectivity, and difficulty to assess in a systematic manner. On the other hand, social constructionism poses that quantitative research is dry, not natural, and reductionistic (Michell, 2004). Historically, quantitative and qualitative methods have been viewed as separate and unable to be integrated. Instead of restricting or constraining a researcher's decisions, mixed methods research attempts to legitimise the use of several approaches in answering research issues.

The paradigm of pragmatism (Bhaskar, 2013) offers a middle ground to the opposing aims of positivist and constructivist philosophies (Ivankova et al., 2006; Yardley & Bishop, 2017). When it comes to research, pragmatists choose the methodologies which are best suited to addressing the research question. As a result, those who follow this path do not limit their methodological alternatives depending on their philosophical beliefs. If this strategy is used, the methodology that is chosen is the one most likely to improve comprehension of the research problem (Teddlie & Tashakkori, 2011; Yardley & Bishop, 2017; Yardley, Morrison, et al., 2015). The pragmatist approach also rejects the need to distinguish between qualitative and quantitative methodologies. As a result, pragmatism provides a possibility to mix these two methodologies in research (Yardley & Bishop, 2017).

Traditional paradigms aim to discover the truth, but pragmatism maintains that truth is only provisional and changes with time (Johnson & Onwuegbuzie, 2004; Teddlie & Tashakkori, 2011). The objective-subjective duality is rejected by pragmatism, which claims that truth cannot be determined. This is particularly important for explorations of people’s experiences and illness perceptions, which are of importance in health psychology (Bishop, 2015). Considering pragmatism is outcome-oriented, research questions and methodologies are influenced by the impacts and desired outcomes (Bishop, 2015).

While pragmatism has a number of critiques, such as researchers not being explicit enough about ontological and epistemological perspectives on research or specificity in terms of targets (Bishop, 2015; Johnson & Onwuegbuzie, 2004), pragmatism is a new philosophy and paradigm for research that goes beyond existing previous philosophies of knowledge. Pragmatism does not dispute the nature of reality or knowledge; rather, it specifies the values that should lead a meaningful investigation. Finally, pragmatism's goal is to bring about positive change (Bishop, 2015).

This thesis was underpinned by a pragmatist perspective in aiming to recommend guiding principles for future interventions to improve quality of life for people with asthma. This thesis used the added benefits of both qualitative and quantitative methods, and the specific methods of inquiry were informed by the respective research questions, as framed by a pragmatist epistemology (Bishop, 2015).

Understanding the role of illness perceptions or cognitions, as well as the emotional interpretation of living with asthma is of particular importance to the discussion of findings within this thesis. Philosophers have long argued for the divide between ‘mind’ and ‘body’, in this case explained by the fact that people’s objective symptoms do not always translate in similar experiences (for example, Beecher’s 1946 classic study on the discrepancy between tissue damage and pain experience is a good illustration of this phenomenon). Other philosophical considerations include concepts like qualia. ‘Qualia’ refers to introspectively accessible phenomenal aspects of our experience. The philosophical argument here states that people have subjective interpretations of experiences and phenomena. These are determined by so many combinations of extrinsic and intrinsic factors that it would be incredibly difficult, if not impossible, to predict someone's experience. The problem arising from this phenomenon is something philosophers labelled as 'the explanatory gap'. This means that feelings and experiences are subjective, which make them impossible to describe through a shared language that would be fully understood by the received (Levine, 2001). In the context of this thesis, it is important to have some awareness of the concepts mentioned above as it informs the interpretation of mixed-methods results in the care of papers 2 and 3.

2.3 Using a Mixed Methods Approach

Mixed-methods research has been defined as "mixing [qualitative and quantitative methods] within a single study; a mixed method program would involve mixing within a program of research and the mixing might occur across a closely related set of studies" (Johnson et al., 2007). Further to this, the authors expand that combining both quantitative and qualitative methods approaches has the benefit of expanding our understanding and knowledge (Dures et al., 2011; Johnson et al., 2007).

Several ways of combining the different strands of data (individual components, such as qualitative or quantitative data) have been proposed (Creswell & Clark, 2017). The authors describe level of interaction (independent or interactive, based on whether one strand affects data collection or analysis of the other), priority (whether strands included are offered equal priority or whether one is weighted higher than others), and finally timing, which refers to whether data is collected at the same time (concurrent), or has distinct phases (sequential or multiphase). Within an empirical study, qualitative and quantitative data can be combined at recruitment, at data collection, at data analysis or not at all until the very end. The timing of analysis divides mixed methods design into sequential and simultaneous (Morse, 2009).

Effective integration is one of the main challenges of mixed methods designs. Previous studies have been criticised for combining qualitative and quantitative methodologies without taking into account the arguments and disputes described in the sections above (Kelle, 2006). For instance, it is crucial to consider quality criteria for all methods combined in a mixed methods study. Some criteria to ensure quality, such as transparency, are applicable to any research method, while others are only relevant to specific methodologies (Elliott et al., 1999; Yardley, 2000). For example, factors like statistical power and bias removal are solely applicable to quantitative research. Attention to themes like owning one's perspective (Elliott et al., 1999) and sensitivity to context, commitment, and rigour (Yardley, 2000) have been identified as key factors to consider when evaluating qualitative research. Researchers may unwittingly violate assumptions of one or both methods, or fail to maximise the unique potential of each method if they do not have a thorough understanding of the paradigms. For example, qualitative research is typically utilised as an add-on to quantitative research, with the goal of elaborating or illustrating quantitative findings rather than being used to challenge and discover. Furthermore, qualitative evidence risks being rejected as weaker and less objective, rather than being interpreted as a new level of evidence, expanding understanding, if findings are conflicting(Yardley & Bishop, 2017). While there might not be simple solutions to these problems, some steps have been suggested: increased clarity about reasons for using certain methodologies, the precise goals of each component, how findings from several paradigms will be combined, and which approach, if any, would be favoured (e.g. Dures et al., 2011; Yardley & Bishop, 2017).

In this thesis, a mixed methods research design was chosen and applied in two different ways. Firstly, a number of methodologies is used to answer the research questions relevant to each paper in turn. This thesis included: a) a systematic review, where included papers were synthesised using narrative synthesis, b) a mixed-methods study which included: qualitative interviews analysed using thematic analysis, longitudinal questionnaire data, analysed using correlations, and usage data, and c) an in-depth qualitative study, using interpretative phenomenological analysis. This thesis aimed to use qualitative and quantitative methods in conjunction to benefit from the advantages of several methodologies in attempting to answer the research question (Creswell & Clark, 2017). In combining qualitative and quantitative methods, the papers presented in this thesis aim to take this criticism into account. These are then combined in the final chapter to present overarching findings and suggest guiding principles. Secondly, paper 2 describes a convergent parallel design (Greene et al., 1989). This method was proposed as a means to combine the strengths of both quantitative and qualitative perspectives while also addressing their flaws. Further detail on this is presented in section 2.4 below.

2.3.1 Reflection on Quality in Qualitative Research

The methodologies presented in the sections below referring to the papers comprising this thesis all work under the assumption that the researcher is an integral part of the research process, rendering it therefore impossible for the researcher to be separated from the research findings (Bishop, 2015). This is consistent with a pragmatic epistemology and encouraged in particular by the qualitative methods used here, specifically IPA and thematic analysis, which are both presented below. As this thesis relies mainly on qualitative methodologies, it is important to note that some traditional quality markers, often applicable to quantitative research, such as sample size calculation or generalisability, are not relevant to this thesis (Yardley, 2000). Instead, four main quality criteria for qualitative research have been followed throughout the design and conducting the studies comprising this thesis. They are: *sensitivity to context, transparency and coherence, commitment and rigour, and impact and importance* (Yardley, 2000). *Sensitivity to context* is particularly important, especially in the context of participants in the studies of this thesis, namely people with asthma. This criterion includes the use of theory and relevant literature (summarised in Chapter 1), including participants' perspectives and individual contexts, as well as taking into account ethical issues. This became critical during the COVID-19 pandemic, as is described in Chapters 5 and 6. *Transparency and coherence* refer to the clarity of the description, data presentation and detail on the method used, as well as reflexivity. These are presented both in Chapter 2, from a theoretical standpoint, as well as in individual chapters describing the three papers. *Commitment and rigour* refer to the methodological competence, depth of analysis and data collection, and an in-depth engagement with the topic. This criterion in particular guided the researcher's reflection throughout the design of the three studies, as well as throughout data collection, analysis and write up. A summary of the reflexive account is presented in Chapter 2. Finally, *impact and importance* refer to the 'so what?' question asked of research papers. This thesis aims to add to the body of knowledge, and make recommendations for future person-based non-pharmacological interventions.

These four criteria were considered throughout the research process of all three papers presented below, and are particularly relevant to this thesis as the context is a crucial aspect to asthma outcomes. Due to the three paper thesis format, not all of the methodological details relevant to each study can be included in each paper, therefore additional details on the methodology of each paper is presented in section 2.4.

2.4 Overview of thesis methods

This section will describe the methods for data collection and analysis employed by each paper.

2.4.1 Paper 1 – Systematic Review

The systematic review aimed to identify any potential psychosocial factor that might have an impact on quality of life in people with asthma. This included health factors, including chronic conditions, anxiety or depression, illness perceptions, and coping styles, but did not include demographic factors (age, gender, ethnicity) or wider determinants of health (such as education, health literacy, access to services etc.), since these could not be successfully targeted with a non-pharmacological intervention at individual level. In order to synthesise the findings of the systematic review, narrative synthesis was used, following guidance from (Popay et al., 2006). The goal of narrative synthesis is to tell a story by describing and grouping similar findings, and attempting to find emerging patterns in the literature. This is an approach to systematic reviews involving the synthesis of findings and relies primarily on word and text to summarise the findings, by "telling the story" of the results. The systematic review followed closely the steps for narrative synthesis proposed by (Popay et al., 2006). These included:

1. *Consideration of theory* – this is important to inform decisions about the review questions and the inclusion and exclusion criteria. More detail for this can be found in chapter 1, where the main theories used here (such as the definition of multimorbidity, or the common sense model to better understand illness perceptions) are addressed.
2. *Preliminary synthesis* – to develop an initial description of the results. These were organised to facilitate the observation of patterns, by using:

a. Textual description of studies; this was done using a data extraction table;

b. Grouping and clusters (initial grouping based on the factors included in studies); papers were grouped based on the factors they were exploring and groups created from the patterns. As many studies looked at more than just one measure, they fell within multiple themes;

c. Tabulation; as previously mentioned, grouping papers by factor and by quality of life measure facilitated the synthesis process.

d. Vote counting as a descriptive tool; this was done to some extent for the present review, but effect sizes were often difficult to establish or calculate, particularly due to reporting of individual study results.

e. Translating data – this involved the principles of thematic analysis to describe findings and group papers based on their meaning, in an inductive manner. For instance, papers were compared if they were measuring the same factor.

f. Translating data – content analysis similar to vote counting; this was used to identify consistent findings and contrast them with dissonant findings, in an attempt to draw conclusive statements. For instance, study characteristics were compared where result were apparently divergent or contradictory (more detail on individual comparisons is presented in Chapter 3).

3. Exploration of relationships between studies – identifying factors that explain differences in direction and size of effect across studies (while also acknowledging why some factors show effects while others don't).
4. Assessing the robustness of the synthesis – this can be the methodological quality of the primary studies and the trustworthiness of the synthesis. This was achieved by using the AXIS quality appraisal tool. This allowed for a qualitative assessment of individual studies (more details are presented in Chapter 3). Studies were not excluded on the basis of quality alone. As per guidance (Popay et al., 2006), the overall findings were assessed in order to address the overall trustworthiness of the findings of the review.

2.4.2 Paper 2 - Mixed-methods process exploration

2.4.2.1 Data Sources

To further elaborate from section 2.2, there can be several approaches to mixed methods studies, but they combine at least one qualitative with at least one quantitative method. The decision to use a mixed methods design in paper 2 comes from the aim to answer a research question that would benefit from the added advantages of both questionnaires and information on usage of a digital intervention, as well as in-depth qualitative interviews. The goal of this paper was to gain a deeper understanding of the experience of asthma, and the role that a mindfulness app might have in improving quality of life. Questionnaire data were collected from participants at baseline (the point of enrolling in the study), at six weeks and at three months, to look at correlates and predictors of asthma related quality of life as well as the relationship between usage and changes in time, while interview data was collected to understand questions such as 'why' Headspace might help or what people with asthma might find useful in a non-pharmacological intervention. In addition to questionnaires, this paper explored usage data which looked at patterns for people accessing and engaging with Headspace. This complemented user experience, and outcomes found by quantitative analysis (Miller et al., 2019). A more detailed description of analysis and individual methods used is presented in Chapter 4.

Qualitative data from semi-structured interviews was analysed using reflexive thematic analysis (Braun & Clarke, 2006, 2012). Boyatzis (1998) describes thematic analysis as a tool to be used across qualitative methods, but Braun and Clarke (2006) argue that not only is thematic analysis a standalone method, but it is also the first method that should be taught to aspiring qualitative researchers. There are six steps to conducting thematic analysis. These are: familiarising with the data (transcripts); generating initial codes; searching for themes by collating codes, reviewing and refining themes, naming and defining themes, and finally producing the qualitative report. These were initially described in 2006 (Braun & Clarke, 2006) and further refined in a more recent reflection paper (Braun & Clarke, 2019a). One of the main advantages of thematic analysis is flexibility. Because of this, it is compatible with several epistemological and theoretical frameworks, including the pragmatic one underpinning this thesis. More recently, authors invite researchers to reflect on shortcomings of previous papers such as the use of inappropriate language like 'themes emerged' or unauthorised combinations of techniques like grounded theory or content analysis within the thematic analysis process (Braun & Clarke, 2019a). Further to this, the conceptualisations of themes is discussed, as well as proposing terminology like 'generating' or 'developing' themes as an update from searching for themes. Authors acknowledge the decision to label the method as 'reflexive thematic analysis' to further add rigour to the steps described in the original paper. This thesis used the steps described in the original paper, with further reflections on the updates method being carried out throughout the final write up process.

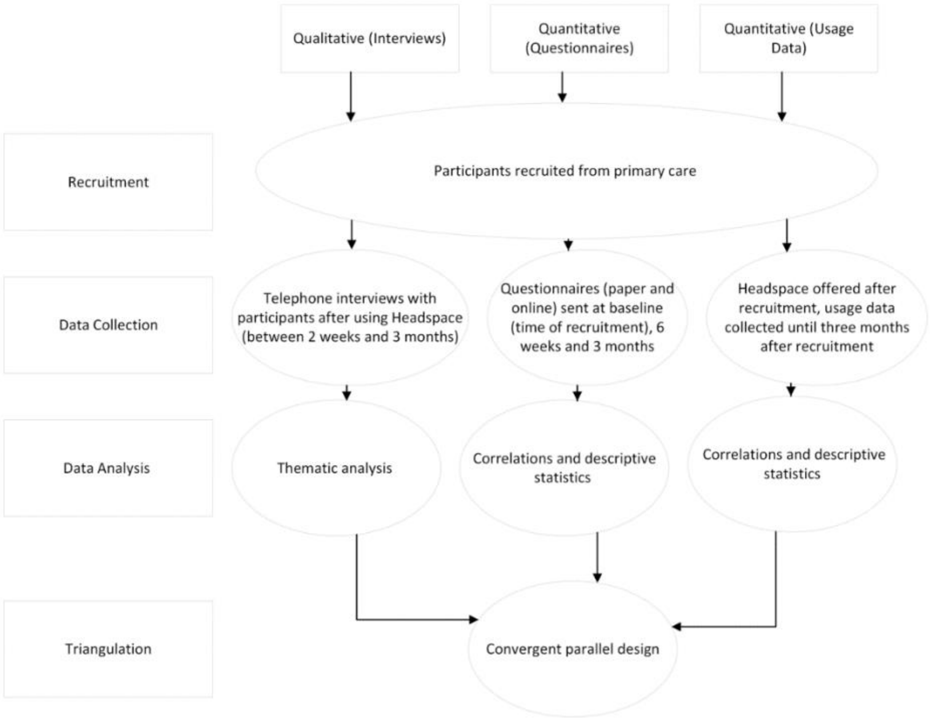
2.4.2.2 Qualitative and Quantitative integration

Several approaches to integrating mixed methods designs exist. Guest and Fleming (Guest & Fleming, 2015) identify three main dimensions to consider with a mixed-method design. These are timing, weighting, and purpose.

Firstly, timing refers to how datasets are used chronologically. This paper used a concurrent (also known as parallel or convergent) design, whereby data collection and analysis were not dependent on one another. In contrast, sequential designs involve integration between chronological phases (Guest & Fleming, 2015), meaning using the findings of one dataset to inform another. The second element is weighting; this refers to which methodology is given more consideration or priority over the other. It does not necessarily imply that the method weighing less is of less importance, just that is less central to the dataset. Data collected and analysed for this paper had equal weighting, allowing for the different methods to complement each other. Finally, Guest and Fleming (Guest & Fleming, 2015) describe purpose, the reason why researchers might integrate different datasets. In the case of this paper, this is to compare datasets and use findings to explore whether they converge, diverge or are contradictory. To facilitate understanding of the methods employed by this study, a visual summary is presented below, in Figure 5.

Figure 7.

A visual representation of convergent parallel design applied to Paper 2



Finally, data was integrated following principles of a convergent parallel design (Guest & Fleming, 2015). This means that data was collected without the researcher being aware of results from other strands. Similarly, data was analysed independently, meaning that statistical analysis did not inform thematic analysis, and thematic analysis followed an inductive approach (Clarke & Braun, 2013). Integration occurred after the researcher was familiar with all three findings. Using triangulation for this purpose allowed for results to complement each other, as well as for qualitative accounts to help the elaboration of quantitative data. For instance, participants talked about their usage, and this was considered in relation to their usage data. Additionally, using several methods increased the trustworthiness of the findings. The findings were combined with the aim of answering the research questions proposed by the research study.

2.4.3 Paper 3 - In-depth qualitative study

2.4.3.1 Interpretative Phenomenological Analysis

Interpretative phenomenological analysis (IPA; (IPA; Smith, 2009)) stems in health psychology and was created to allow in-depth explorations of idiographic subject experiences. In other words, at its core, IPA concerns itself with individual and shared interpretations of people's experiences.

As a theory, IPA relies on *phenomenology*, *hermeneutics and idiographic approaches*. Phenomenology refers to a philosophical approach to studying experience. Originally developed by Husserl, with other key proponents including Heidegger and Sartre (Zahavi, 2018), it provides a rich source of ideas about how we conceptualise lived experience. The argument this paper relies on is that experience can only be explored and described as it happened and how it was perceived by the person going through this experience (Smith, 2009). Hermeneutics refers to the theory of interpretation. In conducting IPA, researchers undergo a hermeneutic cycle, or what is described as double hermeneutics: making sense (as a researcher) of how participants make sense of their experience. The researcher's attempt at understanding the participants' experience is interpretative in the sense that uses the researcher's input into finding meaning from lived experience. Finally, the approach used within IPA is idiographic, as it focuses on individual participants and detailed experiences in their personal context, at the same time as trying to find shared experiences or perceptions. This comes in contrast with other branches of psychology research, which focus on nomothetic approaches, i.e. those concerned with identifying patterns at population level. This method is particularly suited to researchers guided by a biopsychosocial approach, such as the current thinking within healthcare and more specifically within asthma research (Smith, 2009).

2.4.4 Reflexive account of conducting research

Reflecting on the role of the researcher within the studies of this thesis is important in order to set some of the context for understanding the findings. For ease of reading and to give a true account of the reflexive process, I will write this section in first person.

When I first started interviewing people with asthma (in 2015) I was a relatively young, female, researcher with some (albeit limited) experience in conducting interviews. I do not have asthma and do not have any close friends or family members with asthma. I was however interested, from an academic point of view, in the experience of chronic illness, the impact of multimorbidity, and the individual and personal interpretation of the meaning of quality of life. I felt quite self-conscious at first when talking to people about their asthma, which I think came across to participants, especially at the beginning of the PhD, when several participants asked me if I had asthma myself. This was a very important reflection point, as many have mentioned (and indeed literature has often suggested similar findings) that people who don't have asthma might not be able to understand the challenges that someone with asthma faces. Through the research and reflection process I was able to understand that my lack of personal knowledge and experience of asthma meant I could use 'bracketing' (ignoring my own values or beliefs when interpreting interview findings) successfully, and focus on participants' accounts without any pre-existing knowledge (other than reading and conversations with other researchers). Very interestingly, being honest about my lack of personal knowledge of asthma has facilitated participants to open and share their experience and beliefs, even when they felt some of those beliefs might be contradictory to those shared by their clinicians. I found that general awareness of the medical aspects of asthma, such as treatments or the NHS pathways was very helpful to facilitate conversations and build trust. This was a key driver for my research, and I tried to consider 'understanding' people's experience when planning my next studies. This concept of better understanding people with asthma might help or facilitate the development of effective interventions, which was the goal of my thesis. This was also consistent with my pragmatic approach to answering the research question and suggesting positive change. Finding myself at the end of my second study, placing further focus on understanding participants' experience played a big part in choosing the approach for the third study. I felt I was in a more experienced role to undertake a methodology like IPA, and I was more confident in my ability which would hopefully result in better conversations with people with asthma. I didn't feel that my age or my gender have been a barrier, although I have had some challenging (but very nice) conversations about my accent (I am from Romania) whilst conducting the interviews. I don't think this had any impact on the quality of the results, but it created a reason for 'small talk' which hopefully helped built a rapport with participants.

Chapter 3 A Systematic Review of Psychological, Physical Health Factors and Quality of Life in Adult Asthma (Paper 1)

Full Reference: Stanescu, S., Kirby, S. E., Thomas, M., Yardley, L., & Ainsworth, B. (2019). A systematic review of psychological, physical health factors, and quality of life in adult asthma. *NPJ primary care respiratory medicine*, *29*(1), 37. DOI: https://doi.org/10.1038/s41533-019-0149-3

3.1 Abstract

Asthma is a common non-communicable disease, often characterised by activity limitation, negative effects on social life and relationships, problems with finding and keeping employment, and poor quality of life. The objective of the present study was to conduct a systematic review of the literature investigating the potential factors impacting quality of life (QoL) in asthma. Electronic searches were carried out on: MEDLINE, EMBASE, PsycINFO, the Cochrane Library and Web of Science (initial search April 2017 and updated in January 2019. The study was published at the end of 2019). All primary research studies including asthma, psychological or physical health factors and quality of life were included. Narrative synthesis was used to develop themes of variables impacting QoL in asthma. The search retrieved 43 eligible studies, that were grouped into three themes: psychological factors (including anxiety and depression, other mental health conditions, illness representations and emotion regulation), physical health factors (including BMI and chronic physical conditions) and multifactorial aspects, including the interplay of health and psychological factors and asthma. These were found to have a substantial impact on QoL in asthma, both directly and indirectly, by affecting self-management, activity levels and other outcomes. Findings suggest a complex and negative effect of health and psychological factors on QoL in asthma. The experience of living with asthma is multifaceted, and future research and intervention development studies should take this into account.

3.2 Introduction

Over 235 million people worldwide are living with asthma, which is one of the leading non-communicable diseases worldwide (ASTHMA UK, 2018; World Health Organization, 2018). Symptoms, exacerbations, and triggers in asthma are associated with lower quality of life (QoL), tiredness, activity limitation, negative effects on social life and relationships, problems with finding and keeping employment, and reduced productivity (Accordini et al., 2008; Goeman & Douglass, 2005; Goeman et al., 2002; Juniper, 1997; Pickles et al., 2018). People with asthma are up to six times more likely than the general population to have anxiety or depression (Thomas, Bruton, Moffat, et al., 2011), and 16% of people with asthma in the UK have panic disorder (Goodwin et al., 2004), compared to 1% in the general population (Jenkins et al., 1997). People with brittle asthma (difficult-to-control asthma with severe, recurrent attacks) demonstrate even greater co-morbidity and maladaptive coping styles (such as avoidance, denial, emotion-focused coping) (Miles et al., 1997). Psychological dysfunction (such as anxiety and depression) is often unrecognized in primary care, despite being significantly associated with poor asthma outcomes, including asthma control and QoL (Juniper et al., 1993; Lavoie, Cartier, Labrecque, Bacon, Lemière, et al., 2005; Thomas, Bruton, Moffat, et al., 2011). Indeed, the European Asthma Research and Innovation Partnership (EARIP) has identified understanding the role of factors such as anxiety and depression as an unmet need in improving asthma outcomes (Edwards et al., 2017a; Masefield et al., 2017). They propose that anxiety and depression are present at all three stages of the experience of asthma: onset, progression and exacerbation (Edwards et al., 2017a).

A recent meta-analysis found that asthma diagnoses significantly increased the risk of psychological and health conditions (such as cardio-/cerebrovascular diseases, obesity, hypertension, diabetes, psychiatric and neurological comorbidities, gut and urinary conditions, cancer, and respiratory problems other than asthma) (Su et al., 2016). Additionally, studies have pointed towards an impact on QoL in people with asthma of additional health and psychological factors such as co-morbid anxiety or depression, higher BMI, professional status and feelings of lack of control over health (for example (Adams, Wilson, Taylor, et al., 2004; Leynaert et al., 2000)). Such evidence reinforces the argument that the needs of people with asthma should be approached in conjunction with these additional factors, rather than using a single-illness approach, aiming to reduce the adversity of people’s experience. However, the extent to which psychological and physical health factors interact and impact asthma outcomes is yet to be systematically explored. This systematic review aims to provide a narrative synthesis of the literature exploring psychological and physical health factors that influence quality of life in adults with asthma.

3.3 Method

3.3.1 Search Strategy

The initial search was carried out in April 2017, and was updated in January 2019, and was published in October 2019. Databases searched included MEDLINE, EMBASE, PsycINFO, the Cochrane Library and Web of Science. Search terms were determined following scoping searches that focused on quality of life in asthma. They comprised a combination of the following key terms: asthma (MESH term), psychological/psychosocial and factor/determinant/predictor, comorbid, multimorbid, anxiety, depression, illness perception, illness cognition, illness representation, locus of control, self-efficacy, risk factor, quality of life, health-related quality of life, wellbeing, distress, health status, burden. Additionally, a hand search of all the references of included papers was performed as well as a grey literature search on Google Scholar.

3.3.2 Study selection

Studies were included if they investigated psychological or physical health factors and included quality of life in adults with asthma as primary or secondary outcome. Psychological factors were considered any modifiable factors including thoughts, beliefs, attitudes or emotions of people with asthma, as well as the presence of any co-occurring mental health condition. Physical health factors were defined as any physical co-morbid or multimorbid condition or risk factor. These were chosen to allow as much inclusivity as possible, and to reflect the exploratory nature of this review. Intervention studies were excluded, as they rarely considered the impact of health or psychological factors on QoL, but rather investigated how interventions improved asthma outcomes. Studies were excluded if they were conference abstracts, reviews, or not primary research or the full text not in English, German or Spanish language.

3.3.3 Data Extraction and Quality Appraisal

Data extracted comprised authors, year of publication, study sample, predictors, QoL measurement (outcome), and findings (see appendix A). The AXIS tool (Downes et al., 2016) was used to assess the quality of included papers (longitudinal papers were only assessed at baseline, as only this aspect was relevant for the aim and synthesis of this review). This contains questions on study design, sample size justification, target population, sampling frame, sample selection, measurement validity & reliability, and overall methods and does not offer a numerical scale. No papers were excluded or weighted based on the quality assessment.

3.3.4 Data Synthesis

Due to heterogeneity of QoL measures and the range of variables used in the included studies, narrative synthesis was used to describe and group similar findings, explore patterns identified in the literature, and develop a narrative account of the results (Popay et al., 2006). This is an approach to systematic reviews involving the synthesis of findings from multiple sources and relies primarily on word and text to summarise the findings.

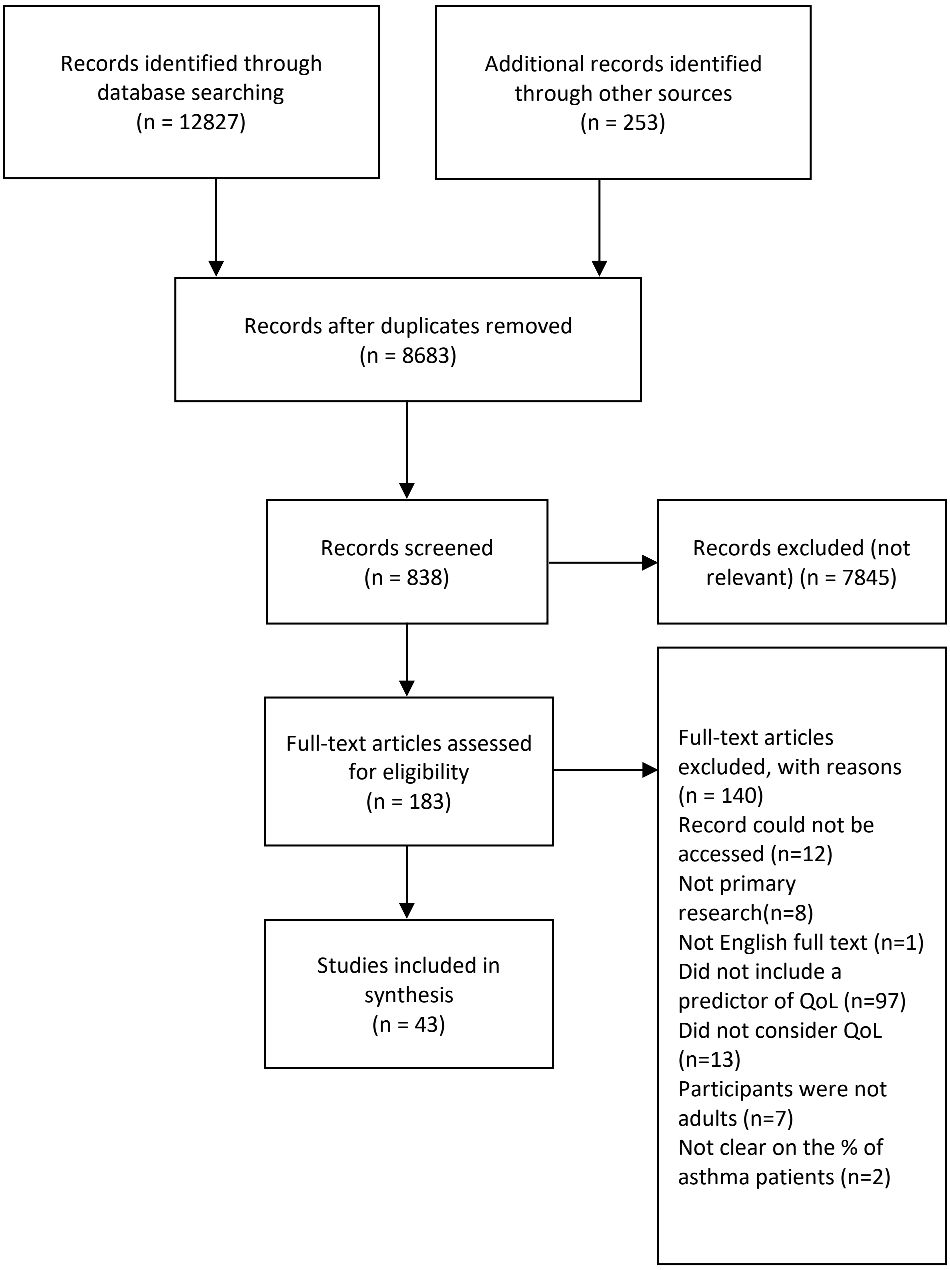
3.4 Results

3.4.1 Study Characteristics

The search and screening process identified 43 eligible papers, published between 2003 and 2019 (see Figure 1 for PRISMA flowchart (Moher et al., 2009)).

Figure 8.

PRISMA statement of included and excluded papers



The characteristics of each study are summarised in Appendix A. Twelve studies were conducted in Europe (Al-Kalemji et al., 2013; Bohmer et al., 2016; Coban & Aydemir, 2014; Ekici et al., 2006; Gonzalez-Barcala et al., 2012; Kullowatz et al., 2007; Lomper et al., 2016; Oğuztürk et al., 2005; Sandez et al., 2005; Vazquez et al., 2010; Wijnhoven et al., 2003; Yilmaz et al., 2014), 17 in North America (Afari et al., 2001; Avallone et al., 2012; Erickson et al., 2002; Favreau et al., 2014;

Hommel et al., 2002; Hullmann et al., 2013; Krauskopf et al., 2013; Lavoie, Bacon, Barone, et al., 2006; Lavoie et al., 2008; Lavoie, Cartier, Labrecque, Bacon, Lemière, et al., 2005; Mancuso et al., 2000; McCormick et al., 2014; Miedinger et al., 2011; Pate et al., 2018; Strine et al., 2008; Urbstonaitis et al., 2019; Vortmann & Eisner, 2008), 7 in Australia (Adams, Wilson, Smith, et al., 2004; Adams, Wilson, Taylor, et al., 2004; Adams et al., 2006; Deshmukh et al., 2008; Goldney, Ruffin, Fisher, et al., 2003; Powell et al., 2015; Tay et al., 2016), 4 in Asia (Choi et al., 2014; Faye et al., 2015; Nishimura et al., 2004; Oga et al., 2007), and 3 in Africa (Adeyeye et al., 2017; Kolawole et al., 2011; Maalej et al., 2012). All papers employed a quantitative approach comprising 2 longitudinal studies (Favreau et al., 2014; Yilmaz et al., 2014) and 41 cross-sectional studies. Only 4 studies included a control group (Al-Kalemji et al., 2013; Ekici et al., 2006; Oğuztürk et al., 2005; Yilmaz et al., 2014). Overall, the majority of papers had a large sample size (ranging between 40 and 39,321 participants; 30 papers included a sample size of over 100). The majority of studies recruited from primary care or the general population, using self-report to confirm a diagnosis of asthma. Only a few studies recruited from secondary and tertiary asthma clinics (Adeyeye et al., 2017; Coban & Aydemir, 2014; Favreau et al., 2014; Lavoie, Cartier, Labrecque, Bacon, Lemière, et al., 2005; Mancuso et al., 2000; McCormick et al., 2014; Tay et al., 2016). There was a high occurrence (n=14) of exclusion criteria relating to specific demographic, or asthma characteristics, as well as mental health conditions and comorbidities, which restricted the study sample without a reason being given. Most studies used self-report measures (Adams, Wilson, Smith, et al., 2004; Adams, Wilson, Taylor, et al., 2004; Adams et al., 2006; Adeyeye et al., 2017; Al-Kalemji et al., 2013; Avallone et al., 2012; Bohmer et al., 2016; Choi et al., 2014; Coban & Aydemir, 2014; Deshmukh et al., 2008; Ekici et al., 2006; Erickson et al., 2002; Favreau et al., 2014; Faye et al., 2015; Gonzalez-Barcala et al., 2012; Hommel et al., 2002; Hullmann et al., 2013; Kolawole et al., 2011; Krauskopf et al., 2013; Kullowatz et al., 2007; Lavoie et al., 2008; Lomper et al., 2016; Maalej et al., 2012; Mancuso et al., 2000; McCormick et al., 2014; Miedinger et al., 2011; Nishimura et al., 2004; Oga et al., 2007; Oğuztürk et al., 2005; Pate et al., 2018; Powell et al., 2015; Sandez et al., 2005; Strine et al., 2008; Tay et al., 2016; Vazquez et al., 2010; Vortmann & Eisner, 2008; Wijnhoven et al., 2003), with a small proportion using psychiatric interviews to screen for mental health conditions (Afari et al., 2001; Goldney, Ruffin, Fisher, et al., 2003; Lavoie, Bacon, Barone, et al., 2006; Lavoie, Cartier, Labrecque, Bacon, Lemière, et al., 2005; Yilmaz et al., 2014). The majority of studies used asthma-specific QoL measures (n=29)(Adams, Wilson, Smith, et al., 2004; Adeyeye et al., 2017; Avallone et al., 2012; Choi et al., 2014; Coban & Aydemir, 2014; Deshmukh et al., 2008; Ekici et al., 2006; Erickson et al., 2002; Favreau et al., 2014; Goldney, Ruffin, Fisher, et al., 2003; Hommel et al., 2002; Kolawole et al., 2011; Krauskopf et al., 2013; Kullowatz et al., 2007; Lavoie, Bacon, Barone, et al., 2006; Lavoie et al., 2008;

Lavoie, Cartier, Labrecque, Bacon, Lemiere, et al., 2005; Maalej et al., 2012; Mancuso et al., 2000; McCormick et al., 2014; Miedinger et al., 2011; Nishimura et al., 2004; Oga et al., 2007; Oğuztürk et al., 2005; Powell et al., 2015; Tay et al., 2016; Vazquez et al., 2010; Vortmann & Eisner, 2008; Wijnhoven et al., 2003), 17 included a HRQOL measure (n=18) (Adams, Wilson, Smith, et al., 2004; Adams, Wilson, Taylor, et al., 2004; Adams et al., 2006; Afari et al., 2001); Bohmer et al. (2016); (Ekici et al., 2006; Erickson et al., 2002; Goldney, Ruffin, Fisher, et al., 2003; Hullmann et al., 2013; Kullowatz et al., 2007; Lomper et al., 2016; Mancuso et al., 2000; Nishimura et al., 2004; Sandez et al., 2005; Vazquez et al., 2010; Vortmann & Eisner, 2008; Wijnhoven et al., 2003; Yilmaz et al., 2014), and 4 used general measures of QoL (n=7)(Al-Kalemji et al., 2013; Faye et al., 2015; Gonzalez-Barcala et al., 2012; Pate et al., 2018; Strine et al., 2008; Urbstonaitis et al., 2019; Vortmann & Eisner, 2008); eleven papers used more than one measure of QoL (Adams, Wilson, Smith, et al., 2004; Ekici et al., 2006; Erickson et al., 2002; Goldney, Ruffin, Fisher, et al., 2003; Kullowatz et al., 2007; Mancuso et al., 2000; Miedinger et al., 2011; Nishimura et al., 2004; Vazquez et al., 2010; Vortmann & Eisner, 2008; Wijnhoven et al., 2003). The average age across included studies was 42.1 years (and 61.57% were female). Papers report prevalence rates of between 16.8% and 48.9% for depression and between 13.3% and 44.4% for anxiety (Adeyeye et al., 2017; Afari et al., 2001; Bohmer et al., 2016; Choi et al., 2014; Coban & Aydemir, 2014; Goldney, Ruffin, Fisher, et al., 2003; Kolawole et al., 2011; Krauskopf et al., 2013), with an average of 28.31% for a diagnosis of anxiety or depression. Across several studies, the prevalence of other mental health conditions was 28.31% on average (ranging between 28% and 80%) (Afari et al., 2001; Lavoie, Bacon, Barone, et al., 2006; Lavoie et al., 2008; Lavoie, Cartier, Labrecque, Bacon, Lemière, et al., 2005; Miedinger et al., 2011). Between 72% and 86.9% of people with asthma had at least one additional physical condition, and between 21% and 26.3% had two or more (Choi et al., 2014; Erickson et al., 2002; Wijnhoven et al., 2003); 26.36% had on average, at least one other physical health condition. On average, people with asthma were significantly more likely to have a BMI of over 30 (and between 61% and 75.1% had a BMI over 25) (Gonzalez-Barcala et al., 2012; Maalej et al., 2012; Strine et al., 2008). The quality assessment identified that most studies were of a reasonable quality, however, it should be noted that some measures used could be considered inappropriate for the research aim or the population under investigation. Examples include measuring general QoL with an asthma-specific measure or administering a geriatric depression questionnaire to a young adult population.

3.4.2 Narrative synthesis

Narrative synthesis generated three overarching themes: psychological factors, health factors and multifactorial aspects (see Table 1 for themes and subtheme descriptions).

Table 1

Themes, sub-themes and descriptions

Theme	**Subtheme**	**Description**
Psychological Factors	Anxiety and Depression	Included people with clinical anxiety or depression (Adams, Wilson, Taylor, et al., 2004; Adeyeye et al., 2017; Afari et al., 2001; Al-Kalemji et al., 2013; Choi et al., 2014; Coban & Aydemir, 2014; Deshmukh et al., 2008; Favreau et al., 2014; Faye et al., 2015; Goldney, Ruffin, Fisher, et al., 2003; Hommel et al., 2002; Krauskopf et al., 2013; Lavoie, Bacon, Barone, et al., 2006; Lavoie et al., 2008; Lavoie, Cartier, Labrecque, Bacon, Lemiere, et al., 2005; Pate et al., 2018; Strine et al., 2008; Tay et al., 2016), as well as people showing symptoms (or scoring high on scales such as the HADS) (Adams, Wilson, Taylor, et al., 2004; Al-Kalemji et al., 2013; Bohmer et al., 2016; Coban & Aydemir, 2014; Deshmukh et al., 2008; Kolawole et al., 2011; Kullowatz et al., 2007; Lomper et al., 2016; Mancuso et al., 2000; Miedinger et al., 2011; Nishimura et al., 2004; Oga et al., 2007; Oğuztürk et al., 2005; Sandez et al., 2005; Vazquez et al., 2010).
	Other Mental Health Conditions	Panic disorder with or without agoraphobia (Afari et al., 2001; Favreau et al., 2014; Faye et al., 2015; Sandez et al., 2005), personality disorders (Yilmaz et al., 2014), alexithymia (Vazquez et al., 2010), somatization (Afari et al., 2001), mood disorders (Faye et al., 2015; Lavoie, Bacon, Barone, et al., 2006; Lavoie, Cartier, Labrecque, Bacon, Lemière, et al., 2005), schizophrenia, eating disorders, substance use disorders (Afari et al., 2001) and general occurrence of any psychiatric disorder (Adams, Wilson, Taylor, et al., 2004; Lavoie, Cartier, Labrecque, Bacon, Lemière, et al., 2005)

	Emotion Regulation	Negative affect (Avallone et al., 2012; Ekici et al., 2006), or coping (Adams, Wilson, Smith, et al., 2004; McCormick et al., 2014).
	Illness Representations	Illness-related cognitions (Adams, Wilson, Smith, et al., 2004; Adeyeye et al., 2017; Erickson et al., 2002; Gonzalez-Barcala et al., 2012; Hullmann et al., 2013; Lavoie et al., 2008; Miedinger et al., 2011), subjective illness severity, uncertainty in illness, illness intrusiveness (Hullmann et al., 2013), perceived disability (Adeyeye et al., 2017), health beliefs and attitudes, perceived severity (Erickson et al., 2002), self-efficacy, satisfaction with illness (Adams, Wilson, Smith, et al., 2004), anxiety sensitivity to physical concerns (Avallone et al., 2012) and satisfaction with life (Miedinger et al., 2011)
Physical Health Factors	Physical Health Conditions	Diabetes (Tay et al., 2016; Wijnhoven et al., 2003), obesity (Tay et al., 2016), hypertension (Avallone et al., 2012; Wijnhoven et al., 2003), gastro-oesophageal reflux disorder (Tay et al., 2016), rhinitis (Powell et al., 2015; Tay et al., 2016), vocal cord dysfunction (Tay et al., 2016), sleep apnoea (Tay et al., 2016), musculoskeletal disorders (Avallone et al., 2012; Wijnhoven et al., 2003), arthritis (Adams et al., 2006; Avallone et al., 2012), heart disease (Wijnhoven et al., 2003), stroke (Adams et al., 2006; Avallone et al., 2012), cancer (Adams et al., 2006; Avallone et al., 2012), osteoporosis (Adams et al., 2006), dysfunctional breathing (Tay et al., 2016), headaches (Avallone et al., 2012) and allergic status (Avallone et al., 2012; Coban & Aydemir, 2014) or the presence of additional chronic conditions (Adams et al., 2006; Avallone et al., 2012; Choi et al., 2014; Coban & Aydemir, 2014; Deshmukh et al., 2008; Erickson et al., 2002; Krauskopf et al., 2013; Maalej et al., 2012; Mancuso et al., 2000; Pate et al., 2018; Powell et al., 2015; Tay et al., 2016; Urbstonaitis et al., 2019; Wijnhoven et al., 2003).
	BMI	BMI (Al-Kalemji et al., 2013; Choi et al., 2014; Ekici et al., 2006; Favreau et al., 2014; Gonzalez-Barcala et al., 2012; Lavoie et al.,

	2008; Maalej et al., 2012; Pate et al., 2018; Strine et al., 2008; Tay et al., 2016; Urbstonaitis et al., 2019; Vortmann & Eisner, 2008; Wijnhoven et al., 2003)
Multifactorial Aspects	Interactions between conditions, BMI, psychological factors and anxiety and depression (Adams, Wilson, Taylor, et al., 2004; Choi et al., 2014; Goldney, Ruffin, Fisher, et al., 2003; Lavoie et al., 2008; Maalej et al., 2012; Strine et al., 2008; Vortmann & Eisner, 2008)

Overall, patients with asthma demonstrated impaired QoL, which was further decreased by psychological factors (e.g. anxiety, depression, emotion regulation, illness perceptions), health risk factors (such as an increased BMI), and the presence of a co-existing mental health or physical condition (such as rhinitis, cardiovascular disease, diabetes, etc.). Having more than one co-existing condition or psychological factor impacted overall QoL even more substantially. Results for each of the aspects found are presented below.

3.4.2.1 Psychological Factors

Within this first theme, four subthemes were generated. These comprised 'anxiety and depression', 'other mental health conditions', 'emotional regulation', and 'illness representations'.

Anxiety and depression were notably the most commonly considered factors (n=30). A high prevalence of people with asthma showed symptoms of or clinical diagnoses of anxiety or depression, which appeared to play a key role in understanding the relationship between asthma and QoL. Overall, having a diagnosis of anxiety or depression was associated with poorer quality of life across all dimensions (e.g. activity limitation, physical or mental wellbeing, social or role functioning etc.), as well as health perceptions (Goldney, Ruffin, Fisher, et al., 2003; Mancuso et al., 2000; Oga et al., 2007; Pate et al., 2018; Sandez et al., 2005). In particular, one study (of undergraduate students aged 18-25, with childhood onset asthma) found that anxiety was significantly associated with asthma QOL, as was the interaction between anxiety and depression (Hommel et al., 2002), while others found that generally anxiety and depression both predicted worse quality of life independently ((Adeyeye et al., 2017; Afari et al., 2001; Al-Kalemji et al., 2013; Choi et al., 2014; Favreau et al., 2014; Krauskopf et al., 2013; Lavoie et al., 2008; Lavoie, Cartier, Labrecque, Bacon, Lemière, et al., 2005)). One study found that the average asthma-related QoL scores for people with asthma and depression were 1.4 times lower compared to people with asthma and no depression (Krauskopf et al., 2013). Having current depression or anxiety was associated with worse QoL than was having a lifetime diagnosis; this was in turn was greater than having no depression or anxiety (Strine et al., 2008). Having a history of major depression was also significantly associated with worse physical and mental functioning, compared to those with asthma and no depression (Afari et al., 2001). There was considerable variability across variance explained, with depression found to account for between 3% (Lavoie, Bacon, Barone, et al., 2006) and 56% (Kullowatz et al., 2007) of the variance in QoL, whereas anxiety was found to account for between 2% (Lavoie, Bacon, Barone, et al., 2006) and 68% (Oğuztürk et al., 2005).

In contrast, one study found that having either a depressive or an anxiety disorder significantly reduced asthma QoL, but having both was not significantly different than only having one (Lavoie, Bacon, Barone, et al., 2006), which is dissonant with other studies. Another study, of 90 people with difficult asthma found that having anxiety or depression had no significant effect on QoL (Tay et al., 2016). Additionally, although depression was associated with poorer QoL, it did not inflate the relationship between asthma severity and QoL (Al-Kalemji et al., 2013). All other studies were significant but showed only small to moderate effect sizes. Having a full clinical diagnosis of anxiety or depression was not significantly worse (in terms of QoL) than having only some symptoms of anxiety and depression.

Studies also considered the impact of anxiety and depression on specific sub-domains of QoL and asthma-specific QoL. Having anxiety was not associated with physical functioning, mental health or health perception (Afari et al., 2001) or the physical component of QoL (Bohmer et al., 2016). Depression, however, was associated with significantly poorer QoL on physical dimensions and activity limitation (Afari et al., 2001; Bohmer et al., 2016; Deshmukh et al., 2008; Kolawole et al., 2011; Kullowatz et al., 2007; Nishimura et al., 2004; Oğuztürk et al., 2005; Strine et al., 2008; Vazquez et al., 2010), although one study found significant results only for participants with uncontrolled asthma (Lomper et al., 2016). In relation to asthma-specific QoL, depression and anxiety were significantly associated with decreased asthma-specific QoL (Adams, Wilson, Taylor, et al., 2004; Coban & Aydemir, 2014; Deshmukh et al., 2008; Ekici et al., 2006; Goldney, Ruffin, Fisher, et al., 2003; Hommel et al., 2002; Kolawole et al., 2011; Krauskopf et al., 2013; Lavoie, Bacon, Barone, et al., 2006; Mancuso et al., 2000; Miedinger et al., 2011; Nishimura et al., 2004; Oga et al., 2007; Oğuztürk et al., 2005; Vazquez et al., 2010).

Nine studies looked at other mental health conditions, such as panic disorder with or without agoraphobia (Afari et al., 2001; Favreau et al., 2014; Faye et al., 2015; Sandez et al., 2005), personality disorders (Yilmaz et al., 2014), alexithymia (Vazquez et al., 2010), somatization (Afari et al., 2001), mood disorders (Faye et al., 2015; Lavoie, Bacon, Barone, et al., 2006; Lavoie, Cartier, Labrecque, Bacon, Lemière, et al., 2005), schizophrenia, eating disorders, substance use disorders (Afari et al., 2001) and general occurrence of any psychiatric disorder (Adams, Wilson, Taylor, et al., 2004; Lavoie, Cartier, Labrecque, Bacon, Lemière, et al., 2005). The results in this sub-theme were mixed, but overall, they suggest that the presence of an additional mental health condition is significantly associated with a decrease in QoL in patients with asthma (Adams, Wilson, Taylor, et al., 2004; Lavoie, Cartier, Labrecque, Bacon, Lemière, et al., 2005). Panic disorder was also shown to be both significantly (Sandez et al., 2005) and non-significantly (Faye et al., 2015) associated with poorer mental and physical components of QoL. Alexithymia in people with asthma was not associated with poorer QoL (Vazquez et al., 2010). Having asthma and a personality disorder was associated with lower general QoL (Yilmaz et al., 2014), as well as lower scores for physical health, vitality, pain, general health, social function, mental health and emotional role (physical function was not significant). This association was not found for people without asthma, suggesting that it is the combination of conditions (asthma and co-existing mental health conditions) that may lead to the negative impact on QoL (Yilmaz et al., 2014).

The emotion regulation subtheme included studies that explored the relationship between emotional states, negative affect (not related to anxiety, depression or other mental health conditions) or coping and QoL in people with asthma. QoL in asthma was found to be influenced by affect and a predisposition to negative states, as found by four studies (Adams, Wilson, Smith, et al., 2004; Avallone et al., 2012; Ekici et al., 2006; McCormick et al., 2014). For instance, a model of age, gender, negative affect and medical problems accounted for 20% of symptoms and 23% of activity limitation (Avallone et al., 2012). This was supported by findings that negative mood is associated with poor scores on both the mental and physical components of the Asthma Quality of Life Questionnaires (AQLQ) (Ekici et al., 2006), as well as a positive correlation between active coping and asthma QoL (Adams, Wilson, Smith, et al., 2004). Despite heterogeneity, the impaired QoL was associated with impulsive-careless coping (McCormick et al., 2014), and avoidant coping (Adams, Wilson, Smith, et al., 2004). Overall, the presence of psychological distress seemed to affect people with asthma more than people without asthma in terms of QoL.

Illness-related cognitions are people’s patterns of beliefs about the characteristics of their conditions, which in turn influence their appraisal of severity and can determine future behaviours (Petrie & Weinman, 2006). A number of illness-related cognitions and perceptions significantly predicted QoL in seven studies (Adams, Wilson, Smith, et al., 2004; Adeyeye et al., 2017; Erickson et al., 2002; Gonzalez-Barcala et al., 2012; Hullmann et al., 2013; Lavoie et al., 2008; Miedinger et al., 2011). For instance, asthma self-efficacy (Lavoie et al., 2008) was positively associated with QoL. However, decreased QoL was significantly predicted by a series of varied illness perceptions: subjective illness severity, uncertainty in illness, illness intrusiveness (Hullmann et al., 2013), perceived disability (Adeyeye et al., 2017), health beliefs and attitudes (Erickson et al., 2002), perceived severity (Erickson et al., 2002), level of confidence or self-efficacy in managing asthma (Adams, Wilson, Smith, et al., 2004), satisfaction with illness (Adams, Wilson, Smith, et al., 2004), anxiety sensitivity for physical concerns(Avallone et al., 2012) and satisfaction with life (Miedinger et al., 2011). Additionally, a model of subjective and objective illness severity accounted for 24% of the variance in QoL, further supporting the effect of illness perceptions on QoL(Erickson et al., 2002).

3.4.2.2 Physical Health Factors

Two sub-themes were generated in the physical health factors theme: additional physical conditions and BMI.

Ten papers examined additional physical conditions in relation to quality of life in asthma (Adams et al., 2006; Avallone et al., 2012; Coban & Aydemir, 2014; Deshmukh et al., 2008; Erickson et al., 2002; Pate et al., 2018; Powell et al., 2015; Tay et al., 2016; Urbstonaitis et al., 2019; Wijnhoven et al., 2003); most only referred to “co-morbidity” or “medical problems” as a measure of frequency of additional conditions (Avallone et al., 2012; Erickson et al., 2002; Mancuso et al., 2000). Some studies looked at both general and individual co-existing conditions (Adams et al., 2006; Tay et al., 2016; Wijnhoven et al., 2003) and others counted chronic conditions but did not include them in further analyses (Choi et al., 2014; Krauskopf et al., 2013; Maalej et al., 2012; Mancuso et al., 2000). Of the ones that did explore individual conditions, the highest impact seemed to be provoked by musculoskeletal conditions (Wijnhoven et al., 2003). Similarly, statistically and clinically significant decreases in activity levels were also found for people with asthma and multimorbid conditions (Adams et al., 2006). Other conditions investigated included respiratory conditions (Urbstonaitis et al., 2019), diabetes (Tay et al., 2016; Wijnhoven et al., 2003), obesity (Tay et al., 2016), hypertension (Avallone et al., 2012; Wijnhoven et al., 2003), gastro-oesophageal reflux disorder (Tay et al., 2016), rhinitis (Powell et al., 2015; Tay et al., 2016), vocal cord dysfunction (Tay et al., 2016), sleep apnoea (Tay et al., 2016), musculoskeletal disorders (Avallone et al., 2012; Wijnhoven et al., 2003), arthritis (Adams et al., 2006; Avallone et al., 2012), heart disease (Wijnhoven et al., 2003), stroke (Adams et al., 2006; Avallone et al., 2012), cancer (Adams et al., 2006; Avallone et al., 2012), osteoporosis (Adams et al., 2006), dysfunctional breathing (Tay et al., 2016), headaches (Avallone et al., 2012) and allergic status (Avallone et al., 2012; Coban & Aydemir, 2014). The consensus was that having an additional physical condition significantly decreased QoL in asthma, with the effect being amplified with the addition of further conditions.

Eleven papers exploring BMI found that it consistently influenced QoL for people with asthma both directly as a multimorbid factor, and indirectly by increasing the chance of additional conditions and activity limitation (Al-Kalemji et al., 2013; Choi et al., 2014; Ekici et al., 2006; Favreau et al., 2014; Gonzalez-Barcala et al., 2012; Lavoie et al., 2008; Maalej et al., 2012; Strine et al., 2008; Tay et al., 2016; Vortmann & Eisner, 2008; Wijnhoven et al., 2003). In particular, one study found that generic health status decreased for overweight and obese patients with asthma. People with asthma with obesity had on average 5.05 more restricted activity days than people without obesity or without asthma (Vortmann & Eisner, 2008). Other studies found that increased BMI was an independent factor in predicting poorer QoL (Tay et al., 2016) and that QoL was two times worse in overweight and 3 times worse in obese people with asthma (Maalej et al., 2012). In contrast, one study found that overweight BMI made no difference, however, being obese did (Coban & Aydemir, 2014). Almost ½ of obese patients, and 25% overweight patients had problems with mobility, pain, discomfort, self-care and usual activities (compared to less than 15% people with asthma of normal weight) (Gonzalez-Barcala et al., 2012).

3.4.2.3 Multifactorial Aspects

Seven studies included statistical analyses to explore potential mechanisms for the relationship between asthma QoL and additional physical conditions, BMI, and psychological factors (Adams, Wilson, Taylor, et al., 2004; Choi et al., 2014; Goldney, Ruffin, Fisher, et al., 2003; Lavoie et al., 2008; Maalej et al., 2012; Strine et al., 2008; Vortmann & Eisner, 2008). Results from studies in this group are complex, indicating that people with asthma are at a higher risk of adverse outcomes (such as exacerbated symptoms or decreased QoL) if they also have a high BMI and depression (Choi et al., 2014; Lavoie et al., 2008; Maalej et al., 2012; Vortmann & Eisner, 2008). People with current depression and asthma are more likely to be obese and 3.9 times more likely to report fair or poor general health (Strine et al., 2008). A few of these studies have explored the relationship between these factors further. For example, people with asthma and obesity were more likely to have additional physical co-morbidities and poorer QoL (Maalej et al., 2012). Significant increases in major depression were associated with dyspnoea (Goldney, Ruffin, Fisher, et al., 2003), and depression and perceived control of asthma significantly mediated between BMI and QoL (Vortmann & Eisner, 2008). Higher BMI has also been associated with worse asthma-specific self-efficacy, which was in turn associated with decreased QoL (Lavoie et al., 2008).

3.5 Discussion

The aim of the present review was to synthesise the literature exploring health and psychological factors that influence QoL in adults with asthma. Previous evidence shows that QoL is generally lower in people with asthma and compounded by poor asthma control and severity (Juniper et al., 1993). The narrative synthesis in the present study builds on this by identifying three themes, encompassing a number of factors that substantially explain further impairment in QoL for people with asthma. These were not limited to individual components but also combinations of co-existing conditions, risk factors, health and psychological factors, which consistently showed a negative impact on QoL.

Anxiety and depression were the most commonly reported psychological factors associated with impaired QoL, but effects were also found for other mental health conditions, illness representations and emotion regulation. These results are generally consistent with previous research showing not only that among people with asthma there are more people with depression than without (Thomas, Bruton, Moffat, et al., 2011), but with an increase in depression, the risk of asthma increased (Gerald & Moreno, 2016). Although the relationship between anxiety and depression and asthma-specific QoL were not further considered in the primary sources, they point towards either a link with activity limitation, or a cumulative impact of the interaction between these psychological factors, which in turn affect the quality of life of people with asthma. Additionally, it is argued that people with asthma use more emotion-focused, and generally maladaptive coping strategies, such as avoidance or denial (Barton et al., 2003). Despite this, psychotherapy, such as cognitive-behavioural therapy and counselling has had limited effectiveness in improving asthma outcomes (Yorke et al., 2015).

Physical health factors, such as high BMI and co-occurring health conditions, were extremely common in people with asthma, consistent with existing literature (Su et al., 2016). This affects quality of life both directly and indirectly, affecting self-management and illness perceptions. As such, non-pharmacological treatments such as lifestyle change and activity promotion could prove effective. For instance, a higher proportion of people with asthma seem to have overweight or obese BMI (Lavoie, Bacon, Labrecque, et al., 2006) and weight loss interventions studies have been associated with improvements in asthma symptoms (Smita Pakhale, 2015).

One of the fundamental components of reduced QoL is activity limitation, which is especially relevant to people with asthma, with or without additional conditions or psychological risk factors. This has been widely acknowledged by previous research, to the extent that it has been included as one of the components of asthma-related QoL measures, such as the AQLQ (Juniper, Buist, et al., 1999). Furthermore, it is not surprising that decreased QoL in adults with asthma is associated with depression or high BMI, both of which have been consistently associated with activity limitation (Breslin et al., 2006; Hassan et al., 2003). Additionally, depression was found to affect QoL on the physical components as well as the mental ones, which has interesting implications for future research and clinical practice.

It is important to note the high prevalence of anxiety, depression, and chronic conditions, despite frequent exclusion of comorbid psychiatric conditions. This was found throughout the included papers and is consistent with previous research (e.g. (Su et al., 2016; Thomas, Bruton, Moffat, et al., 2011)). This does not only mean that psychological and health factors significantly add to the burden of living with asthma, but also that the occurrence of psychological dysfunction (such as anxiety and depression) and health risk factors seem to be common in people with asthma. In addition, the complex nature of patients with chronic diseases such as asthma, with factors interacting, adds to the negative experience of living with asthma. Results are similar to previous meta-analyses and reviews (Fortin et al., 2004; Thomas, Bruton, Moffatt, et al., 2011), pointing towards conclusive evidence that additional factors (physical or psychological) decrease quality of life and functionality in asthma. Finally, these effects were consistent, regardless of the measure of QoL used (either asthma-specific, health-related or general). This suggests that the identified factors may affect people with asthma more than people without asthma, or that the cumulative impact of co-morbidities is greater than arithmetically assumed.

3.5.1 Methodological Considerations

The quality of the present review needs to be discussed in relation to the methodology and robustness of the synthesis, determined by the quantity and quality of individual studies included (Popay et al., 2006). The quality assessment identified that most studies were of a reasonable quality overall, although all papers had one or two elements that were of a slightly lower quality (this included aspects such as recruitment from only one hospital reducing generalisability, or self-report vs objective measurement of weight for BMI calculations). However, this was not problematic for the purposes of this review as the focus was to identify potential factors considered in research rather than classify the methodological quality used to measure their impact on QoL. Additionally, the choice of search terms in this review could have limited the number and kind of studies included. For instance, not every potential co-morbid condition was listed. This could be a focus for future research. Socio-demographic factors were not included, which can also be considered a limitation, however, the breadth of the area was deemed too much for the scope of the present review and could also be the focus of future research. The majority of included studies were observational, and as such could not be used to determine causal mechanisms. However, the aim of this review was only to identify potential factors involved in decreased QoL in asthma, rather than build a causal model. Similarly, the impact of individual factors was not measured, and could be explored in future research.

A strength of the present review is that it uses a novel approach to QoL in asthma, by systematically taking into account additional aspects that influence the experience of living with asthma and impact QoL. Results suggest both a direct association of the identified aspects, as well as indirectly through interactions with other aspects of living with asthma, such as overarching illness perceptions and activity limitation.

3.5.2 Implications

The present review emphasizes some interesting and novel findings for asthma and quality of life research. Three main implications for future research and practice are proposed. Firstly, for future research, the findings of this review should be used to further explore and understand the factors impacting QoL in people with asthma. It is crucial to explore the needs and experience of patients with complex medical problems, in order to unpick the different factors impacting on QoL. Secondly, the results are relevant for practitioners, particularly in primary care, as they draw attention to the prevalence of various physical and mental health factors that can interact and affect asthma outcomes. This could influence training or guidelines on potential factors to consider during appointments and consultations. Finally, most current non-pharmacological interventions for patients with chronic conditions tend to overlook the complex needs of patients in a multimorbidity context. As such, it is suggested that future intervention development should use a personalised, tailored approach that aims to address the needs of patients with complex medical problems in the wider context of their experience of living with asthma.

3.6 Conclusion

This review demonstrates that the themes and factors identified through inductive narrative synthesis illustrate that QoL in asthma cannot be determined in a simplistic way. The findings suggest a complex experience in living with asthma, one that has a stronger impact on QoL than the sum its of parts. People with asthma and their QoL cannot be viewed separately from the psychological and other health elements that they experience. Future research is encouraged to take a function-oriented approach to QoL in asthma, including management of multimorbid conditions when planning studies; clinical practice should also acknowledge the additional and complex needs of people with asthma by offering relevant, person-based tailored interventions.

Chapter 4 “Breathing is the absolute key”: a mixed-methods exploration of a digital mindfulness intervention to improve quality of life and illness perceptions in adults with asthma. (Paper 2)

Full reference: Stanescu, S., Kirby, S., Liddiard, M., Stuart, B., Djukanovic, R., Russell, D., Thomas, M., & Ainsworth, B. (2021). “Breathing is the absolute key”: using mixed-methods to understand how a digital mindfulness intervention can improve quality of life for adults with asthma. Psyrxiv. https://doi.org/10.31234/osf.io/axh3s This paper is currently under submission at NPJ Primary Care Respiratory Medicine.

4.1 Abstract

Introduction: Despite effective pharmacotherapy, patient-reported asthma outcomes such as quality of life remain suboptimal. Digital mindfulness interventions may be helpful for people with asthma by targeting psychological dysfunction such as illness perceptions, anxiety and depression.

Methods: In a mixed-methods process evaluation, we examined how ‘Headspace’, a widely-used digital mindfulness intervention, was used in a randomised controlled feasibility trial of adults with asthma from 16 UK GP practices. 94 adults who were allocated to the intervention completed questionnaire measures of anxiety, depression, quality of life and illness perceptions, and 27 were selected to complete in-depth qualitative interviews. Findings were triangulated with ‘back-end’ usage data from the Headspace digital intervention.

Results: Interviews explored participant perceptions of mindfulness interventions (and non-pharmacological interventions more broadly), as well as wider psychological factors relevant in asthma, such as anxiety, depression, mindful acceptance and awareness, and psychological inflexibility. The amount that Headspace was used was not associated with the degree of improvement in outcome measures and in general participants perceived the intervention as useful, and reported it was helpful for their wellbeing. They were generally positive about mindfulness interventions, especially digital ones.

Conclusions: Digital mindfulness interventions are acceptable for people with asthma and disease specific content should be used to target illness perceptions that may underlie reduced quality of life for people with asthma.

4.2 Introduction

Respiratory conditions are one of the leading causes of mortality and disability worldwide (World Health Organization, 2020b). One of the most common respiratory conditions is asthma, a non-communicable condition characterised by recurrent attacks of breathlessness, which may vary in severity and frequency between people (Network, 2018). People with asthma often rely on treatment to control symptoms, but it remains under-diagnosed and under-treated (World Health Organization, 2020a). As asthma is an incurable condition, rather than focus solely on reduction of symptoms, functional measures, such as quality of life, are recommended as intervention outcomes (Edwards et al., 2017b). Research commonly reports poor quality of life in people with asthma (Juniper et al., 1993) and a recent systematic review found that poor quality of life in people with asthma is associated with the presence of comorbid conditions such as anxiety, and depression, as well as illness perceptions reflecting a more threatening view of asthma (Stanescu et al., 2019).

Anxiety and depression are 1.5 – 2.4 times more common in people with asthma than people without asthma (Gada et al., 2014; Goldney, Ruffin, Wilson, et al., 2003; Walters et al., 2011). This is often unrecognized in primary care, despite anxiety and depression being significantly associated with poor asthma outcomes, such as asthma control and quality of life (Goldney, Ruffin, Wilson, et al., 2003; Thomas, Bruton, Moffatt, et al., 2011). With regards to illness perceptions, these are defined as the organised cognitive representations or beliefs that patients have about their illness or treatments (Weinman, 2013). Illness perceptions reflecting a more threatening view of asthma (i.e. more serious consequences, a longer timeline, lower personal control, lower treatment control, more symptoms, more concerns, a poorer understanding of asthma, and a greater emotional impact) are associated with poorer outcomes in asthma, such as medication adherence, beliefs about asthma and treatments, asthma control, and quality of life (Kaptein et al., 2008; Kaptein et al., 2010; Stanescu et al., 2019). Furthermore, it has been recommended that future intervention development takes illness perceptions into consideration, as they are crucial in influencing how people perceive and self-manage their condition (Kaptein et al., 2008; Kaptein et al., 2010).

Several psychological and behavioural interventions have been proposed to improve quality of life in people with asthma, with mixed results (Yorke et al., 2015). One such intervention that is obtaining positive results/increasing in use is mindfulness. Mindfulness is a type of meditation-based therapy, which involves non-judgemental awareness and acknowledgement of individual thoughts and experiences (Roemer & Orsillo, 2003). Mindfulness-based therapy is particularly effective for anxiety and depression (Khoury et al., 2013), and a systematic review has found emerging evidence of mindfulness being effective in improving health-related quality of life in people with long-term conditions (such as chronic pain, COPD, hypertension etc.(Crowe et al., 2016). Additionally, a meta-analysis found mindfulness-based therapy effective for people seeking treatment for various psychological problems, when compared with other active treatments (such as psychoeducation or supportive therapy, but not cognitive behavioural therapy (Khoury et al., 2013). In relation to asthma, recent evidence has found that mindfulness interventions were associated with improved quality of life and decreased anxiety and depression in people with asthma (Pbert et al., 2012) (Kraemer & McLeish, 2019). However, these mindfulness-based interventions were delivered face to face, therefore more research is needed to explore the efficacy of mindfulness-based therapy in people with asthma when delivered via other modalities. Previous research has shown that digital interventions are an acceptable and feasible way to deliver self-management interventions to people with asthma, and have demonstrated equivalent effects when compared with face-to-face interventions (Ainsworth et al., 2019; Bruton et al., 2018; Crowe et al., 2016). Therefore, digital mindfulness may be a suitable non-pharmacological adjunct intervention in asthma. While several mindfulness websites and apps exist, with varying degrees of popularity and evidence base, the combined website and app “Headspace” is the highest-rated (Mani et al., 2015). Research exploring Headspace in the general population has found Headspace to be acceptable and useful (Howells et al., 2016), as well as effective in reducing anxiety (Bostock & Steptoe, 2013). However, this has so far not included people with asthma, and to date, no study has explored the question of how people with asthma perceive digital mindfulness interventions.

As such, the aim of this paper is to use mixed methods to explore participants’ experiences and perceptions of their asthma and quality of life, and evaluate the usage and acceptability of a digital mindfulness intervention (Headspace) in people with asthma. This aim will be broken down into two research questions:

- **Research Question 1:** What are participants’ experiences and perceptions of living with asthma and how do they perceive its impact on quality of life?
- **Research Question 2:** What are participant’s perceptions and experiences (including usage and acceptability) of using a digital mindfulness intervention (Headspace)?

4.3 Methods

4.3.1 Headspace

Headspace is a market-leading commercially available mindfulness app, with over 11 million users worldwide. It can be accessed through desktop computers and major app stores and is available from www.headspace.com. It mainly consists of audio-guided practices, ranging in duration (3, 5, 10, or 20 minutes long). The first, “basic” sessions are introductory to mindful breathing and wider concepts of mindfulness. Following this, users can access different topic-specific packs and sessions (e.g. focusing on sleep, anxiety, public speaking, fear of flying etc.). In this study, participants received a 6-month free access code and instructions about how to sign up with Headspace. There were no specific sessions within Headspace relating to Asthma, and participants were free to choose any topic they wished to follow.

4.3.2 Study Design and Participants

The study design is a mixed methods process analysis that followed guidance for process analyses of complex interventions (Steckler et al., 2002). The study was nested within a prospective randomized-controlled feasibility study, which aimed to evaluate the Headspace digital mindfulness intervention to see if it improved asthma-related quality of life for primary care patients - The Mobile Mindfulness for Asthma study; MOMA; reported elsewhere (Ainsworth et al., 2022). The present study comprised a quantitative longitudinal questionnaire component including quantitative usage data with the 94 people with asthma who had been allocated to the digital intervention group, and qualitative in-depth interviews with a sub-sample of 27 participants who were purposively selected to include a range of responses in relation to quality of life, anxiety and depression. Triangulation used a convergent parallel analysis (John & Creswell, 2000), in which both sets of results were given equal weighting. This analysis involved the design, data collection and initial data analysis being conducted separately. Then the two sets of results were combined to identify content areas represented in both and to compare, contrast and explicitly bring the two together. It is this combined analysis that is reported in the results section. The reporting of the study design, data collection, data analysis, and findings was done using the CASP for qualitative findings (CASP, 2013), and GRAMMS tool for mixed methods (O'cathain et al., 2008).

4.3.3 Data Collection

Quantitative data were collected at the same time as the main data was collected for the MOMA study (Ainsworth et al., 2022). This was at baseline, and then 6 weeks and 3 months after starting to use the digital intervention. Demographic characteristics, comprising age, gender, education and ethnicity, were collected, along with the following measures:

The Mini Asthma Quality of Life Questionnaire – AQLQ (Juniper, Buist, et al., 1999), contains 15 questions answered on a 7 point Likert scale (ranging from ‘severely impaired‘ to ‘not impaired at all’). Higher scores are associated with better quality of life, and a score of below 5.5 indicates impaired quality of life. The questionnaire has 4 subscales: symptoms, activity limitation, emotional function and environmental stimuli (α = .92).

The Hospital Anxiety and Depression Scale - HADS, (Zigmond & Snaith, 1983) is a 14-item scale to measure anxiety and depression (7 items each), on a 4 point scale. Higher scores are associated with greater anxiety/depression, with a score of over 8 being indicative of moderate anxiety/depression, and a score of over 11 being considered clinical (α = .87 for anxiety and α = .84 for depression).

The Brief Illness Perceptions Questionnaire - B-IPQ, (Broadbent et al., 2006) contains 8 Likert-scale questions, answered on a scale of 0-10. Each of the items represents one dimension of illness perception respectively: consequences, timeline, personal control, treatment control, identity, illness concern, coherence, and emotional representation. Responses are also summed, with a higher score reflecting a more threatening view of the illness. In line with the questionnaire guidance, the word “illness” was replaced with “asthma” to make it more relevant to the population.

Philadelphia Mindfulness Scale - PHLMS, (Cardaciotto et al., 2008) is a 20-item measure consisting of two subscales (acceptance and present moment awareness). They are scored from 1 (‘never’) to 5 (‘very often) with higher scores being indicative of higher mindful awareness and acceptance (α = .83 for awareness and α = .88 for acceptance).

Usage data was obtained from Headspace on the number of mindfulness sessions completed by each participant at the end of the three-month period. Further analyses of other aspects of usage data are reported in the main MOMA paper (Ainsworth et al., 2022).

Semi-structured interviews (Barriball & While, 1994) were used to explore participants’ experiences of living with asthma, their perceived impact of asthma on quality of life, and their perceptions on using a digital mindfulness intervention, reflecting on their experience of Headspace. Qualitative interviews took place after participants had started to use the digital mindfulness intervention, most participants being in their second month of using the intervention. The interviewer used a pre-determined script that was flexible to participants' responses (Rubin & Rubin, 2011). Telephone interviews were used for their advantage of extended access to participants (Opdenakker, 2006). Interview topics included the experience of living with asthma, representations of quality of life, and thoughts about Headspace and non-pharmacological interventions. All interviews were conducted by one researcher (SS, a female PhD student experienced in qualitative methods, who had no relationship to the participants for this or the main MOMA study), and then transcribed verbatim and recordings deleted. Purposive sampling was used in order to recruit participants reflecting a range of quality of life, anxiety and depression scores, in order to allow for a more diverse experience of living with asthma (Braun & Clarke, 2019b; Byrne, 2001). The interviews ranged in length between 10 and 60 minutes, with an average of 22 minutes (SD=10.54).

4.3.4 Ethical considerations

Ethical approval was obtained from the University of Southampton Ethics Committee (ERGO ID: 30754), and South-Central Hampshire Research Ethics Committee (17/SC/0088). Participants consented to take part in the study and for their questionnaire and usage data to be used, and to be contacted with an interview invitation. For those who chose to take part in the interview, verbal consent was obtained for the interview to be recorded and the data being analysed and used for the purposes of the research.

4.3.5 Data Analysis

Indices of multiple deprivation (IMD) were calculated for the GP practices recruited into the study to explore the socio-economic status of participants (McLennan et al., 2011). Statistical analyses were conducted in SPSS version 25 (SPSS, 2013). Descriptive statistics were conducted to present the means and standard deviations at the three time points for the included questionnaires. Repeated measures analyses of variances (ANOVAs) were conducted to examine change in illness perceptions over time. Bivariate correlations were conducted to explore the relationship between anxiety, depression, and mindfulness, with the outcome variables of illness perceptions and quality of life. Additional bivariate correlations explored associations between usage (the number of sessions using Headspace), quality of life, anxiety, depression, mindfulness, and illness perceptions at 6 weeks and 3 months follow-up. Missing data was not inputted and the results presented here represent complete cases. More detail is provided elsewhere (Ainsworth et al., 2022).

Qualitative interviews were analysed using NVIVO version 11 (Castleberry, 2014). An inductive approach was used by identifying, analysing and reporting patterns within the qualitative data (Boyatzis, 1998) without previous expectations. Scripts were analysed using reflexive thematic analysis (Braun & Clarke, 2014), focusing on semantic content only. Analysis was data-driven, using open coding (reading and immersing in the scripts). Common patterns were identified in the data and grouped into nodes, which were refined and developed into themes. Development of the coding manual was initially carried out by one researcher (SS), with themes then being revised and discussed with other co-authors.

Finally, triangulation was used to combine the qualitative and quantitative results. These combined triangulated results (reported below) present how the two sets converge, diverge, or produce a more complete understanding, focusing on addressing the two research questions and hypotheses.

4.4 Results

Ninety-four participants completed demographic measures. The mean age was 49.9 years (SD=14.64); 52.1% were female; 76.8% of participants reporting having a diploma, University degree, or postgraduate degree; and 71.3% were white. The overall IMD scores for the GP practices taking part in the study showed that 61.5% of the practices were in areas of lower deprivation (or higher socio-economic status) than the average for the South East region. The interviewed sample was 53.93 years old on average (range 18-69), and 48% of the sample were female. Table 2 shows a summary comparison between the overall sample and the interviewed sample at baseline.

Table 2

Characteristics of people participating in interviews, compared to overall sample

	Interviewed Participants (N=27)	**Overall Sample (N=94)**
Mean Age	M_{age}= 53.93 (SD=14.39)	M_{age}= 49.9 (SD=14.64)
Gender (N, % female)	N=14, 48%	N=59, 63%
Average anxiety at baseline	M = 8.61 (SD=4.36)	M = 8.24 (SD=4.3)

Average depression at baseline	M = 5.89 (SD=4.46)	M = 4.74 (SD = 3.90)
Average QoL at baseline	M = 5.01 (SD=0.87)	M=5.32 (SD=1.04)
Average illness perceptions score	M = 39.46 (SD = 10.35)	M = 32.21 (SD = 11.96)

Results from the triangulation of qualitative and quantitative findings identified two themes that related to the first research question (Perceptions of asthma; and perceptions of quality of life in asthma), and three themes that mapped onto the second (views of non-pharmacological digital interventions for asthma; perceived acceptability and perceived effectiveness of Headspace; and engagement with Headspace). A diagram representing the themes corresponding to each of the research questions is shown below, in Table 3. Each of these are reported below.

Table 3

Summary of research questions, themes, and qualitative and quantitative components

	Theme	**Qualitative Component**	**Quantitative Component**
Research Question 1: What are participant's experiences of living with asthma and how do they perceive its impact on quality of life?	Theme 1: Perceptions of Asthma	Accounts of living with asthma, including the impact of treatment, adjusting to a life with asthma, anxiety, other long-term conditions	Descriptive statistics at baseline for illness perceptions, anxiety, and depression
	Theme 2: Perceptions of quality of life in asthma	Subjective concepts of what quality of life means, and the impact asthma has on quality of life, what would 'good' or 'ideal' quality of life look like	Descriptive statistics of quality of life at baseline Bi-variate correlations to explore the relationship between illness perceptions, quality of life and psychological

			aspects of asthma, such as anxiety depression, mindful awareness and acceptance
Research Question 2: What are participants' perceptions and experiences of using a digital mindfulness intervention?	Theme 1: Views of non-pharmacological digital interventions for asthma	Accounts of acceptability of non-pharmacological and digital interventions to improve quality of life in asthma, more generally than their experience with Headspace	*No quantitative data mapped onto this theme*
	Theme 2: Perceived acceptability and perceived effectiveness of Headspace	Participants reported on the perceived impact of Headspace on their asthma, and wider on their wellbeing, as well as the positive effect of mindful breathing	ANOVAs and post-hoc tests to investigate changes in illness perceptions over time Descriptive statistics exploring changes in quality of life
	Theme 3: Engagement with Headspace	Reports of using the app, building a routine, and decision making around which meditations to choose within Headspace	Bi-variate correlations to explore the relationship between engagement (measured by number of sessions of Headspace completed) and illness perceptions, quality of life, anxiety, depression, and mindfulness

4.4.1 Research Question 1: What are participant's experiences of living with asthma and how do they perceive its impact on quality of life?

Within this research question, qualitative accounts included reports on the experience of living with asthma, people's views on what quality of life means to them, and how asthma impacts quality of life. Quantitative data analysis explored illness perceptions, anxiety, depression, mindfulness, and quality of life at baseline. Two themes were identified within the triangulated analysis, these were: perceptions of asthma, and perceptions of quality of life in asthma.

4.4.1.1 Theme 1: Perceptions of asthma

Participants reported maintaining an overall positive attitude around living with asthma, mostly talking about asthma as part of their lives. Participants mentioned they had learnt to adjust to their condition. Descriptive statistics were conducted for each of the components of the B-IPQ at baseline (see Table 4). Results were consistent with qualitative findings, in particular for illness concern and emotional representation items of the B-IPQ, indicating that participants have low levels of concerns about having asthma and a low emotional impact, as shown by average baseline values in Table 4.

Table 4

Descriptive statistics and Repeated-measures ANOVAs for individual sub-scales of the B-IPQ and total score

Illness Perceptions Dimension [a]	M, SD baseline	M, SD 6 weeks	M, SD 3 months	Repeated-measures ANOVA (F, p)	Partial Eta Squared	Follow up test: Baseline vs. 6 weeks Mean difference; 95% CI	Follow up test: Baseline vs. 3 months Mean difference, 95% CI
1 Consequences	3.19 (2.34)	2.55 (1.81)	2.29 (1.81)	F (1.647, 49.397) = 5.398, p=.011*	.152	.645; (-0.104, 1.394)	0.903; (0.069, 0.738)
2 Timeline	9.19 (2.17)	9.52 (1.71)	9.26 (1.97)	-	-	-	-
3 Personal control	6.94 (2.11)	7.77 (1.58)	7.61 (1.96)	F (2, 60) = 2.899, p=.063	.088	n/a	n/a
4 Treatment Control	7.97 (2.29)	8.10 (1.96)	8.29 (1.97)	F (2, 60) = 0.502, p=.608	.016	n/a	n/a
5 Identity	4.26 (2.31)	3.65 (1.94)	3.42 (1.96)	F (2, 60) = 3.492, p=.036	.104	n/a	n/a
6 Illness Concern	4.38 (2.77)	3.84 (2.58)	3.00 (2.49)	F (2, 60) = 11.438, p<.001*	.276	0.839; (0.006, 1.671)	1.677; (0.749, 2.606)*
7 Coherence	7.61 (2.19)	8.16 (1.86)	8.16 (1.48)	F (2, 60) = 2.061, p=.136	.064	n/a	n/a
8 Emotional Representation	2.71 (2.76)	2.36 (2.30)	1.91 (1.98)	F (1.631, 89.728) = 4.750, p=.019*	.077	0.357; (-0.316, 1.030)*	0.804; (0.029, 1.578)*
Total	32.16 (12.68)	27.97 (9.74)	25.81 (10.12)	F (1.684, 50.527) = 9.658, p=.001*	.244	4.194; (0.875, 7.512)*	6.355; (1.892, 10.818)*

[a] Each item is scored 0-10, with scores averaged across participants. High scores indicate more serious consequences, a longer timeline, greater personal control, greater treatment control, more symptoms, more concerns, better understanding of asthma, more emotional impact. * indicates a significant result (p<.025) following Bonferroni correction. Partial eta squared values reflect a small, medium, and large effect size at .01, .06 and .14 respectively.

In the quantitative analysis a 'ceiling' effect was observed for Timeline, mirroring reports from the majority of the interviewed sample of having had asthma since childhood, or for a long period of time. Consistent with this, participants perceived their asthma as a part of their identity, moving to a place of acceptance.

> *"So living with it, I don't really think about it, it's just part of who I am, you know"* (P01).

Table 5 shows the proportion of people with clinical anxiety and depression, as well as impaired quality of life, according to cut off points suggested by the authors (Juniper, Buist, et al., 1999; Zigmond & Snaith, 1983). Overall, people reported high levels of anxiety related to their asthma. Most participants reported scores for anxiety above cut-off values indicative of possible clinical anxiety (8 and above).

Table 5

Proportion of participants with clinical anxiety, depression, and impaired quality of life (N = 94)

Questionnaire		N(%)
Anxiety (HADS-A)	Non-clinical (<=7)	42 (44.7%)
	Possible Clinical (8-10)	23 (24.5%)
	Clinical (>=11)	29 (30.1%)
Depression (HADS-D)	Non-clinical (<=7)	69 (73.4%)
	Possible Clinical (8-10)	16 (17%)
	Clinical (>=11)	9 (9.6%)
Quality of Life (AQLQ)	Not impaired (5.6-7)	55 (53.6%)
	Impaired (0-5.5)	39 (46.4%)

Participants reported feelings of anxiety either towards the possibility of having an asthma attack, which seemed unpredictable and scary, or anxiety about the evolution and prognosis of their asthma. This was sometimes referred to in terms of activities they had to restrict or be particularly careful about.

> *"I think it's the unpredictability of it, that I can be alright one minute and suddenly the asthma will start and I will find myself breathless"* (P19)

Participants often described their feelings towards having asthma. While overall positive and accepting, they mentioned feeling anger and frustration towards the diagnosis and symptoms of asthma.

> *"I'm not angry about it anymore, I used to be, I did get frustrated with it, back in the day but… you can't expect to go through life without the odd thing going wrong you know, so I'm fairly relaxed about it."* (P04)

Some participants mentioned having additional conditions, either anxiety, depression, or chronic physical conditions. This sometimes influenced their management of asthma, as well as the perceived severity of asthma and the interaction with other conditions.

> *"I've got POTs, this postural orthostatic tachycardia thing and with that my pulse goes right up the moment I stand up so it sort of makes you breathless and things, so it's sort of been a mixed bag of things like is it asthma or is it that I'm breathing wrong, what is it now is it my pulse... so I think my living with asthma and that is thinking, my worst fear at the minute was can I get through this winter without catching anything or without it being worse again"* (P15)

4.4.1.2 Theme 2: Perceptions of quality of life in asthma

Quality of life was one of the main subjects discussed in the interviews and was a principal outcome measure of the quantitative arm of the present study. Interestingly, participants mostly reported a positive attitude towards their asthma, and overall feeling that their quality of life was very little affected by their asthma. Quantitative AQLQ scores suggest that asthma-related quality of life was considered impaired at baseline (M = 5.31, SD = 1.06), however, it increased significantly at six weeks (M = 5.65, SD = 0.97) and three months (M = 5.73, SD = 0.93), reflecting it was no longer considered impaired, according to cut-off values of 5.5 for impaired quality of life (Juniper, Buist, et al., 1999). People generally described their quality of life in terms of restricting their activities, consistent with the finding that the quantitative sample had impaired activity limitation based on this AQLQ subscale at baseline.

Some participants mentioned their quality of life was hardly affected by their asthma, and they were leading a good life despite their illness.

> *"I would say that I don't allow it to affect it, at no point do I use my asthma as an excuse for something"* (P13)

On the other hand, others reported restricting or adjusting their activities or activity levels, as a result of their asthma.

> *"If I want to go swimming, I need to make sure I'm nice and dry, because it's cold, I… so I've had struggles with exercise … I think I'm just scared, … because I am taking my medication and there should be no reason for it to affect me, but I don't want to risk it"* (P11)

Most participants described ideal quality of life as the ability to do what they wanted without any restrictions or anxiety that they might have an asthma exacerbation.

> *"not to have to think about… 'am I going to be able to do this?' before I do something, you know… just be like 'oh yeah, let's just do that, let's go here, go there', not to need that time to check my bag for my inhaler, to check that I've always got it on me"* (P02)

Additionally, participants talked about acceptance and the need to redefine ideal quality of life, in the context of a long-term condition.

> *"I've had it for so long really, maybe you just have different expectations, you know what you can and can't do and that's what you do."* (P17)

Bi-variate correlations were conducted to explore the relationship between illness perceptions, quality of life and psychological aspects of asthma, such as anxiety depression, mindful awareness and acceptance. Poor quality of life was significantly associated with illness perceptions that reflected a view of a more threatening asthma (where a large effect size was observed), higher anxiety, and higher depression (showing medium effect sizes), as well as reduced mindful acceptance (showing a small effect size; see Table 6).

Table 6

Bivariate correlations between psychological aspects of asthma (illness perceptions, anxiety, depression, awareness, and acceptance) and quality of life at baseline.

	Illness Perceptions	Quality of Life
Illness Perceptions	-	*r* =-.773, *p*<.001*
Anxiety	*r* = .193, *p* = .092	*r* =-.322, *p*<.001*
Depression	*r* =.299, *p*=.008*	*r* =-.384, *p*<.001*
Mindful Awareness	*r* =.168, *p*=.143	*r* =-.215, *p*=.014
Mindful Acceptance	*r* =-.119, *p*=.304	*r* =-.243, *p*=.005*

note: * indicates a significant result (p<.0083) following Bonferroni correction. A small effect size is considered at r=.1, a medium effect size at r=.3, and a large effect size at r=.5.

A few participants mentioned their family and the quality of life of their family as being more important than their own quality of life.

> *"for me, the quality of life of my children is more important, them growing up happy and knowing that they're loved and supported, that sort of thing. Ahm… in terms of myself, yeah, I'm quite realistic but I always try to be optimistic, there are worse things that can happen"* (P11)

4.4.2 Research Question 2: What are participants' perceptions and experiences of using a digital mindfulness intervention?

Following triangulation, three themes were developed relating to participants' perceptions and experiences of using a digital mindfulness intervention for asthma. These were: views of non-pharmacological digital interventions for asthma; perceived acceptability and perceived effectiveness of Headspace; and engagement with Headspace. Qualitative accounts report on the views of non-pharmacological digital interventions for asthma, perceptions of mindfulness and the experience of using Headspace more specifically. Quantitative data investigated the changes in illness perceptions over time, and explored the relationship between levels of usage and quality of life, mindfulness, and illness perceptions. Each of the themes is presented below.

4.4.2.1 Theme 1: Views of non-pharmacological digital interventions for asthma

Participants unanimously recognised the value of digital interventions and mentioned accessibility and privacy as some of the main advantages of using digital interventions.

> *"I think it's quite a good thing, you can do it in the comfort of your own home. In your own timescales and whenever you feel like it. I'm pleasantly surprised and I still think quite positive."* (P21)

Generally, participants were positive towards the idea of non-pharmacological interventions, and while some considered them as an alternative to medication, others considered that it was a good idea, but not applicable for them.

> *"I think it they work then obviously… ahm they would be a really nice thing to do because you don't have the same… I know asthma drugs are very safe but it's still… people do get anxious and I certainly wonder sometimes what the long-term effects of taking drugs are, even though I know they're quite well studied. So I would like an alternative"* (P08)

However, other participants mentioned they saw value in non-pharmacological interventions to complement medication and help with acceptance and the psychological side of their condition.

> *"I think they have a value, because actually a lot of things, from my point of view, the worry about taking my inhalers out is just a worry, it's no real evidence, … so actually having some ways just getting with things to help you overcome the other side, the medical bit you can treat with medicine, but actually the mind bit it's much harder to treat with medicine"* (P06)

4.4.2.2 **Theme 2: Perceived acceptability and perceived effectiveness of Headspace**

With regards to acceptability, participants reported a positive attitude about mindfulness in general, and Headspace in particular, with all participants discussing the beneficial effects of the intervention.

> *"I think it's good, just being aware of everything, it opens up new avenues."* (P11)

These benefits of using Headspace were mentioned most in relation to overall wellbeing, as well as reducing anxiety or depression.

> *"Headspace definitely improved my wellbeing and generally my anxiety and stress are generally lower."* (P24)

Participants particularly appreciated the deep breathing exercises that were part of the mindfulness meditation.

> *"Yeah the breathing is the key! It's the absolute key for me, because if you're only focusing on the breathing, then you can't let all these extraneous thoughts in your head I think, and that's the essence"* (P04)

In relation to the perceived effectiveness of Headspace on asthma related illness perceptions, exploratory repeated-measures ANOVAs were conducted to look at the change in illness perceptions over time (reported in Table 4). The total score significantly improved, reflecting a less threatening perception of asthma at both 6 weeks and 3 months compared with baseline, and a large effect size was observed. The sub-scales of consequences, illness concern and emotional representation improved over time. This suggests participants perceived their asthma as having less severe consequences, were less concerned over their asthma, and reported a decreased emotional impact of asthma. Large effect sizes were observed for illness concern and consequences, with medium effect sizes for emotional representation. This seems in contrast with participant reports, which indicated a struggle to see how Headspace helped them specifically with how they perceived their asthma.

> *"My asthma, I haven't seen any real positive effect, maybe those surveys that I've done will bring up something different, but as far as I can tell I've got a peak flow metre, I do that once a week, but I still know I can't run anywhere." (P23)*

However, the dimensions of personal control, treatment control, identity and coherence were non-significant. This is consistent with the qualitative reports that Headspace was not beneficial to asthma. This separation of illness perceptions dimensions may reflect participants' accounts that their asthma had not improved in ways visible to them (such as reduced frequency or symptoms or need for treatment). Participants defined their asthma more functionally, rather than including concerns, emotional representations or consequences in their appraisal.

4.4.2.3 Theme 3: Engagement with Headspace

Participants mentioned they found that fitting the meditations into their daily routines and developing it into a habit was particularly beneficial, with those who could not do this being more likely to forget to use the app regularly.

> *"it becomes a habit I guess and like any habit, once you do it and become used to doing it, it becomes part of your life"* (P01)
>
> *"I'd say I'd do it when I get home later, but later something else would come up and I'd forget and it would be 2 days before I did it or… I think that was a contributing fact to what I do, it needs to be a routine*."(P10)

Participants also appeared to tailor how they navigated through the Headspace app according to personal circumstances relating to their quality of life, rather than beliefs about what would benefit their asthma.

> *"I've* been *working through the free basic blocks and I've completed the anxiety and I'm two thirds away through the depression, because they're the ones I tend to say would help me." (P26)*
>
> *"The sleep one, because I'm in menopause so the sleep one is helping me at the moment, so I use that alongside help you get to sleep."* (P16)

This was also reflected in the exploratory bivariate correlations, which examined the association between the number of times Headspace was used in the 3-month period and changes in outcome measures at 3 months (see Table 7). Although there were no associations between usage and changes in the total score for illness perceptions, using Headspace more frequently was significantly associated with improved emotional representation (where a medium effect size was observed), quality of life (a small effect size was observed), decreased anxiety, decreased depression, both showing medium effect sizes and improved mindfulness in both the acceptance, and reduced awareness subscales, where small effect sizes were observed.

Table 7

Correlations between number of sessions completed and change in scores between baseline and 3 months

	Correlation with Number of Sessions Completed	
	r	*p*
Illness Perceptions – Total Score	.213	.180
1 Consequences	.235	.139
2 Timeline	-.141	.379

3 Personal control	-.135	.401
4 Treatment Control	-.277	.079
5 Identity	.105	.514
6 Illness Concern	.098	.542
7 Coherence	.024	.882
8 Emotional Representation	.324*	.039
Quality of Life	.23*	.04
Anxiety	-.32*	.006
Depression	-.45*	<.001
Mindful Acceptance	.28*	.02
Mindful Awareness	-.26*	.03

* indicates a significant result (p<.05), no corrections have been applied. A small effect size is considered at r=.1, a medium effect size at r=.3, and a large effect size at r=.5.

4.5 Discussion

The aim of the present study was to carry out a mixed methods investigation into the experiences and perceptions of living with asthma, and how asthma is perceived to impact on quality of life. The study also aimed to explore the participants experiences, perceptions, usage and acceptability of a digital mindfulness intervention (Headspace), and whether using the intervention is associated with improvements in illness perceptions, anxiety, depression, mindfulness, and quality of life. The results of the study identified five main themes that related to the two research questions. These themes were perceptions of asthma, and perceptions of quality of life in asthma for the first research question, and for the second research question the themes were views of non-pharmacological digital interventions for asthma; perceived acceptability and perceived effectiveness of Headspace; and engagement with Headspace.

In relation to the first research question, participants reported an overall positive attitude towards living with asthma. This often involved making adjustments to daily life, to help them try to overcome anxiety and uncertainty and accept their condition. However, the success of this approach was not always as hoped for, as the quantitative measures taken at baseline, indicated that more than half of participants reported possible clinical (24.5%) or clinical (30.1%) levels of anxiety, and approximately a quarter of participants reported possible clinical (17%), or clinical (9.6%) levels of depression. This is consistent with previous research showing that anxiety is a prevalent and meaningful factor contributing to asthma outcomes (Stanescu et al., 2019; Thomas, Bruton, Moffatt, et al., 2011). Illness perceptions at baseline were also similar to average values found in previous studies with participants with asthma (Petrie et al., 2012). Compared to participants in this study, lower scores for illness concern and emotional concern, as well as high scores for coherence were observed in the present study. This can be due to living with asthma for a long time, with people incorporating asthma and its management into their lives (as was highlighted in the qualitative accounts).

Despite the positive attitude being described by participants, they also described a more negative impact of asthma on their quality of life in terms of activity limitation, and anxiety towards a future with asthma. Quantitative findings were congruent with this, as almost half of participants (46.4%) reported baseline levels of asthma-related quality of life that were classified as ‘impaired’. Quality of life was also negatively associated with increased anxiety and depression, reduced mindfulness, and having illness perceptions that indicated a threatening view of asthma. These findings are consistent with previous research, which found that illness perceptions, anxiety and depression are contributors to reduced quality of life in people with asthma (Stanescu et al., 2019). Further, this association supports previous studies reporting that people with asthma experience several problems due to living with asthma, including activity limitation, social life and employment problems (Accordini et al., 2008; Goeman & Douglass, 2005; Pickles et al., 2018). These findings only partially support Hypothesis 1, as although illness perceptions were associated with depression, it was not related to anxiety or mindfulness. Given that anxiety and depression usually show similar patterns (Kaufman & Charney, 2000), this apparent difference could benefit from further investigation by future research. In relation to the second research question, participants reported a positive attitude towards non-pharmacological interventions for asthma including mindfulness and were positive about using digital interventions to improve asthma outcomes. Although this could be criticised as one of the effects of a self-selecting sample, it is consistent with previous qualitative research (Arden-Close et al., 2013). In terms of their experience of Headspace specifically, participants perceived the intervention as useful, and reported that it was helpful for their wellbeing. This is in line with the findings of the randomised controlled feasibility trial that this study was nested within (the MOMA study), which found that Headspace was effective in improving quality of life, and reducing anxiety and depression (Ainsworth et al., 2022). However, the current study also found that while participants felt that Headspace improved their general wellbeing and gave them a thinking space and made them more mindfully aware of the present moment, qualitative comments indicated that participants did not feel the app helped them specifically with their asthma. This is consistent with previous research which has investigated the effectiveness of breathing retraining on asthma and found it to be beneficial for asthma-related quality of life, but not for lung function or airway inflammation (Bruton et al., 2018). For example, this could be linked with targeting anxiety-related psychological dysfunction, rather than specific illness-related cognition (Deshmukh et al., 2007).

Additionally, participants mentioned that their engagement with Headspace was benefited by incorporating it into daily routines and developing a habit of using it, supporting prior findings on habit formation (Deshmukh et al., 2007).

The total illness perceptions score significantly improved, reflecting a less threatening perception of asthma 6 weeks and 3 months after starting to use the intervention. Similarly, the sub-scales of consequences, illness concern and emotional representation also improved over time. The dimensions of personal control, treatment control, identity and coherence reflected no perceived changes in symptoms, understanding, or treatment of asthma. This could suggest that participants viewed their asthma mainly in a functional way, in terms of symptoms and need for treatment. This perception that if an intervention hasn't improved their symptoms then it hasn't helped their asthma, is similar to the 'no symptoms, no asthma' perception, which has been previously reported as negatively impacting on adherence and self-management as well as quality of life and asthma control (Halm et al., 2006). It should be noted that Headspace does not include any asthma specific sessions, therefore it may be possible that if Headspace had sessions that were specifically targeted for asthma, these elements of illness perceptions may also be improved. As research focusing on other chronic conditions supports the need for illness-specific interventions (Schmidt et al., 2018), it would be useful if future development of and research using Headspace could consider this.

Finally, levels of usage at 3 months had been predicted to be associated with better outcomes. Correlations revealed significant associations between a higher number of Headspace sessions used and improvements in quality of life, anxiety, depression, and mindfulness (both acceptance and awareness sub-scales), partially confirming the third hypothesis. This is consistent with prior research on Headspace (Bostock & Steptoe, 2013; Howells et al., 2016), as well as wider research exploring the effects of mindfulness in people without asthma (Pbert et al., 2012). As anxiety is a contributor to asthma outcomes, particularly quality of life (Stanescu et al., 2019), it adds support for further promoting the use of mindfulness for people with asthma. These results also suggest that ongoing engagement is needed in order to maintain positive effects on these variables. However, the third hypothesis was not supported in relation to illness perceptions, as analysis of usage data indicated that the number of sessions used was not correlated with changes in illness perceptions. This is particularly noteworthy given that illness perceptions did significantly improve from baseline to 6 weeks and 3 months, reflecting a less threatening perception of asthma over this time. It seems that participants only needed to look at a low number of sessions in order to understand what to do, and provide enough engagement to be able to produce an effect on illness perceptions (Bostock & Steptoe, 2013; Economides et al., 2018). This lack of association with amount of exposure to the intervention indicates that improvement might be related to factors other than the amount Headspace was used, as only a small ‘dose’ was needed to observe positive effects. It may also be the case that participants’ offline behaviour may be more predictive than number of sessions used. This was not measured in this study and would benefit from exploration by future research.

4.5.1 Methodological Considerations

The present study is the first to use mixed methods to explore a digital mindfulness intervention for asthma. The results of this study support the benefits of Headspace for people with asthma, but it should be acknowledged that all interventions are unique and therefore the results of this study should not be generalised to all digital mindfulness interventions, nor to non-pharmacological interventions for people with asthma more broadly (Yorke et al., 2015). However, comparisons between interventions could be explored in future research. The findings also have relevant implications for future digital mindfulness intervention development and evaluation, as they indicate that the perceived acceptability and perceived effectiveness may be improved by developing asthma-specific tailored sessions (see (Schubart et al., 2011) for a review on this topic). This is important especially in the context of digital interventions having been already successfully trialled for people with asthma (Ainsworth et al., 2019) Given the significant changes identified in this current study, further research should also consider the inclusion of illness perceptions as an outcome measure (Kaptein et al., 2008).

However, this study has several limitations. For instance, the fact that participants had self-selected into a digital mindfulness trial (Ainsworth et al., 2022), raises the likelihood that they would view digital mindfulness interventions and non-pharmacological interventions positively. This is likely to have also biased the findings of the qualitative element of the current study. With regards to the asthma related characteristics of participants, most people tended to have moderate asthma and fairly good control. Therefore, the perceived acceptability and perceived effectiveness of Headspace found in this study might not be transferable to a population of people with severe or difficult to control asthma. Finally, asthma-related quality of life questionnaires (such as the AQLQ used in this study) often include questions about concepts such as anxiety and depression, which indicates an overlap of these outcome concepts used in this study.

4.6 Conclusions

People with asthma often need long-term self-management and treatment adherence. They often experience anxiety and depression, as well as poor quality of life. Symptom exacerbations can pose a serious threat and can cause elevated anxiety. Through semi-structured qualitative interviews, and a longitudinal questionnaire study of people taking part in a digital mindfulness intervention, we found that participants felt positive about non-pharmacological interventions, as well as digital interventions. Using the mindfulness app was associated with improvements in quality of life, and changes in illness perceptions towards a less threatening view of asthma. Quality of life was described in relation to activity limitation and anxiety, and all these concepts were found to be highly correlated. Finally, people mentioned preferring an asthma-specific intervention, with usage data, such as the number of sessions completed using the app being associated with improved quality of life and decreased anxiety and depression, with more benefits being reported by those who built Headspace into a daily routine. Future research could build on these findings, with the ultimate goal of delivering a more effective, relevant and acceptable intervention for people with asthma.

Chapter 5 'If I could have one day when I could just breathe': An interpretative account of severe asthma, quality of life and multimorbidity (Paper 3)

Written for submission to Qualitative Health Research.

5.1 Abstract

Severe or difficult asthma refer to a separate diagnosis from mild and moderate asthma, encompassing a complex and often negative experience, significant co-morbidity and multimorbidity, decreased quality of life, and high rates of anxiety and depression. People often rely on multiple medications to treat their asthma and other co-occurring conditions, resulting in significant side-effects. Despite this, there is limited research exploring the need of people with difficult asthma and their needs, in particular in relation to non-pharmacological interventions to improve quality of life. This study aimed to explore the experience of living with difficult asthma, the impact on quality of life, the added burden of multimorbidity and the relevance of non-pharmacological interventions in this context. It used semi-structured interviews with a total of five participants and interpretative phenomenological analysis to structure and develop common accounts, while taking into account the context. Findings include accounts of a complex relationship with treatments, the need to depend on others, significant activity limitation, and often anxiety toward a future with asthma. Furthermore, they highlight the importance of multimorbidity as a contextual factor. Findings are discussed reflectively, and suggestions for future research are presented, alongside important considerations of the impact of the context in which this study took place (immediately prior to the COVID-19 pandemic).

5.2 Introduction

The UK has one of the highest prevalence of asthma in the world; nearly 12% of the UK population have asthma, comprising over 8 million people, most of whom are managed in primary care (NICE, 2021). Around 5.4 million are currently receiving treatment (NICE, 2021). It is estimated that about half of everyone with asthma will experience severe symptoms at some point in their lives (Stubbs et al., 2019).

Severe asthma describes a separate diagnosis, defined by the European Respiratory Society (ERS) as asthma requiring treatment with high-dose inhaled corticosteroids, a second controller inhaler, or oral steroids to prevent it from becoming uncontrolled (Levy et al., 2023). People with severe asthma live with daily symptoms and overall poor control, despite medication, and often experience side effects and comorbidities (O'Neil et al., 2015). Despite only around 5% of people with asthma having severe asthma, this results for over half of all asthma related costs (Côté et al., 2020) for instance due to differences in treatment needs or access to healthcare, in particular emergency services. There are fundamental differences between 'severe' and 'difficult to control' asthma, which are important to acknowledge. They arise from clinical differences between asthma severity and asthma control (Lavoie, Bacon, Barone, et al., 2006). While these are distinct concepts, and people could asthma could have poorly controlled mild, or conversely well-controlled severe asthma, often these two concepts are used interchangeably (Goeman & Douglass, 2005; Reddel et al., 2009). While they both refer to patients who have uncontrolled symptoms despite high-intensity treatment, they have some fundamental differences. Difficult asthma refers to people with uncontrolled symptoms due to poor adherence to treatment, psychosocial factors, comorbidities or exposure to allergens or toxic substances (Chung et al., 2014). Conversely, severe asthma covers the group of people with uncontrolled symptoms, when all the factors mentioned above have been excluded. Whether their type falls under "difficult to control" or "severe", these terms describe people who have poorly controlled asthma, despite being prescribed the maximum levels of pharmacotherapy. It is recognised that people in this population are more likely to have comorbidities, in particular psychological problems such as anxiety or depression, and would benefit from a systematic assessment and complex approaches to treatment and therapy (Robinson et al., 2003). Furthermore, a Canadian-based longitudinal study found co-morbidities accounted for over half of medical costs in people with severe asthma. Having a personalised course of therapy or treatment based on systematic assessments has been found to have positive impacts on quality of life (Gibeon et al., 2015). Difficult to control asthma represents a small proportion (estimated at approximatively 10%) of the asthma population, yet it is responsible with the largest part of morbidity, mortality and cost of disease (Rönnebjerg et al., 2021).

A systematic review of qualitative studies of people with severe asthma (Eassey et al., 2019) (Eassey et al., 2018) found that people felt disempowered and were constantly trying to adjust and cope to living with severe asthma, as well as struggling to deal with symptoms and treatment, and showed a significant emotional burden. The review also identified a lack of eligible studies (only 5 meeting inclusion criteria), and recommended that future research should seek to understand self-management strategies and personal goals, which could inform the development of effective and relevant interventions. A different review explored the concept of “treatable traits” in asthma (Tay & Hew, 2018), including asthma-specific factors such as inhaler technique or treatment adherence, as well as the management of co-occurring conditions (multimorbidity). Multimorbidity is a particular problem for people with difficult to control asthma, as it involves contacts with multiple healthcare systems (e.g primary care and various departments in secondary care), which can leave patients feeling disillusioned and less likely to adhere to treatment and guidance (Varkonyi-Sepp et al., 2022). These treatable traits can often be improved with the use of non-pharmacological interventions, which will need to be relevant and acceptable to people with difficult asthma in order to be effective (Yardley, Morrison, et al., 2015). More in-depth and holistic research focusing on people with difficult to control asthma is crucial, as often the context of their experience, such as effects of treatment, wider determinants or the presence of other chronic conditions can impact asthma outcomes (Varkonyi-Sepp et al., 2022).

In general, people with asthma report increased levels of psychological distress, when compared to the general population (Thomas, Bruton, Moffat, et al., 2011). This relationship is stronger in people with difficult to control asthma (Fong et al., 2022). Increased anxiety and psychological distress strongly impact people’s perceptions and negative impact of breathlessness, which has been found to affect health status and quality of life more than lung function (Harrison et al., 2021). Patients with difficult to control asthma are even more likely to live with psychological or physical morbidities, which further impact quality of life and asthma control (Robinson et al., 2003). The European Asthma Research and Innovation Partnership (EARIP) has identified understanding the role of psychological factors as an unmet need to improve asthma outcomes (Masefield et al., 2017), highlighting the effect of anxiety and depression on asthma outcomes, and the role of obesity. In line with this, a meta-analysis found that asthma diagnoses significantly increased risk of health and psychological conditions (Su et al., 2016).

Asthma is a heterogeneous long-term condition, and this is even more apparent in severe or difficult to control asthma. This means people with asthma experience a vast number of different symptoms, they live with a number of different co-existing long-term condition, and are affected by a vast amount of external and environmental factors. It is crucial to understand how people with asthma experience their asthma in the context of other long-term conditions, psycho-social and other environmental factors (Ainsworth et al., 2023), in order to understand the principles of developing effective interventions for people with asthma. In response to the paucity of studies exploring the experience of difficult to control or severe asthma in the context of other co-occurring conditions, the present study aims to explore and interpret the experience of people with severe or difficult to control asthma, their self-management strategies, their perceptions of co-morbidities and multimorbidity, activity limitation and quality of life. The research question is: “What are the perspectives of people with difficult to control asthma about living with and managing their condition?

5.3 Methods

5.3.1 Participants

Participants were people with difficult asthma (regardless of clinical sub-type which was outside the scope of this paper), recruited from the Wessex Asthma Cohort (WATCH). The WATCH study is described as a ‘real-life’ longitudinal study on asthma, including a vast number of demographic, clinical, psychological and functional (E.g. QoL, asthma control) measures. Clinical and questionnaire data are collected at the same time as clinical follow up appointments with asthma clinicians. More detail about the WATCH group is described elsewhere (Azim et al., 2019). Participants were not excluded if they were taking part in other WATCH studies (participants in the WATCH group have already given consent to be contacted regarding future research studies). People identified from the database were sent an invitation letter inviting them to take part in the study. The letter mentioned they were identified because they attended the WATCH ‘clinic’ but participation in this study would not interact in any way with their participation in other WATCH studies, or affect their care. The letter contained a copy of the information sheet. If interested, they were invited to contact the researcher by replying to the letter, sending an email or calling/texting a mobile number. Interested people were then asked for a suitable time and a preferred location to conduct the interview. Thirty letters were sent out by the time recruitment paused, and seven contacted the researcher to organise an interview. Five interviews were completed between December 2019 and February 2020, with the remaining two being cancelled due to the start of the COVID-19 pandemic.

5.3.2 Data Collection

This study employed a qualitative methodology, through in-depth interviews. All interviews were recorded using a digital recorder. Upon the completion of the interviews, they were transcribed verbatim. In line with IPA guidance (Smith, 2009), recordings were used in conjunction with transcripts throughout the analysis process. Semi-structured interviews were used to explore participant’s experiences and thoughts. The interview questions were initially developed by the main researcher in consultation with the rest of the research team. They were based on previous literature around the experience of living with severe asthma, barriers in adherence to medication and self-management strategies, multimorbidity, anxiety and depression, good asthma control (Miles et al., 2017), the burden of living with asthma and the need for non-pharmacological interventions (Yardley, Morrison, et al., 2015). The questions were open-ended and general, so that the participant could be in charge of the focus of the conversation, as suggested by IPA guidance (Smith, 2009). The final content of the questions, as well as the overall length of the interview was discussed and then agreed with the WATCH steering group, which included lay members who had severe asthma.

5.3.3 Data Analysis

In order to analyse, explore patterns, and develop themes, interpretative phenomenological analysis was used (IPA; Smith, 2009). This aimed to provide a description and interpretation of people's experiences, as well as how they 'make sense' of this experience (a framework referred to as double hermeneutics, (Creswell et al., 2011). Underpinning this, one of the theoretical assumptions of IPA is that people generally value good health, and will share thoughts, emotions and beliefs about their health through discourse (Matarazzo, 1980). The analysis placed focus on semantic content only (assuming that people's responses to interview questions are a direct reflection of their thoughts, attitudes and emotions). IPA is considered appropriate especially in under-researched areas, where the aim is to explore the experience of people living with a chronic condition (Brocki & Wearden, 2006), as is the case with the present study.

The present study used an idiographic case-study approach (Shaw, 2011). This involves reading and immersing in transcripts alongside recordings, starting with the first one and working through the subsequent ones, one at a time, while also making use of a reflective journal, to record the researcher's thoughts, immediately after an interview, as well as throughout the analysis (as recommended by Fade, 2004). The initial transcript was coded inductively, with no pre-determined expectations to ensure that themes reflect the participant's thoughts about their experience, as well as what they deemed to be important (Smith, 2011). A deductive-inductive approach was used for subsequent transcripts, both to map new codes onto existing themes, as well as to identify new relevant codes from the data (Smith, 2011). Finally, in writing up the results for this study the emphasis was placed on shared ideas as well as individual accounts, in order to understand and explain people's experience of living with severe asthma.

This approach of the present study is based on the principles of the person-based approach (PBA; Yardley, Morrison, et al., 2015). PBA recommends a focus on the understanding and an attempt to accommodate the views and preferences of the target population in intervention development, and to incorporate the users' perspectives with theory-based and evidence-based approaches to behaviour change. This is done, according to the authors, in two steps: firstly, qualitative research should be done with members of the target population, to identify needs and preferences, and to anticipate not only accessibility, but future usage and uptake in the context of the users; secondly, "guiding principles" should be developed for intervention planning that can address behaviour change in a context relevant to the future users (Yardley, Ainsworth, et al., 2015). The present study aims to follow the first step in order to identify what issues around people's asthma they would like addressed, as well as subtler issues such as the preferred method of delivery and time constraints.

As part of the interview process, the researcher kept a detailed journal of reflective notes, written before and immediately after conducting each interview, which will be mentioned throughout the findings and has guided the interpretation.

5.3.4 Ethical Considerations

This study received ethical approval from the University of Southampton, as well as NHS Ethics (Study ID: 265716). It also complied with the additional ethical requirements of the WATCH group. For instance, the study was approved by the WATCH steering group, as well as the Biomedical Research Centre Clinical Studies Forum within University Hospital Southampton. Participants who were interviewed at University College Southampton (UHS) signed a consent form. Participants whose interviews took place over the phone also gave verbal informed consent which was recorded and kept securely and separately from the interview recording.

5.4 Findings

Five participants took part in this study. They were all female and their ages ranged between early 30s to late 60s. As IPA requires an in-depth interpretation of the experience, participants have pseudonyms to make their stories easier to relate to in context. These were Amanda, Brianna, Claire, Diana and Ellen. To understand participants' experience of living with asthma, this section will first explore the context of each individual person by briefly outlining each of the five conversations, and will then move on to discussing the elements they shared and issues they had in common.

Amanda was diagnosed with adult-onset asthma in her mid-40s, about 10 years before the interview. Asthma started for her with significant allergies, then pneumonia and that led to severe and unpredictable asthma. Amanda is on significant treatment and has a complicated regimen to remember, but she mentions adaptations to her new ‘routine’. Amanda told me she has post-traumatic stress disorder (PTSD) from a particularly traumatic episode with her asthma, and she is currently attending therapy to manage this. Hospital stays, A&E visits and ambulances are common for Amanda, who talks about trying to avoid these at all costs. It’s not the asthma that’s debilitating, Amanda says, “it’s the fear”. The anxiety, the panic, fear of asthma getting worse and of ending up in hospital again. This experience has left Amanda with phobias and the habit of avoiding certain situations she believes will make her asthma worse. The physiological aspects of panic make her asthma worse and any breathing difficulty triggers anxiety, which leads to a vicious cycle of anxiety and asthma exacerbating each other. For Amanda, quality of life is about negotiating all of these aspects in an attempt to reduce activity limitation, or to be more able to do things unrestricted.

Brianna has had asthma for about 20 years. She also has type 2 diabetes and reports that the steroids for her asthma causes problems with the management of her diabetes. She is on significant treatment for both conditions, and she struggles with managing all the drugs, inhalers, and diabetes medication. She also struggles with constantly feeling unwell and is frequently having to try something new in terms of treatment. She feels in charge of her treatment and taking her medication, which she finds a big pressure. She feels lucky to live with her husband who ‘organises’ everything, including her medication. She has significant fatigue, and her memory is impaired. She has several other conditions, diabetes, fibroids, allergies, sinus problems, and she struggles to prioritise her conditions, and experiences significant anxiety. She is anxious of going back to hospital and is also anxious of forgetting things, mostly important information about loved ones (like birthdays or appointments), but also medication. Brianna is very worried about being alone, in case she has an asthma attack or another emergency. She describes her quality of life as ‘not good anymore’ and she would love to be able to do more with her family. She feels like a burden to others and many of her interactions with loved ones are around her health. She tries to take a positive approach to each day and focuses on what she can do that brings her joy, and what she can do to make her health and wellbeing better.

Claire is middle-aged and has been living with asthma for most of her adult life. She lives alone with her dog, who she is very attached to. Claire has significant multimorbidity, including several chronic conditions and mental health problems. Talking about quality of life is difficult for her, as she struggles to do house chores and sometimes to go out of the house for basics like shopping or the pharmacy. She talked about her chronic conditions and navigating health care services. For instance, sleep is an issue for her and while she isn’t sure of the exact cause for her sleep problem, it feels that when asked about it by the asthma nurse, she can’t answer honestly or clearly because whilst she doesn’t sleep, it’s not due to breathing difficulties or wheezing. She feels stressed about managing it all and thinking about different conditions and symptoms, and often prioritises the one that bothers her most at a particular time. She talked to me about her family problems and how they play into her overall feeling like a failure. She feels her body and her mind are failing her, and now external factors seem to confirm those thoughts for her. Although Claire shared she struggles with her mental health, she talks about it from a place of acceptance, having learnt to find joy in little things and takes it one day at a time, doing as much as she can on a good day, trying again tomorrow.

Diana is a health care professional who has had asthma for over 30 years, since childhood. She also has had allergies, hayfever, recurrent lung infections, gastro-oesophageal reflux, and she has struggled with her mental health, mentioning OCD and depression in the past. She mentioned from the start he tries her best to overcome activity limitation. '*I don't let it stop me'* she said, while talking passionately about her work and her wanting to make a difference. She also lists all the competitive sports and activities she has been involved in since she was young. Her health background also means she feels she understand the mechanisms of asthma, and also is reluctant to go to hospital too frequently. She understands the 'boom and bust' phenomenon mostly typical of chronic pain, but relevant still to her experience. Overdoing it means worse symptoms further down the line, followed by more restricted activity. Diana, like all other participants, takes several medication and told me about significant side effects. She would never consider stopping the medication (for example steroids) which she considers lifesaving. Diana had asthma for a long time, and emotionally describes having to 'adapt' and constantly living with the fear of asthma getting worse, an attack, not being able to breathe, going to A&E.

Ellen has had asthma since childhood, and she now feels she knows herself and her symptoms better. She has young children and her concept of quality of life revolves around her children. She wants to be a fun and active mum, take the children out, have outdoors holidays and 'participate', she talks a lot about activity limitation being restricted participation, her world shrinking. She wants to 'do the things I want to do' and is hopeful of new medication she is just starting. Mostly, she feels tired, low, and anxious. She has anxiety, and she is frightened of her asthma getting worse. She fears having an asthma attack as much as she is scared of having a panic attack, and she worries because breathing difficulties trigger anxiety and panic means her breathing becomes shallow. She is worried about frightening her children or people around her and she thinks asthma clinicians should teach young children what attacks feel and look like, so they're not scared about becoming ill.

Through interpretation and considering each of the five cases individually in an idiographic manner, four themes were developed. These were all concerned with the experience of living with severe asthma, but centred around treatments, anxiety, quality of life, and multimorbidity. Themes were labelled using the participants' own words: the first theme, '*Nothing seems to work'* talks about their experience of multiple treatments; the second theme, *'Panic and asthma go hand in hand'* summarises accounts about anxiety and asthma, as well as sometimes being unsure whether they experience anxiety or an asthma attack; the third theme, '*Can't lock down which one it is'* reflects experiences of multimorbidity and living with interacting conditions; the fourth theme, *'You can do whatever you want to do, you can be what you want to be – Bullshit!'* encapsulates quality of life, including activity limitation. They are each described below.

'I'm on 40 different things, nothing seems to work'

All five participants talked about treatment. It is a big part of their day and they all take several types of medication for their conditions. *'I'm on 40 different things'*, said Brianna. They all talk about managing and 'being in charge' of their treatment. It's a lot from a cognitive point of view. Brianna says she is lucky to rely on her husband to help with organising medication, but this has left her worried about being on her own. Ellen on the other hand felt hopeful about trying new medication, as she thought it might help her participate more in activities. She does feel very anxious about being out as she needs to be sure she has access to her medication. Diana talks about the side effects of some medications sometimes being worse than the asthma itself, and Brianna thinks they make her other condition worse. Diana makes a light joke about her 'truckload' of medications, but admits they have taken over her morning routine:

> *"I have to align all my meds up. And everyone else spends like umpteen 100 minutes doing their teeth and putting on makeup. I don't wear makeup because I react to it because it's got salicylates in it. Okay, so my makeup routine is my drug. And it's kind of exhausting, mentally and a bit like I entertain myself when I go to friends' houses and they'd like to stay the night. No. And when I do stay over the night, I have to come with my truckload of medications. Yeah. And then they're like, so what you have in for breakfast? Well, first, I'm going to have my eight tablets."*

They all unanimously agree their treatment is 'lifesaving' and Ellen goes on to say she finds it *'frustrating when people don't take their meds'*.

'Panic and asthma go hand in hand'

It was important that this theme was discussed separately to multimorbidity, as it seems anxiety is central to the experience of severe asthma for the five ladies who were interviewed. Brianna said '*I don't know if it's asthma or an anxiety attack*', and Claire, Ellen and Amanda all mentioned the similarities between asthma and anxiety in terms of shortness of breath. Struggling to breathe due to asthma triggers the anxiety and makes them think *'is this going to be an asthma attack'*, and equally, anxiety can cause shallow breathing which might make the asthma worse. Claire summarises this confusion between asthma symptoms and anxiety, which in her view is made worse by her sleep problems:

"I'm so bloody tired, I don't know, if it's my anxiety, or my asthma, you know, like a panic attack? Because the symptoms are also blasted similar. So I don't know, and because I'm so tired I can't, I find it impossible to monitor myself at that moment. You know, was that my asthma? Or was it a panic attack? By the time I'm awake, my mind's awake enough to focus on it, I'll probably forgotten it."

Participants all talked about mental health and wellbeing, and the psychological impact of asthma generally as a chronic condition, but it certainly seemed to them that anxiety was making their asthma worse. For example, Ellen talks about going for a walk:

"I seem to get panic with breathing… your heart rate goes up, my panic response. I'm trying to just do small walks because I need my body to function. And it's quite bad, I mean I did five minutes, after that I could feel the panic and I was on my own and not just that I was to be having a panic attack with strangers but it's because I was just not getting enough oxygen"

They all mentioned fear of hospitals, of emergency care, ambulances and significant interventions if they had an attack. This was for various reasons, Ellen because it would take her away from her children, Claire because she would be a burden (and feed into her thoughts that she is a failure). It would keep Diana from doing her very important work and make Amanda's PTSD worse.

'Can't lock down which one it is'

All participants mainly talked about their experience of living with asthma, but mentioned living with other chronic conditions early in the interview. Some conditions mentioned were 'related' to asthma, like allergies or eczema, some were not, like diabetes, back pain or cardiovascular problems. They struggle to prioritise between management of individual conditions and identify when they experience a symptom, what condition it might be linked to. Brianna thinks her allergies are the worst because they're unpredictable, but for Claire it's the incontinence because it’s stopping her from going out. For Amanda, it’s the panic. ‘*I always seem to be unwell’*, says Brianna thinking about her different treatments and how they help one condition but make another worse. She adds to refer to the struggle of her long-term conditions and treatments interacting, for example steroids worsening her diabetes:

“I take steroids practically full time at the moment and they really interacts. I've got diabetes, so they interact with my diabetes and make my diabetes level soar. It means I can’t have a normal life.”

Some participants talked about sleep problems. Claire has struggled with sleep for a long time and she finds it’s a difficult topic to discuss with health care professionals. She needs to fill in questionnaires and she feels she can’t give accurate responses because while she doesn’t sleep well, it’s not due to asthma symptoms, but there seems to be a mismatch of communication:

“It winds me up because they want to know how many times the asthma wakes me up during the night. Well, because I've got the chronic pain…. Because I've got the chronic pain plus my anxieties plus double incontinence. It's very, very rare that I get any bloody sleep. Yeah, of course, if you're not asleep, how can you regulate? How many times you're getting woken up by your asthma? Of course, yeah. Because I am, so by the time I do get some sleep, and I wake up, because I'm so bloody tired, I don't know, if it's my anxiety, or my asthma, you know, like a panic attack? Because the symptoms are also so similar. Yeah, yeah. No, and because I'm so tired. I can't. Also it's also impossible to monitor myself at that moment. You know, was that my asthma? Or was it a panic attack?”

Finally, across all accounts there were reflections of these conditions affecting most of their lives, with different ones taking priority at different times. For example, Brianna talks about her allergies and asthma as a trade off between which condition gets most attention, or in her own words ‘gets to rule my life’:

“I’ve had my allergies and sinus problems since I was about three, I’ve struggled with breathing problems, they have been there my whole life. It just seems to be ruled by it one or the other, now it's ruled by asthma.”

‘ You can do whatever you want to do, you can be what you want to be – Bullshit!’

This theme was about exploring how participants see quality of life for them, as an outcome or how they frame the positive and negative aspects of living with asthma. This theme is perhaps the most difficult to view outside of individual experience context. Ellen says '*Breathing takes so much energy'* and fatigue certainly is a central aspect to the five ladies' experience and their experience of activity limitation. Claire struggles to do chores and go out for necessities, and struggles to do some of the house activities she used to enjoy:

> *"Going out is difficult. I can't use that way as a way of relaxation other than around my own garden. Which again stresses me out because I can't do as much in the garden as I used to be able to do. So it's getting to a point that I'm not finding any pleasure in the garden because there's so much that needs to do and that I can't do and there's no one to help me do it"*

Brianna would love to play more with her children, which she elaborates after telling me '*my quality of life is not good anymore',* while Ellen says '*It makes your world shrink'*. Amanda is worried about being treated differently at work, so she decided not to tell her colleagues or managers. She says she is '*lucky*' and that she has '*good quality of life'*, which she describes as being able to go on holidays with her family. For Diana, it's all about being able to do her work. '*I don't let it stop me'* she says while listing all the exciting activities she tries to do '*despite*' her symptoms.

5.5 Discussion

The aim of the present study was to explore people's experience of severe asthma or difficult to control asthma, their self-management strategies, their perceptions of co-morbidities and multimorbidity, activity limitation and quality of life. The overarching research question was "What are the perspectives of people with difficult to control asthma about living with and managing their condition?". The study sought to understand and make sense of this experience, by using an interpretative phenomenological approach. Four main themes were identified, these were: '*Nothing seems to work'* (describing experiences on multiple treatments), *'Panic and asthma go hand in hand'* (referring to accounts of anxiety and asthma), '*Can't lock down which one it is'* (reflecting on experience of multimorbidity), and *'You can do whatever you want to do, you can be what you want to be – Bullshit!'* (which encompasses descriptions of quality of life).

Participants talked about their asthma within the wider context of their personal experience. They also talked about their families, their friends, and their quality of life. They mentioned they spent a significant part of their lives adjusting and adapting to the challenges and barriers of asthma. All participants had lived with asthma for a long time, and they spoke of it as something which was part of them, very much something on their mind every day, first thing in the morning, last thing at night. This is consistent with previous qualitative accounts of severe asthma, where asthma is described as resulting in people changing or adapting their favourite activities, which leads to a threat to participants' identity (Eassey et al., 2019). These accounts are also in line previous research which reports that people with chronic conditions reach a point of acceptance and reframe their identity as a person with a chronic illness (Forestier et al., 2019). Accounts of living with asthma are consistent with previous literature, particularly around regaining autonomy and 'focusing on what I can do' (Eassey et al., 2019). They are however it is contrasting with the idea of 'no symptoms no asthma' which is more apparent in people with mild or moderate asthma (Halm et al., 2006). This common illness belief of people with asthma refers to people believing they no longer have asthma in the periods of time where they don't experience asthma symptoms, which has implications on adherence to treatment, avoiding asthma triggers, as well as psychological distress. Living with asthma can have a detrimental impact on people's confidence, and literature as well as participants in this study talk about 'coping' by adapting and reframing aspects of their lives (Lavoie et al., 2010). The current study builds on these accounts of living with asthma by also reporting a more in-depth exploration of perceptions of quality of life in this context, as well as multimorbidity which is a very prevalent issue for people with severe asthma.

Similarities can be drawn between all participants, and particularly regarding anxiety of future attacks, and mentioning the need to plan activities taking into account environmental factors or availability of inhalers for instance. All five participants mentioned they also lived with several other chronic conditions. Within this context, they mentioned priorities shifting based on severity or new treatments. Some conditions and their treatments can affect others, indeed asthma and anxiety seem to negatively affect each other, something consistent with existing research. Prioritizing conditions refers to bringing one chronic condition at the forefront of one's mind in terms of management, treatment, or anxiety. Participants see this as something health care professionals do (consistent with existing research such as (Gibbons et al., 2013)) so they have gotten used to thinking about their conditions individually. They also prioritise management based on which one is more difficult to manage. Participant reflected on treatment, but focused on new treatments, experimental methods and always trying new approaches, as well as expressed frustration towards others who don't see the importance of 'life-saving' treatment. They had several strategies and prompts in place to remember to take their treatments, often relying on significant others. Further to this, they mentioned emergency treatment, hospitals, and ambulances with familiarity, and were anxious about needing emergency care in the future. This is again contrasting with literature mainly exploring adherence in people with mild or moderate asthma, where rates of adherence are generally low (Kaplan & Price, 2020).

Finally, they reflected and thought about quality of life, anxiety, and activity limitation. It's a cycle of being afraid of 'doing things' because of their asthma, then feeling they can't do some of the things they used to enjoy. Ideal quality of life would be to all of them the ability to do any activity unrestricted. Activity limitation is a documented aspect of QoL, especially in asthma and this relationship is even stronger in people with poorly controlled asthma (Haselkorn et al., 2010). They all mentioned trying not to let asthma get in their way, but it does. Even with the positive outlook typical of people with chronic illness (Kristjansdottir et al., 2018), all five participants were emotional and cried throughout our conversations, which is indicative of severe asthma being a significant burden to people with asthma, as well as their loved ones.

Published qualitative studies mention the negative experience of treatment for severe asthma (Hyland et al., 2015), and findings from the present study support a markedly different experience to people with mild and moderate asthma, where treatment adherence is a challenge to achieving good asthma control. Findings seem contradictory with studies showing poor adherence more generally among people with asthma (e.g. Corsico et al., 2007), as all participants in this study considered their medication to be life-saving and described the complexity of taking all their treatments daily. This could be interpreted by considering the overall impact of their difficult asthma on several aspects of their lives. Overall negative feelings about medication, particularly being reliant on it and side effects have also been noted as they are consistent with existing literature (Hyland et al., 2015; Moffat et al., 2007; Sofianou et al., 2013).

The present study provides some insightful findings, is to our knowledge the first interpretative study of the experience of severe asthma, and as such adds to the body of knowledge in asthma, but has some limitations. Participants for this interview study were selected from the WATCH cohort who were experienced in participating in research. All participants volunteering were female, so the shared experience and patterns might only be relevant in this particular context.

IPA (Biggerstaff & Thompson, 2008) was developed to allow a more in-depth exploration of experiences in an idiographic manner. This makes it suitable especially for those approaching illness from a biopsychosocial approach, as does this paper. This further mirrors the current thinking in healthcare research. IPA as a methodology, allows us to obtain a rich source of ideas about how we understand lived experience. This was presented in the way it happened, and in the context perceived of the person with the lived experience. The researcher's role was to understand through interpretation and through finding meaning from that experience. Central to this analysis was the hermeneutic cycle, meaning that statements or words were interpreted and discussed within the context they occur in the participants' speech. For example, if participants talked about a topic seemingly 'irrelevant' to the research question, it highlights that specific topic as important to the participant experience. For instance, Claire chose to talk in detail about issues in her family. While this was not directly linked to her asthma, it played into her feeling as a failure, which is central to her experience of asthma. This feeling exacerbated by relationship problems made her less motivated to manage her conditions and reduce activity limitation.

In IPA, researchers are invited to use 'bracketing' (Smith & Osborn, 2015). This is a process of mentally setting aside any previous knowledge and experience on the topic, in an attempt to be non-judgmental and better make sense of participants' experience. Using a reflective diary was instrumental in achieving this in this particular study, however certain reflection on previous experience warrants mentioning. For instance, the researcher conducting the interviews for this study had some experience in interviewing people with asthma. These were however recruited from primary care, and spoke of a markedly different experience. While attempting bracketing, it is possible that these comparisons inherently affected the interpretation (double hermeneutics) process, which can be considered a limitation of the present study.

In February 2020, the UK government released 'shielding' advice for people at high risk of developing illness due to the COVID-19 pandemic, a respiratory illness that could be fatal for people with severe asthma. The day after this advice, I had two interviews scheduled over the phone. I called the first participant at the agreed time and found her incredibly distressed. She mentioned being very anxious about the prospect of getting COVID-19, I talked with her for a few minutes and decided it was not appropriate to continue with the interview, but I made sure she was safe and suggested we get back in touch in a few weeks (after which we estimated that the immediate threat would have passed). I had a very similar conversation with the second participant that day, they were again very distressed and I thought it would not be right to ask them personal questions which would make their anxiety worse. Once many months had passed and the immediate threat began to reduce, with our increased understanding of protective factors and disease mechanisms I found myself in a challenging position of going back to the interview script, which was written before the pandemic, and considering the differences in the experience of severe asthma before and after this significant event. Living with severe asthma during a respiratory disease pandemic caused significant anxiety to participants, and it would have been challenging to ask questions about the experience of asthma that wouldn't be tied close to the experience of shielding, self-isolating, wearing masks or avoiding social contact. The research team decided to stop recruitment and write this study up in its current form, with the suggestion and invitation for future research to further refine and improve the questions to include reflections of people's experience of living with asthma through the COVID pandemic.

Finally, participants mentioned significant anxiety, as well as confusing similarities between anxiety and asthma, in terms of dysfunctional breathing. It is crucial to acknowledge this in terms of illness perceptions and their potential link with acceptability of interventions and adherence. In conducting future research, as well as future clinical practice, it is crucial to acknowledge the difference in experience between mild/moderate and severe or difficult to control asthma. In addition, future research and clinical practice should take into account multimorbidity and the individual impact, such as activity limitation, when exploring poorly controlled asthma, the relevance of certain outcome measures (for instance sleep or anxiety). Finally, future interventions should consider the shared challenge of disruption in breathing shared by asthma and anxiety, and the potential of non-pharmacological interventions such as breathing retraining or mindfulness in improving this.

5.6 Conclusion

The present study adds to the body of literature and knowledge on the experience of difficult asthma. People with difficult asthma have different views on treatment (and treatment adherence), quality of life and their asthma, compared to people with mild or moderate asthma, and their perception is influenced by the presence of multimorbidity. Interpretative accounts of this experience allows for an in-depth understanding of this experience, which can act as an initial pillar to building effective interventions to improve quality of life in people with asthma, and difficult asthma in particular.

Chapter 6 Discussion

The aim of the present thesis was to explore and understand asthma and quality of life in adults with asthma, in order to identify and suggest guiding principles for future effective interventions targeting people with asthma. This thesis was made up of three papers. The following objectives were met:

- To identify the potential factors influencing QoL in adults with asthma and to explore the relationships between health and psychological factors and asthma, and their impact on QoL (Systematic review, Paper 1 reported in Chapter 3);
- To explore the experience of people living with asthma, their understanding of QoL and associated psychological factors, and how non-pharmacological interventions can support these factors (Mixed methods study, Paper 2 reported in Chapter 4);
- To explore the needs and experiences of people with difficult to control asthma, their perceptions and representations of their conditions and treatment, their psychological and physical co-morbidities, and to understand how these experiences can inform future therapies (Qualitative IPA study, Paper 3, reported in Chapter 5)
- To highlight gaps in the literature and suggest further lines of inquiry to be addressed by future research, to inform guiding principles of a non-pharmacological intervention to improve quality of life in asthma; this refers to the overarching-chapters (Introduction – Chapter 1; Methodology – Chapter 2; and Discussion – Chapter 6).

Within chapters 3 - 5, several research questions and hypotheses are proposed. This chapter will firstly consider the main findings of this thesis and their contribution to existing literature. It will then suggest guiding principles for non-pharmacological interventions to improve QoL for people with asthma, following the process outlined by the PBA (Yardley et al., 2015). It will then reflect on overall methodological considerations, before finally suggesting implications for future research and practice.

6.1 Overview and Major Findings

This thesis comprises three papers. The first, a systematic review, explored the factors predicting QoL and was focused on health and psychological factors. This is described in detail in Chapter 3. The rationale behind this focus was to identify potentially modifiable factors that are associated with QoL. Demographic and asthma related factors (such as age of onset) were excluded, as were social factors, because they could not be targeted with a non-pharmacological (and behavioural) intervention. There was also a large enough body of literature on social factors to warrant a separate review, which could be conducted by researchers in the future. Education and health literacy were also excluded, as studies looking at these factors were mostly intervention studies, rather than exploring the relationship between education/health literacy and QoL. The systematic review used a narrative synthesis methodology, which showed that anxiety, depression, illness perceptions and health factors (e.g. high BMI, additional chronic conditions), as well as the combination between these were all associated with decreased QoL. Results indicated that people with asthma tend to have higher rates of anxiety, depression, and other co-existing physical chronic conditions than the general population or people with other long-term conditions. Taken together, these factors create a cumulative negative impact on QoL beyond the effects of each factor alone. As QoL was generally impaired in people with asthma, and as illness perceptions seem to play a crucial role in this, there was a need to gain a greater understanding of the meaning of QoL in people with asthma, as well as their illness perceptions.

To achieve this, the second study of this thesis, a mixed-methods study, used in-depth qualitative and longitudinal quantitative components. The study is described in detail in Chapter 4. A total of 104 participants were given a 6-month access code to the mindfulness meditation app, Headspace, and completed questionnaires at baseline, 6 weeks and 3 months. In-depth, semi-structured qualitative interviews were conducted with 27 of these participants and usage data was also collected. Qualitative findings indicated an overall accepting attitude towards having a diagnosis of asthma, with a few participants feeling negative emotions towards their asthma diagnosis or symptoms. In terms of ideal quality of life, most participants described it as the ability to do activities unrestricted, as well as a lack of anxiety towards future asthma symptoms. Participants were largely positive about non-pharmacological interventions, as well as digital interventions. Participants were very appreciative of mindfulness, and most reported using the Headspace app regularly, and although many participants reported feeling that their wellbeing had improved, they did not think it was specifically helpful for their asthma. This is because they either did not understand how it was meant to help with asthma, or they struggled to see improvements in terms of their asthma. This is an important finding as results of the feasibility trial (Ainsworth et al., 2022) reported improvements in asthma control and QoL. A few people reported better breathing, and even better treatment adherence and reduced number of attacks, but only a minority of participants discussed this. Quantitative results complement these findings, but also raise some conflicting points that should be investigated further. For instance, qualitative interviews indicated that participants have a generally positive attitude, but quantitative findings indicate that average QoL score at baseline was considered “impaired”. Another finding indicated that the majority of interviewed participants reported having additional chronic conditions, as well as a high prevalence of anxiety and depression. The presence of chronic conditions was not measured quantitatively, but scores for anxiety and depression of people who qualitatively reported additional chronic conditions showed that on average at baseline participants could be considered in the ‘mild’ anxiety group (suggesting probable clinical anxiety). Together, these results suggest that at least some psychological dysfunction is the norm rather than the exception in asthma. This is supported by the systematic review findings (in Chapter 3), as well as previous literature (Su et al., 2016; Thomas, Bruton, Moffatt, et al., 2011).

Following reflection on findings from the systematic review and mixed methods study, as well as existing literature particularly exploring the experience of people with severe or difficult to control asthma, the final study looked to explore more in-depth personal accounts of people with severe asthma. This is reported in Chapter 5. People were recruited from a severe asthma clinic and asked questions about living with asthma, their quality of life, as well as how they see a potential improvement in quality of life. This study used semi-structured interviews and an interpretative phenomenological analysis (IPA; Smith, 2009) to interpret and generate themes. Participants talked about their asthma as being a central part of their lives, as well as significant levels of anxiety they experienced as a result or in relation to their asthma. Participants reflected on also living with additional conditions and the impact of this, navigating healthcare and coping with daily tasks. They also mentioned a constant cycle of adapting and changing expectations as a coping strategy, reframing ‘can nots’ to ‘can dos’ and trying to find the positive side of every day. They talked differently about treatment and thought it was lifesaving and felt that asthma had a strong and negative impact on their lives. They had experience of several non-pharmacological interventions and were very open to something that might complement their medication and support them to cope better with asthma and other long-term conditions.

6.2 Guiding principles for future interventions to improve Quality of Life in asthma

The PBA (Yardley, Ainsworth, et al., 2015) recommends that the first step to developing effective interventions is exploring the needs and preferences of the target population. This should then be formulated into ‘guiding principles’ which include design objectives of the proposed intervention. Guiding principles highlight what the intervention must achieve – in the case of this thesis to improve QoL as well as consider the target users’ preferences and perspectives to maximise engagement and acceptability (Morrison et al., 2014). Design objectives are then mapped onto key features of the interventions in order to meet the intervention objectives. In addition, considering the planning stage of developing complex interventions includes understanding the target group and developing relevant programme theory (O'Cathain et al., 2019). This has been considered in particular in Chapters 1-2.

Findings from the three papers that make up this thesis are discussed together in this sub-section, focusing on the key themes developed from the results, with the aim of proposing intervention design objectives, which correspond to guiding principles for a new non-pharmacological intervention to improve QoL for people with asthma. This is summarised in Table 8. Finally, key features have been mapped onto core intervention targets to include in future planning, which include Quality of Life, Anxiety and Breathing, Multimorbidity and Asthma Specificity, and are summarised below. The intervention design objectives relate to the target group of adults with asthma.

Table 8

Guiding principles for non-pharmacological interventions for people with asthma, including design objectives and key features.

Intervention Design Objective	Key Features	Evidence
To support people to self-manage breathing and associated anxiety	Interventions should improve health literacy about anxiety, breathing and the overlap between asthma and anxiety Interventions should support maintaining positive illness perceptions Interventions should consider mindfulness-based stress reduction	Paper 2 Paper 3
To acknowledge the different experience of living with asthma alongside other long-term conditions	Interventions should persuade and educate to improve health literacy and acknowledge the shift of illness perceptions in the context of multiple long-term conditions (E.g. prioritising or the	Paper 1 Paper 3

	stress of attributing a symptom to one condition)	
To support quality of life and acknowledge the subjective nature of what 'good quality of life' represents	Interventions should improve reflection and self-awareness to facilitate self-management and improvement of functional measures. Examples could include goal setting, planning, problem solving	Paper 1 Paper 2
To encourage people with asthma to use non-pharmacological interventions to support QoL	Interventions should highlight and inform about existing evidence on how non-pharmacological interventions can 'help' people with asthma Intervention should consider tailoring information and support	Paper 2

6.2.1 Quality of Life

Like most people with chronic illness who participate in interviews, there is a significant sense of coping, of 'I get on with it' and 'I try to not let it stop me from doing things' (Petrie & Jones, 2019). This is an important point for people with asthma, as activity limitation is a significant issue for people with asthma and their quality of life (Eassey et al., 2019). Quality of life is a latent term and people have defined their own 'ideal' when it comes to their experience (Schalock, 2004). Participants often talked about reframing, changing, adapting and being happy with less than before, such as replacing aspirations to run a long distance race with walking the dog, or focusing on going outdoors with the family as opposed to playing a competitive sport. Future intervention development work should take this into account, and support self-efficacy and self-awareness in relation to what people's goals might be in terms of quality of life, as well as how to reframe these goals during different situations. This could be achieved by educating participants, and supporting problem solving and goal setting.

6.2.2 Anxiety and breathing

Participants describe feelings of significant anxiety, especially anticipating having an exacerbation or an attack when trying to do an enjoyable activity or a chore. Hospitals, emergency departments and ambulances are normal to them and they are also worried about being a burden, both to their loved ones and to the healthcare system. Anxiety is certainly prevalent in asthma (Thomas, Bruton, Moffat, et al., 2011), very common in people with severe asthma (Lavoie et al., 2010).

A key element mentioned by participants, regardless of the severity of asthma, was breathing – this was mentioned in relation to both asthma and anxiety. This is consistent with research suggesting mindfulness and breathing retraining are effective in improving asthma outcomes (Bruton et al., 2018; Pbert et al., 2012), and indeed the deep breathing aspect of mindfulness seems to be involved in the mechanism (Bailey et al., 2016). Reframing breathing and supporting mindfulness could be an effective way to support people to reduce anxiety and become more aware of their own breathing patterns.

6.2.3 Multimorbidity

Multimorbidity is very common for people with asthma (Su et al., 2016) and research has identified that illness perceptions shift for people living with multiple long-term conditions (Gibbons et al., 2013). For instance, the focus shifts to understanding what condition is causing a symptom, how to prioritise one condition over others, and any possible interactions between symptoms, treatments, and self-management strategies. Asthma research and clinical practice are heading towards a model of recognising the complexities of multimorbidity and varying needs for people with asthma (Varkonyi-Sepp et al., 2022), and indeed future practice should address training for health care professionals or an awareness of the interactions between multiple chronic conditions and their respective treatments, as well as the constant prioritization that patients have to do when navigating through pathways. Future interventions for people with asthma should consider these in trying to improve health literacy and supporting self-management, not just for asthma, but for any other co-existing conditions.

6.2.4 Illness perceptions

The experience of people with asthma varies significantly with illness perceptions and even more so with severity. The common ‘no symptoms no asthma’ perception so prevalent in asthma literature is common of people with mild or moderate asthma (Halm et al., 2006), often seen in primary care and managing their asthma with ongoing treatment and reviews. This changes when discussing the experience of people with severe, poorly controlled asthma, especially in the context of these participants living with several other chronic conditions (Pickles et al., 2018). They have assumed an identity as a person with asthma, and their asthma is something they think about every day, a finding consistent with similar qualitative accounts of severe asthma (Eassey et al., 2019).

6.2.5 Asthma-specific interventions

Participants in both studies, as well as findings from existing literature suggest people with asthma are generally positive of non-pharmacological interventions (Ainsworth et al., 2019). They did however mention the need for asthma-specific interventions which could be interpreted in several ways: either people with asthma have their asthma at the forefront of their mind, which is consistent with their identity as a person with asthma, as suggested by literature on illness perceptions (Leventhal et al., 2016), or this saliency has been determined by the recruitment strategy. Put simply, recruiting people with asthma in an asthma study and asking them about their asthma led people to be increasingly aware and reflective of their asthma and asthma needs.

People with asthma wanted an asthma-specific intervention, and an element of mindful breathing was very welcome, as well as a component aiming to reduce anxiety. People talked about relying on their loved ones, as well as missing out from social interactions because of their asthma, and suggested peer support might be welcome by people with asthma.

The next step in this process, proposed by the PBA, would be to proceed to the development phase, by suggesting behavioural outcomes and building a logic model and a prototype of an intervention. This would then be tested with participants with asthma (Yardley, Morrison, et al., 2015). The new prototype has to be underpinned by theory and existing literature but was deemed outside of the scope of this thesis as ultimately, it will be directed by practical aspects of implementation, such as funding and capacity.

For future practice, the road is already paved in that the main outcome for asthma should be QoL in clinical practice (Masefield et al., 2017). This thesis further suggests that QoL is subjective, as is the experience of asthma. Clinicians and practitioners should approach people with asthma within this subjective context, and be mindful that people with asthma very likely will feel anxious and possibly have competing conditions they manage, prioritise and think about.

6.3 Strengths and Limitations

The present thesis contributes to the literature by exploring in-depth the experience of living with asthma, illness perceptions and by considering aspects of asthma that should be targeted by a non-pharmacological intervention. Furthermore, it suggests guiding principles for an intervention targeting in particular people with poorly controlled asthma. Despite this, certain limitations have been identified. This section will discuss the strengths and limitations of this thesis. Individual methodological considerations of the three papers are explored in Chapters 3, 4, and 5 respectively.

Firstly, the database search for the systematic review only retrieved quantitative, cross-sectional studies. While this was likely an outcome of the search strategy itself, scoping search and additional searches revealed no further qualitative papers exploring the experience of living with asthma and its impact on quality of life. Several qualitative accounts of asthma have, however, contributed to conclusions and implications of this thesis (e.g. Eassey et al., 2019). In addition, the review focused on potentially modifiable psychosocial factors and their impact on QoL, which left out certain critical wider determinants of health and quality of life, such as the built environment, air quality, access to health care and social and community support (Grant et al., 2022). Instead, a population health focus might have offered certain additional insights in particular to the impact of multiple disadvantages (including demographics such as socio-economic status, or wider determinants such as employment). This could have instead pointed towards the need for a population level (public health) campaign. This was deemed outside of the focus of this thesis however, but could be considered by future research.

Secondly, the mixed-methods study employed a good sample size, but analysis presented elsewhere (Ainsworth et al., 2022) recommended that future research should attempt to replicate findings with a more diverse sample. Similarly, qualitative accounts paint a picture of a general positive attitude towards living with asthma and also to mindfulness interventions, but extending this to more diverse samples could highlight additional issues to consider in future intervention planning. Recruiting from a sample already involved in a trial had both advantages and shortcomings. For instance, having the context of using Headspace provided useful context for participants to reflect on their needs in terms of non-pharmacological interventions, as opposed to thinking of a hypothetical intervention. However, this also meant they were constraint by the features of Headspace, meaning that while they provided critical insight into the positive and negative elements of Headspace, the conversation of alternative formats was limited.

Finally, the interpretative qualitative study was significantly impacted by the COVID-19 pandemic. In March 2020, the WHO declared a global pandemic due to the number of infections with COVID-19. Initially, vulnerable people were told to 'shield', meaning they were not to leave their house for any reason. Local charities, councils and good neighbours mobilised to bring groceries, medicine and any other necessities to these groups of people in what we all hoped will be a few weeks of 'acute response'. Among the initial group of people asked to 'shield' were people with severe asthma. Being a respiratory illness, which was causing increasing number of deaths across the world, people with asthma experienced incredible anxiety at the unknown but potentially fatal effects of catching the new virus. Following this announcement, the UK went through a period of several 'lockdowns' and varying levels of restrictions, from shutting down everything other than shops that sold food, to allowing people to meet outdoors, restricting numbers of people who could socialise, and the requirement to self-isolate for people who tested positive or their contacts. Furthermore, people were required (then advised) to wear a face covering when in indoor spaces. The impact of the pandemic severely affected the third paper of this thesis, as with the first set of guidance on restricting social contact and distance, the hospital closed down for all research that was not essential or not supporting the response to COVID. In practice, this meant that I could not continue to recruit participants and meet them at their usual clinic.

Most importantly, the psychological impact of COVID on people with asthma created a challenging ethical dilemma. Participants were anxious about their asthma, going out for essential reasons, seeing loved ones etc. It seemed unethical at the time to continue to ask in-depth questions about their feelings and beliefs. At the start of the pandemic, as restrictions were starting to be announced two participants broke down over the phone and the interviews were cancelled. In addition, COVID was at the forefront of everyone's mind, particularly for those who could have such significant illness or increase risk of mortality from the virus, such as people with severe asthma. It seemed impossible to have a conversation that followed the original plan of the study that didn't include the imminent threat of the virus. For all the reasons mentioned above, we had to temporarily pause recruitment, and then several months later we decided to stop the study entirely. Therefore, for future practice, this paper could serve as the 'before' to the post-COVID 'after' in exploring people's experience of a respiratory condition in a respiratory pandemic. The findings of this study still provide insight into the experience, the beliefs and thoughts of people 'juggling' chronic conditions, adaptations and coping strategies daily, and points towards the need to support people not just to manage, treat and rehabilitate, but look forwards into the future, redefine outcomes (like QoL) and reduce anxiety.

At this time in my part-time role as a public health practitioner, I took on a lead on COVID response (and was seconded and suspended my PhD to conduct this work). This led to insight into the impact of a respiratory illness particularly on people with severe asthma. Even though data collection had ended before taking this role on, interpretation and viewing my research findings would have been influenced by this.

6.4 Implications for theory and future research

The present thesis is suggesting overarching guiding principles to support further development of an effective and acceptable intervention for people with asthma. They provide objectives for future development work and focus on key elements, which provides a novel approach to non-pharmacological interventions in asthma. Further research should be concerned with carrying this forward to creating and trialling a new intervention. This will likely involve more qualitative exploration with people with asthma, as well as rigorous feasibility planning and testing (Morrison et al., 2014; O'Cathain et al., 2019; Yardley, Ainsworth, et al., 2015).

The link between asthma and anxiety has been well documented both qualitatively (Goeman et al., 2002) and supported by clinical research (Fong et al., 2022). Researchers have started considering the mechanism of this interaction, and findings from this thesis highlight the importance of breathing as an overlapping element between the two. Future research should further explore this mechanism by exploring breathing patterns, as it could provide insights into supporting people with poorly controlled asthma.

This thesis acknowledged the importance of illness perceptions in driving asthma outcomes, both behaviourally (for instance treatment adherence or self-management; Hagger & Orbell, 2003) as well as cognitively, whereby perceptions of more significant illness are correlated with poorer QoL (e.g. as well as findings from Paper 2). Despite considering several models, such as the Health Belief Model (Rosenstock, 1974), central to this thesis was the common sense model of self-regulation, which proposes illness perceptions discussed in Paper 2 (Chapter 4) as well as throughout the thesis (Leventhal et al., 1980). While a significant body of research supports using this theoretical approach in the context of participants living with a single long-term condition (McAndrew et al., 2008), a wider argument is warranted here. This thesis, in particular Paper 2, looked at illness perceptions in asthma using the B-IPQ questionnaire, which is based on the CSM. Findings showed significant associations between illness perceptions and quality of life, as well as a change on some domains over time for people taking part in a digital mindfulness trial. However, the subjective experience of severe asthma, explored in Paper 3, is more complex and moves away from these representations to include ‘multimorbid’ illness perceptions, such as those referring to causal attribution or prioritising. These are significant issues in self-managing multimorbidity (Bower et al., 2012). This approach extending from the CSM should be the focus of future asthma research, since this thesis has added to the body of knowledge reporting on multimorbidity being the norm rather than the exception in people with asthma.

This is however only a small part of a much bigger picture, since illness perceptions in people with multimorbidity are significantly different (Gibbons et al., 2013), and people with asthma experience high rates of multimorbidity. For instance, participants find it cognitively demanding to ‘prioritise’ conditions for example when talking to health care providers, or attributing one symptom they experience to one of the several conditions. This further impacts on quality of life, which has been observed in particular in Paper 3, as well as in existing research on multimorbidity outside of asthma-specific studies. Observing this in the context of wider determinants of health has been the focus of recent public health research (Whitty et al., 2020), and future health psychology research in particular should explore these individual differences.

In relation to wider implications for theory, the findings of this thesis add further support to the body of evidence highlighting the importance of using a biopsychosocial approach to understanding the experience of asthma. Indeed, the centrality of illness perceptions as a key factor determining quality of life, as well as behaviours was evidenced by the findings of this thesis. In particular, findings of Paper 3 support research on biopsychosocial underpinnings of illness progression (Wade & Halligan, 2017) by emphasising the significant impact of subjective experiences such as the trauma of emergency care or hospitalisations, and the impact this anxiety has on treatment adherence as well as quality of life. Further research, in particular clinical approaches investigating effectiveness of asthma treatments should take into account the importance of subjective concepts of asthma severity and quality of life, as well as social and wider determinants of health, which can be key drivers of outcomes.

6.5 Conclusions

The findings from the present thesis led to the following conclusions:

1. Future intervention development studies should consider the guiding principles outlined in this thesis. This will likely lead to a complex intervention for adults with asthma, which will have elements of psycho-education, self-management, and a possible training element for healthcare professionals.
2. It is crucial to consider illness perceptions in the context of the high rates of multimorbidity (or co-morbidity) in people with asthma. The widely used Common-Sense Model (Leventhal et al., 2003) focuses on single illnesses and encourages

people to prioritise, which can lead to feelings of confusion and anxiety, and contribute to poor quality of life.

3. People with severe and poorly controlled asthma have a markedly different experience of living with asthma, but regardless of the experience of asthma, people with asthma acknowledge the importance of psychosocial factors in improving outcomes and are open to non-pharmacological interventions. Future practice should use this awareness to encourage existing non-pharmacological support and signpost people with asthma where possible and appropriate.

Appendix A Systematic Review Search Strategy

Database	Asthma	Psychosocial Factors	Quality of Life
PubMed	Asthma* [MESH]	Psychological (factor* OR determinant* OR predictor*) [keyword] OR social (factor* OR determinant* OR predictor*) [keyword] OR psychosocial factor* OR determinant* OR predictor*) [keyword] OR social support [MESH] OR education [MESH] OR co-morbid [keyword] OR anxiety [MESH] OR depression [MESH] OR illness perception* [keyword] OR illness cognition* [keyword] OR locus of control [keyword] OR self-efficacy [MESH]	Quality of life [MESH] OR QOL OR “health-related” quality of life [keyword] OR HRQOL OR HRQL OR well-being [MESH] OR wellbeing [keyword] OR distress [MESH]
EMBASE		Psychological (factor* OR determinant* OR predictor*) OR social (factor* OR determinant* OR predictor*) OR psychosocial factor* OR determinant* OR predictor*) OR social support OR education OR co-morbid OR anxiety OR depression OR illness perception* OR	Quality of life OR QOL OR “health-related” quality of life OR HRQOL OR HRQL OR well-being OR wellbeing OR distress

		illness cognition* OR locus of control OR self-efficacy	
PscycINFO	Asthma* [MESH]	Psychological (factor* OR determinant* OR predictor*) [keyword] OR social (factor* OR determinant* OR predictor*) [keyword] OR psychosocial factor* OR determinant* OR predictor*) [keyword] OR social support [MESH] OR education [MESH] OR co-morbid [keyword] OR anxiety [MESH] OR depression [MESH] OR illness perception* [keyword] OR illness cognition* [keyword] OR locus of control [keyword] OR self-efficacy [MESH]	Quality of life OR QOL OR “health-related” quality of life OR HRQOL OR HRQL OR well-being OR wellbeing OR distress
Web of Science	((("Quality of life" OR QOL OR “health-related quality of life" OR HRQOL OR HRQL OR well-being OR wellbeing OR distress)) AND ("psychological factor*" OR "psychological determinant*" OR "psychological predictor*" OR "psychosocial factor*" OR "psychosocial determinant*" OR "psychosocial predictor*" OR "social support" OR education OR co-morbid OR anxiety OR depression OR "illness perception*" OR "illness		

	cognition*" OR "locus of control" OR self-efficacy)) AND asthma		

Appendix B Data extraction table for Paper 1

Study	*No*	*Sample*	*Study Design and Recruitment*	*Predictor*	*QOL Measurement*	*Findings- summary*
Adams et al (2004)	1	7619 people from the general population (834 with asthma)	Cross-sectional, population household interview	Kessler Psychological Distress Scale (K10), for a global measure of psychological distress, containing measures of depressive and anxiety symptoms experienced over 4 weeks + self-report of diagnosed psychiatric conditions	SF-12	Psychological distress was more common in people with asthma (17.9% vs 12.2%, p<.01); mental health conditions were more common (16.2% vs 12.2%, p<.01). People with asthma and psychological distress had significantly lower QoL than those with either asthma or psychological distress alone (the physical component summary of the SF-12). Among those with psychological distress, the mental component summary did not differ between people with or without asthma.
Adams et al (2004)b	2	293 adults with asthma, at baseline and 232 at 12-months	Longitudinal study (measures at baseline and 12-month follow-up), patients recruited from outpatient clinics, emergency departments	Coping scales to measure active, avoidance and denial coping, as well as other measures such as - self-efficacy in asthma, perceived emotional and social support, satisfaction with illness scale	SF-36 and the Modified Marks AQLQ	Avoidance coping and clinical asthma status were significant predictors of the Marks AQLQ, and the physical and mental components of the SF-36 in a regression model. Less avoidance was associated in an increase greater than one standard deviation for all scales. Similar trends were observed for active coping and self-efficacy, but not denial. Active coping was a significant predictor of the physical component (r^2=0.69) and satisfaction with illness was a significant predictor of the mental component (r^2=0.54).

			and inpatients at 2 hospitals			
Adams et al (2006)	3	7619 people from the general population (834 with asthma)	Cross-sectional, population household interview	Any additional condition from: diabetes, arthritis, heart disease, stroke, cancer, osteoporosis	SF-12	People with asthma were more likely to report a physical-comorbidity (odds ratio 19.9, 95%CI 1.5 to 2.2). People with asthma and other conditions reported more days unable to do usual activities (16.0 compared to 11.3 with asthma alone and 9.2 with other conditions). When controlling for age and gender, additionally, PCS scores significantly (statistic and clinical) decreased with the presence of an additional condition. Having two or more conditions (one of which was asthma) was associated with a lower SF-12 score than expected from the effects of asthma and the chronic condition alone.
Adeyeye et al (2017)	4	201 adult participants with moderate and severe asthma	Cross-sectional, recruited from an asthma outpatient clinic	the Mini International Neuropsychiatric Interview (M.I.N.I) to assess the presence of anxiety and/or depression.	Mini-AQLQ	Presence of anxiety/depression was a significant independent predictor of the mini-AQLQ score, and of the emotional domain ($p<.001$).
Afari et al (2001)	5	50 adult participants with confirmed asthma	Cross-sectional, recruited from an asthma clinic	Diagnostic Interview Schedule for DSM-III-R	SF-36	Asthma patients with a lifetime diagnosis of depression reported worse physical functioning, mental health functioning and health perceptions (Fs ranged between 2.60 and 4.18, ps<.05). Scores for anxiety followed similar trends but were non-significant.

Al-kalemji et al (2013)	6	778 adult participants completed questionnaires (181 with asthma, 597 without)	Cross-sectional, recruited from an earlier cohort	BMI, 2 questions on the 15D and participants were asked (yes/no) if they had anxiety or depression.	15D (measure of global QOL)	Depression was significantly associated with worse QOL on all domains (r= –0.076, CI –0.091 to –0.061), but it did not inflate the relationship between asthma severity and QOL (severity had an independent influence on QOL regardless of psychological state). Anxiety (r= –0.079, CI –0.101 to –0.056) and obese BMI (r= –0.021, CI –0.034 to –0.008) were both significant predictors of QOL.
Avallone et al (2012)	7	127 adult patients with asthma	Cross-sectional, recruited from a community allergy and asthma office	Comorbid conditions: arthritis/rheumatism, frequent or severe headaches, seasonal allergies, heart attack, high blood pressure, diabetes, HIV/AIDS, ulcers, back or neck problems, chronic pain, stroke, heart disease, chronic lung disease and cancer - the number of conditions was included as a covariate in the analysis; the positive and negative affect schedule (PANAS) - a mood measure to assess negative affect; the anxiety sensitivity for fear of negative consequences from anxiety symptoms	Mini-AQLQ	The number of comorbid conditions was significantly associated with QOL on all domains (range -0.21 to -0.33). Negative affect was associated with all dimensions, except for the environmental stimuli domain. AS-Physical concerns was associated with all QOL domains. A model of gender, age, negative affect and number of medical problems significantly predicted QoL, explaining 20.2% of the variance in symptom-related QoL and 22.7% of the variance in activity limitation (gender and age were not significant independent predictors, but both negative affect and number of medical problems were).

Bohmer et al (2016)	8	196 participants with a main diagnosis of asthma	Cross-sectional, recruited for a different study from primary and specialist practices	HADS	SF-12	Scores for both anxiety and depression were significantly associated with worse QoL on the physical and mental dimensions. Increasing age, female gender, higher number of medications and symptoms of depression explained 48% of the variance in the physical component. Living alone and reporting symptoms of anxiety explained 33% of the variance in the mental component.
Choi et al (2014)	9	202 patients: 127 non-elderly (20-64) and 75 elderly (over 65) patients with asthma	Cross-sectional, recruited from five allergy and asthma clinics	Korean version of the PHQ-9	Asthma-Specific QOL (AQOL)	AQOL scores were significantly lower for people with depression and asthma (72.4 vs 98.6, p<.01); this was true for both groups (elderly and non-elderly). Within the elderly group, a higher BMI was significantly associated with depression. Co-morbidities (yes/no) were not more or less prevalent in people with or without depression.
Coban & Aydemir (2014)	10	174 adults with asthma	Cross-sectional, consecutive patients recruited from secondary care	HADs and allergic status	AQLQ	There was no difference between people who had atopic and non-atopic asthma in terms of anxiety, depression or QoL. Participants with a higher general anxiety and depression score had lower QOL (3.62 vs 4.68, p<.01 for anxiety and 3.81 vs 4.80, p<.01 for depression). Average scores for people with asthma and anxiety and/or depression were worse than one standard deviation when compared with people with asthma but without anxiety/depression.
Deshmukh et al (2008)	11	110 adult patients with asthma	Cross-sectional, recruited patients who	HADs	AQLQ	Anxiety (R^2=0.128) was a significant predictor of AQLQ. Having anxiety was correlated with having depression (F=27.17, p<.001). People with anxiety and depression had significantly

			visited an emergency department in the past 18 months			lower QoL scores (F= 11.54 for anxiety and F=26.3 for depression respectively, p<.001). Overall, symptoms of anxiety and depression accounted for 28.3%; anxiety was significantly correlated with emotional functioning and response to environmental stimuli (subscales of the AQLQ) when controlling for depression.
Ekici et al (2006)	12	116 adult asthma patients and 116 matched healthy controls	Cross-sectional, recruited from a respiratory disease clinic (matched controls recruited from the community of visitors to the same hospital)	Negative mood was evaluated with a questionnaire including six mood subscales in 3 categories - nervous-anxious, hostile-angry and fearful-panicky.	SF-36 and AQLQ	Negative mood scores were not different between people with or without asthma. Both components of the SF-36 (mental and physical) were worse in people with asthma. They were associated with negative mood scores (β=-0.37 and β=-0.28, ps<.01 respectively). Negative mood accounted for 67% of the variance in AQLQ (the impact of negative mood on symptoms and activity domains of the AQLQ was significant, but not the emotional and environmental domains).
Erickson et al (2002)	13	603 adults with asthma	Cross-sectional, recruited patients who were enrolled in a managed care organization.	Number of comorbidities and health belief questionnaires (based on the Health Belief Model)	AQLQ and SF-36	Number of comorbidities was significantly associated with decreased QOL on all 10 components and the overall score (β ranging from -0.062 to -0.360, significant for summary AQLQ, activity limitation, symptoms and exposure to environmental stimuli, and all components of the SF-36, including composite mental and physical summaries); Illness perceptions (symptom-derived severity and perceived severity) were both significant predictors of the physical component of the

						SF-36 and of all sub-scales of the AQLQ (β values ranged from -0.155 to -0.237).
Favreau et al (2014)	14	643 adults with asthma	Longitudinal, 4,3 year follow-up, recruited from tertiary care	Primary care evaluation of mental disorders interview (to assess panic disorder), anxiety sensitivity index (to assess panic-anxiety)	AQLQ	Having a diagnosis of PD did not significantly predict total AQLQ scores. Higher anxiety sensitivity at baseline predicted worse symptoms (β = -0.013, p<.01), and emotional distress (β = -0.014, p<.01), but not overall AQLQ. This stayed true when controlling for covariates (age, gender, years of education, smoking, major depression, medication use and basline scores).
Faye et al (2015)	15	60 adults with asthma	Cross-sectional, consecutive patients recruited from an outpatient tertiary care respiratory hospital	DSM-IV-TR criteria for Panic and Agoraphobia (including the Panic and Agoraphobia scale to assess the severity of panic disorder), number of comorbidities	WHO QOL BREF scale and the WHO disability schedule II	83.3% of people with 4 or more panic symptoms (not qualifying for panic attack diagnosis) reported 'sensations of shortness of breath', 'fear of choking' and 'fear of dying'. QOL scores were significantly lower on the physical (44.3 vs 49.3) and environmental (43.5 vs 47.6) domains for participants with panic disorder compared to those without panic disorder. All participants with PD had poor QOL (significantly lower when compared to those without).
Goldney et al (2003)	16	3010 interviews conducted (299 with adults with asthma)	Cross-sectional, population interview (random sample)	Dyspnoea dimension of the AQLQ to determine dyspnoea; PRIME-MD (psychiatric interview tool) to determine depression.	AQLQ and SF-36	Increases in major depression were associated with dyspnoea (44.2% with depression and dyspnoea, compared with 17.9% with depression and no dyspnoea, p<.01). This group of people showed significantly lower scores on all domains of the SF-36 (suggesting that depression could be a mediating factor).

Gonzalez-Barcala et al (2012)	17	2125 adult participants with asthma	Multi-stage cross-sectional, recruited from primary care clinics	BMI, Incidence of Stressful events, presence of allergy sensitization	EQ-5D	32% of people with asthma reported ‘serious problems’ on the anxiety/depression scale of the EQ-5D. Stressful events of giving little importance to adherence to treatment were significant predictors of EQ-5D. Having a BMI of below 25 was significantly associated with better mobility (OR=2.14), less activity limitation (OR=1.43) and less pain (OR=1.75).
Hommel et al (2002)	18	64 adolescents and young adults with asthma (18-25 years old)	Cross-sectional, recruited from the community	IDD (to assess depression), the Beck Anxiety Inventory and subjective illness severity	LVAQ	LVAQ was significantly correlated with subjective severity (r=.48, p<.01). The combined influence of anxiety and depression accounted for 14% of the variance in QoL; depression contributed significantly to variance in QoL (t=2.65; p<.05) before anxiety was introduced in the model; anxiety demonstrated a significant main effect on asthma-specific QoL (t=2.58; p<.05).
Hullmann et al (2013)	19	74 adult participants with asthma (and 74 with allergies)	Cross-sectional, recruited from a university	Mishel Uncertainty in Illness Scale - to assess 4 components of illness uncertainty (ambiguity, uncertainty, lack of information and unpredictability); Illness Intrusiveness Scale - to assess the illness-induced interference with various life activities	SF-36	The overall model (including illness uncertainty and illness intrusiveness, gender and asthma severity) accounted for 59.3% of the variance in SF-36 scores for the physical component and 19.6% for the mental component. Illness Intrusiveness and illness uncertainty were significant independent predictors of the physical component, but not of the mental component.
Kolawole et al (2011)	20	81 adult patients with asthma	Cross-sectional, consecutive patients recruited	HADs	Mini-AQLQ	Presence of anxiety symptoms (χ^2=7.9, p<.05) and depressive (χ^2=6.45, p<.05) symptoms (according to HADs) was significantly associated with decreased QoL.

			from an asthma clinic			
Krauskopf et al (2013)	21	317 participants with asthma aged over 60	Cross-sectional, recruited from outpatient health clinics (secondary care)	PHQ-9 (to assess symptoms of depression)	Mini-AQLQ	Patients with depression showed poorer quality of life than those without (mean score difference in AQLQ = -1.4, p<.001).
Kullowatz et al (2007)	22	88 adult patients with asthma	Cross-sectional, recruited from a larger study conducted at a pulmonary clinic	HADs	Living with asthma questionnaire (LVAQ) and SF-12	After controlling for demographics and symptom severity, anxiety accounted for considerable variance in SF-12 mental wellbeing and LAQ psychological well-being (explaining 22% and 9% of the variance respectively). Including depression accounted for additional variance an additional 8% and 2% respectively) For physical wellbeing, depression was significantly associated, explaining 6% of the variance, but not anxiety. Significant associations were found between anxiety and depression and the functional subscale of the LAQ (explaining 4% and 3% of the variance respectively).
Lavoie et al (2004)	23	406 adult patients with asthma	Cross-sectional, consecutive patients recruited from an asthma clinic	Structured Psychiatric interview - the Primary Care Evaluation of Mental Disorders to detect the most common psychiatric disorders, according to the DSM-IV	AQLQ	Despite no differences in pulmonary functions, people with psychiatric disorders reported significantly lower AQLQ on all individual scores and total score (mean score 5.3 vs 4.6, p<.01).

Lavoie et al (2006)	24	504 adult patients with asthma	Cross-sectional, consecutive patients with asthma recruited in primary care	Primary Care Evaluation of Mental Disorders - PRIME-MD	AQLQ	Independent effects of depression on AQLQ (F=38.5, p<.01) and anxiety on AQLQ (F=18.06, p<.01, total score) but no significant interaction effect (the multiple regression model containing severity, sex, age, depression and anxiety and the interaction accounted for 22% in the interaction). There was a significant independent effect of depression (explaining 3% of the variance in AQLQ) and anxiety (explaining 1% of the variance). They were significant predictors on every sub-scale, explaining between 1% and 3% of the variance in AQLQ subscales.
Lavoie et al (2008)	25	557 adults with asthma	Cross-sectional, patients recruited from a larger study conducted in tertiary care.	Psychiatric Interview to assess mental disorders, Asthma Self-Efficacy Scale	AQLQ	ASES scores were significantly correlated with AQLQ, suggesting that being confident in one's ability to control asthma symptoms is associated with better quality of life (r=0.62, p<.01). Lower ASES scores were also significantly correlated with a higher BMI and having a comorbid mood or anxiety disorder.
Lomper et al (2016)	26	96 adult patients (33 with controlled asthma, 63 with uncontrolled asthma)	Cross-sectional, recruited from an outpatient allergy clinic.	HADs (measured both anxiety and depression but only performed an analysis of correlations between depression and QoL	SF-36	There was a significant difference in the mental component between people with or without depression (51.4 vs 71.8, p<.05) in the group of people with controlled asthma. There was no significant difference between people with or without anxiety. In the uncontrolled asthma group, depression was associated with poorer QoL on both physical and mental components (48.6 vs 30.3 and 57.5 vs 33.7 respectively, ps<.01). Anxiety was also associated with poorer QoL on both

						physical and mental components (54.8 vs 30.8 and 62.7 vs 40.5, ps<.01).
Maalej et al (2011)	27	200 adult participants with asthma	Cross-sectional, recruited from outpatient respiratory departments	BMI and presence of comorbidities (out of diabetes, hypertension, hypercholesterolemia, rhinitis and sinusitis)	AQVAT (Arabic version of the AQLQ)	Higher BMI was correlated with higher number of comorbidities (p<.01 for diabetes, hypertension, hypercholesterolemia, GERD, rhinitis and sinusitis) and with lower QOL (11.48 vs 64.35, p<.01 between people with normal and obese BMI).
Mancuso et al (2000)	28	230 adult people with asthma	Cross-sectional, recruited from outpatients tertiary care	A screening question for depression and the Geriatric Depression Scale	AQLQ and SF-36	Participants with positive screening scores for depressive symptoms had significantly lower AQLQ and SF-36 scores (as well as significantly worse scores on each individual domain, p<.05). Depression score was a significant predictor of AQLQ, explaining 23% of the variance.
McCormick et al (2013)	29	44 adults with asthma	Cross-sectional, recruited from secondary care	Maladaptive coping (based on the transactional stress models of health) assessed with the Social Problem Solving Inventory Revised: Short Form	Mini-AQLQ	Controlling for variance associated with gender, age and income, people with higher impulsive-careless scores scored lower on QoL (β=0.79, p<.01). Problem-solving style was the only significant independent predictor of QOL.
Miedinger et al (2011)	30	60 adult participants with occupational asthma	Cross-sectional, people recruited after being evaluated for a permanent disability indemnity	Primary Care Evaluation of Mental Disorders - PRIME-MD; Psychiatric Symptoms Index	AQLQ & the St-Georges Respiratory Questionnaire	Significant medium to high correlations between the PSI and AQLQ(r=-.619); having any mood or psychiatric disorder according to PRIME-MD showed significant medium correlations with all subscales of the AQLQ (r=0.417 for any psychiatric disorder and composite score of AQLQ).

Nishimura et al (2004)	31	162 adult patients with mild to severe well-controlled asthma	Cross-sectional, consecutive patients recruited from an outpatient secondary care clinic	HADs and presence of dyspnoea	Living with asthma questionnaire (LVAQ) and SF-36	Having anxiety or depression according to HADs scores showed mild but significant correlations with both QOL questionnaires (scores ranging from 0.31 to 0.60). Severity of dyspnoea was also associated with both, with correlation scores ranging from 0.22 to 0.56.
Oga et al (2007)	32	87 adult Patients with stable asthma	Longitudinal, recruited from an outpatient secondary care asthma clinic 6 months after treatment and follow-up 5 years	HADs	AQLQ	Changes in HADs scores were significantly correlated with changes in AQLQ on both anxiety and depression scales (r = -0.6, p<.01 and r = -0.5, p<.01 respectively), but not changes in physiological measures. HADs scores overall remained similar over the 5 year follow-up period.
Oguzturk et al (2005)	33	70 patients (with stable asthma and aged over 60) and 40 age-matched controls	Cross-sectional, recruited from a secondary care respiratory clinic (matched controls were recruited from local mosques)	HADs	AQLQ	Patients with earlier onset asthma (duration >8 years) had lower QoL scores than those with recent onset asthma. Anxiety and depression were significant predictors of AQLQ scores, anxiety accounted for 49% and depression for 41% of the total score.

Pate et al (2018)	34	18856 people with asthma	Cross-sectional, sample recruited from wider telephone population study of 39321 (BRFFS sample)	Additional chronic conditions, BMI, presence of depression	General Health, Activity Limitation, Physical/Mental Health Impairment (Yes/No Questions)	Having additional conditions (PR=4.26), depression (PR=1.97), as well as either underweight (PR=1.82), overweight (PR=1.19) or obese (PR=1.76) BMI were all significantly associated with 14 days or more of activity limitation, as well as self-rated fair/poor health.
Powell et al (2015)	35	218 pregnant women with asthma and rhinitis	Cross-sectional, recruited from an ante-natal clinic	Rhinitis was assessed using a visual analogue scale, Six Item Short-Form State Trait Anxiety Inventory	AQLQ-M	QoL scores were predicted by presence of rhinitis, anxiety and prior history of rhinitis (medians 0.63 vs 1.06, p<.01 for pregnant women with asthma, with and without current rhinitis).
Sandez et al (2005)	36	40 adult patients with near-fatal asthma	Cross-sectional, recruited from an out-patient asthma clinic (secondary care)	Beck's Depression Inventory and the Panic-Fear Scale of the Asthma Symptom Checklist	SF-36 (MCS and PCS components)	Panic-Fear (PF) and age accounted for 22.8% of variance in PCS and depressive symptoms accounted for 48.6% of the variance in MCS. PF was significantly and negatively correlated with both MCS and PCS (r=-0.53 and r=-0.36 respectively, ps<.05). Depressive symptoms were only significantly correlated with MCS (r=-0.69, p<.05).
Strine et al (2008)	37	18856 people with asthma	Cross-sectional, sample recruited from wider telephone population study of 39321 (BRFFS sample)	PHQ-8, self-report diagnosis of depression, BMI	General Health, Activity Limitation, Physical/Mental Health Impairment (Yes/No Questions)	Among adults with asthma, people with current depression were significantly more likely than those without depression to report more mean numbers of days in the past 30 days of physical distress (OR=4.7), mental distress (OR=14.3), activity limitations (OR=7.0), depressive symptoms (OR=23.6), anxiety symptoms (OR=9.8), insufficient sleep (OR=6.3), pain (OR=6.0), and fatigue (OR=13.3). There was a dose response

						relationship between depression severity and the mean number of days of physical distress, mental distress, depressive symptoms, fatigue, anxiety symptoms, and activity limitations. Those with current depression were also significantly more likely to have an obese BMI.
Tay et al (2016)	38	90 adult patients with difficult asthma	Cross-sectional, consecutive patients recruited from a difficult asthma clinic	Having one of 8 comorbidities: Allergic rhinitis, chronic rhinosinusitis, gastroesophageal reflux disease, obesity, obstructive sleep apnoea, anxiety or depression, dysfunctional breathing and vocal cord dysfunction.	AQLQ	BMI was an independent predictor of poor QoL (β=-0.05, p<.01). Dysfunctional breathing predicted poor QoL (β=-0.73, p<.05), as did vocal cord dysfunction ((β=-0.78, p<.05). On Univariate analysis, BMI, VCD, DB, OSA and GORD were significantly associated with decreased QOL.
Urbstonaitis et al (2019)	39	5857 late midlife adults with asthma	Cross-sectional, sample recruited from wider telephone population study of 39321 (BRFFS sample)	BMI, presence of respiratory comorbidity	General Health, Activity Limitation, Physical/Mental Health Impairment (Yes/No Questions)	Respiratory comorbidity was significantly associated with poor QoL on all dimensions, and independent of asthma control (OR=17). People with poorly controlled asthma were more likely to have an obese BMI. The combination of poor control and obese BMI was significantly associated with poorer general health (OR=2.3).
Vasquez et al (2010)	40	76 adults with asthma	Cross-sectional, recruited from a secondary care	Cognitive Depression Index (subscale of the Beck Depression Inventory); Trait Subscale of the State-Trait Anxiety Scale; the Twenty-Item Toronto Alexithymia	SF-36 and The St George's Respiratory Questionnaire to measure	Trait anxiety, depression scores and alexithymia were included in a regression model that explained between 23% and 39% of variance in QoL. Depression was a significant independent predictor and

			pneumology department.	Scale - this has three dimensions: DIF, DDF and EOT;	disease-specific impairment	associated with all sub-scales of the SF-36, as well as all the sub-scales of the SGRQ.
Vortmann & Eisner (2008)	41	843 adult patients with severe asthma	Cross-sectional, recruited patients who were hospitalized for asthma in the previous 4 years.	BMI from self-reported height and weight, atopic history; Center for Epidemiologic Studies Depression Scale	Marks Asthma QOL Questionnaire and the SF-12 and daily activity restriction	Compared to normal BMI, general physical health was significantly worse in those with obese BMI (mean score decrement of -6.31), and overweight BMI (mean score decrement -2.42). Asthma-specific quality of life was significantly worse in the underweight group (mean score difference 8.66 points), and obese group (4.51 points). People with obese BMI also had a higher number of restricted activity days (5.05 days more). Obese patients had significantly higher risk of depressive symptoms. Depression was found to be a significant mediator of the relationship between obesity and health status, asthma QoL and restricted activity days.
Wijnhoven et al (2003)	42	395 patients with asthma, aged 40-75	Cross-sectional, participants recruited from general practice.	Presence or absence of: diabetes mellitus, hypertension, cardiac disease, cerebrovascular disease, musculoskeletal disease and malignancies and asked if they had any other chronic condition. Co-morbidity was defined as 1) presence of co-morbidity; 2) number of co-morbid conditions; 3) presence of specific co-morbidity	Disease-specific instrument: Quality of Life in Respiratory Illness Questionnaire; generic instrument: the Dutch version of the Nottingham Health Profile (NHP)	Having one or more comorbidities was significantly associated with poorer asthma-specific QoL (OR=2.08) and poorer general QoL (OR=2.96). Poorest QoL was found in patients with more than one co-morbid condition (OR=4.77). Cardiac disease and hypertension were significantly associated with poor disease-specific QoL in asthma, and musculoskeletal disorders were most strongly associated with poor general QoL.

Yilmaz et al (2014)	43	97 adult patients with asthma and 97 healthy controls	Cross-sectional, recruited from a secondary care outpatient chest disease clinic.	SCID-II (structured method of interview, according to the DSM-III-R to diagnose axis II personality disorders)	SF-36	People with asthma and personality disorders had significantly lower QoL scores than people with asthma and no personality disorders. This was significant for physical role functioning (42.68 vs 62.50, p<.05), general health (38.56 vs 53.60, p<.01), and mental health (53.75 vs 65.55, p<.01). All physiological measures (FEV, severity of asthma, disease duration etc) were not significantly different between people with or without personality disorders.

Appendix C Quality assessment for systematic review

No	**Citation**	**I.1**	**II.2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**III. 12**	**13**	**14**	**15**	**16**	**IV. 17**	**18**	**V.19**	**20**
1	Bohmer et al (2016)	y	y	n	y	y	n	y	y	y	y	y	n	n	n	y	n	n	y	n	y
2	Oguzturk et al (2005)	n	n	n	y	n	n	n	y	y	y	n	n	y	n	y	y	n	n	n	y
3	Oga et al (2007)	n	n	n	n	n	n	n	n	y	y	y	y	n	n	y	y	y	n	n	y
4	Hommel et al (2002)	y	y	y	n	y	n	n	y	y	y	y	n	n	n	n	y	n	n	n	y
5	Kolawole et al (2011)	n	n	n	n	n	n	n	n	y	n	n	n	n	n	y	n	n	n	n	y
6	Krauskopf et al (2013)	n	y	n	n	n	n	n	y	y	y	y	n	y	n	y	n	n	n	n	y
7	Lomper et al (2016)	n	y	n	n	n	n	n	n	y	y	n	n	y	n	y	n	n	n	n	y
8	Vasquez et al (2010)	y	y	n	y	n	y	y	y	y	y	n	n	y	n	y	n	n	y	n	y
9	Tay et al (2016)	y	y	n	y	y	y	y	n	y	y	n	y	n	n	y	y	y	n	n	y

10	Erikson et al (2002)	y	n	y	y	y	y	y	n	y	n	n	y	n	n	y	n	y	n	n	y
11	Maalej et al (2011)	y	y	n	y	y	y	n	y	y	y	y	y	n	n	y	y	y	y	n	y
12	Powell et al (2015)	y	y	y	n	n	n	y	n	y	n	y	y	n	n	n	y	y	y	n	y
13	Nishimura et al (2004)	y	y	n	n	n	n	n	n	y	y	y	n	y	n	y	y	y	n	n	y
14	Sandez et al (2005)	y	y	n	y	n	n	y	n	y	n	y	y	y	n	y	n	n	n	n	y
15	Wijnhoven et al (2003)	y	y	n	y	y	y	y	y	y	y	y	y	n	n	y	y	y	y	n	y
16	Gonzalez-Barcala et al (2012)	n	y	y	n	n	n	n	n	y	n	n	n	y	n	n	n	n	n	n	y
17	Vortmann & Eisner (2008)	y	y	y	n	y	y	n	y	y	y	y	y	n	n	n	y	y	n	n	y
18	Lavoie et al (2004)	y	y	y	y	y	y	y	y	y	y	y	y	n	y	n	y	n	y	n	y
19	Adams et al (2004)	y	y	n	y	y	y	n	y	y	y	y	y	n	n	y	n	y	y	n	y

20	Coban & Aydemir (2014)	n	y	n	n	n	n	n	y	y	y	y	n	n	n	y	y	n	n	n	y
21	Ekici et al (2006)	n	n	n	y	y	y	n	n	y	y	y	n	n	n	y	y	n	y	n	y
22	Adeyeye et al (2017)	n	n	n	n	n	n	n	n	n	n	n	n	n	n	n	n	n	n	n	y
23	Mancuso et al (2000)	y	y	n	y	n	y	n	n	y	y	y	n	y	y	y	n	y	n	n	y
24	Miedinger et al (2011)	y	y	y	y	y	y	n	y	y	y	y	y	n	n	y	y	y	y	n	y
25	Al-kalemji et al (2013)	y	y	y	y	y	y	n	y	y	n	n	n	n	n	n	n	n	n	n	y
26	Kullowatz et al (2007)	n	y	n	n	n	n	n	y	y	y	y	n	n	n	y	n	y	n	n	y
27	Choi et al (2014)	y	y	n	n	y	n	n	y	y	y	n	n	n	y	y	n	n	y	n	y
28	Afari et al (2001)	n	n	y	n	n	y	n	n	y	n	n	n	y	n	n	n	n	n	n	y
29	Goldney et al (2003)	n	n	n	n	y	y	n	n	y	n	n	n	n	y	n	n	n	n	n	y

30	Avallone et al (2012)	n	y	n	n	n	y	n	n	y	y	y	n	n	n	n	n	y	n	n	y
31	Faye et al (2015)	y	y	y	y	y	y	n	n	y	y	n	y	n	n	y	y	y	y	n	y
32	Lavoie et al (2006)	y	y	n	y	y	y	n	y	y	y	n	n	n	n	y	n	n	y	n	y
33	McCormick et al (2013)	n	n	n	n	n	y	n	n	y	n	n	n	y	n	n	n	n	y	n	y
34	Lavoie et al (2008)	y	n	n	n	n	n	n	y	y	y	y	n	y	n	n	n	n	n	n	y
35	Hullmann et al (2013)	n	y	n	y	y	n	n	n	y	y	y	n	n	n	y	y	n	y	n	y
36	Adams et al (2004)b	n	n	y	y	y	y	n	y	n	n	n	n	n	n	y	y	y	n	n	y
37	Favreau et al (2014)	y	y	y	n	n	n	n	y	y	y	y	n	y	n	n	n	n	y	n	y
38	Yilmaz et al (2014)	y	y	n	n	n	n	n	y	y	n	n	y	n	n	n	y	n	n	n	y
39	Strine et al (2008)	y	y	y	y	y	n	y	y	y	y	n	n	n	n	y	y	n	y	n	y
40	Adams et al (2006)	y	y	n	y	y	y	n	y	y	y	y	y	n	n	y	y	y	y	n	y

41	Deshmukh et al (2008)	y	y	n	y	n	n	n	y	y	y	y	n	n	n	n	y	n	y	n	y

Appendix D Interview Script for Paper 2

Working Title: A Mixed-Methods Study of Illness Perceptions, Mood and Quality of Life in Asthma and Breathing

Introduction:

• Good morning/afternoon/evening, my name is Sabina, I am one of the researchers at the University of Southampton, working as part of the MOMA study. Is this still a good time to have the interview?

Just as a quick reminder, this interview is meant to explore your experience of using Headspace, so the questions will be around your thoughts and views on the app and its content. I just want to reassure you that there are no right or wrong answers; we would like to know about your views and experiences. I will record our conversation and then transcribe it and use it as part of the research study. None of your personal information or identifying details will be used in the transcription, they will be deleted. Is that ok? Also, you can change your mind about taking part at any point during the interview or choose to decline to answer a question. Are you happy with all this? And do you have any questions for me before I turn the recorder on?

- Excellent thank you.

"The questions I am going to ask you are in two sections… the first section will be about your asthma, and the second section will be about your experience in the MOMA study, using Headspace."

I. To start with – can you tell me a little bit about your asthma?
    i. Prompts: What is it like, for you, to live with asthma, on a daily basis?
    ii. How do you feel about having asthma? (remind that participants usually have positive as well as positive impacts)

II. In what ways does your asthma affect your quality of life?
    i. What would it mean to you to have good quality of life?
    ii. Do you think quality of life is an important measure important for people with asthma? In what way?

III. What are your views on using non-drug therapies like mindfulness alongside medication to help difficult asthma? (generally, not just headspace)
    i. What are your thoughts about using well-being to measure the effectiveness of a non-drug therapy for asthma?

The next set of questions are more detailed, and are about your views and experience of the different aspects of using Headspace.…

I just want to remind you that there are no right or wrong answers, so don't worry if you can't remember. We are just trying to understand if there were any parts of Headspace that were more or less helpful than others.

1. I have a few questions prepared but to start off with could you please just tell me what you thought of taking part in the study?
    ii. Prompt: what did you like?
    iii. What did you dislike?
    iv. What would you change?

2. How did you use Headspace?
    v. When did you use Headspace? (Clarification Prompt: How often?)
    vi. Do you think you will use it in the future?
        1. What do you think will influence your decision to use it (or your decision to stop using it) in the future?
        2. When do you think you might use it? (Clarification Prompt: How often?)

3. What did you think about Headspace being an online programme?
    vii. What did you think of the digital usage component?
    viii. Prompt: what did you like?
    ix. What did you dislike?
    x. What would you change?

4. Moving on to the content of the intervention…

   What did you think of the breathing exercises?

- xi. What did you think of having to focus on your breathing and body sensations?
- xii. What did you think of the variety of options for meditations you could choose from? How do you think this could be improved?
- xiii. Were there any meditations that you most enjoyed? Can you tell me a little bit about it/them?
  1. Prompt:

IV.

5. What do you feel you got out of using the Headspace app?
6. How effective do you feel it was?
   - i. How do you feel it helped in your everyday life, such as with stressful or anxious events?
   - ii. How do you feel it helped your breathing or other physical symptoms?
   - iii. How do you think it helped or changed the way you experience or manage asthma?
   - iv. How do you think it helped or changed how you feel about your asthma?
7. What are your thoughts on mindfulness now?
   - v. How are they compared to when you first signed up to this programme?

8. If we were to plan another study such as this one, to design a programme to help people with asthma, what do you think we should focus on?
   - vi. How could we have made this easier for people to take part?
   - vii. What do you think are the barriers for people to take part?
   - viii. Thinking back at your experience with Headspace, would you say that this is a good model to follow?

Is there anything else that you would like to add that you think is relevant and I maybe forgot?

THANK YOU VERY MUCH, I WILL NOW STOP THE RECORDING

Appendix E Excerpt from coding manual for Paper 2

Theme	Topic/Subtheme	Description	Example Quote
Living with Asthma	Anxiety about the future	Views on future with asthma, such as unpredictability of attacks or the anxiety of getting worse or having an attack	"but the anxiety that things might go wrong and I might get into a situation where I get breathless and what do I do" (P06)
	Current feelings about asthma	Present experience of living with asthma	"so it's one of those things I just have to live with, but any stress will certainly make it worse" (P19)
	Identity	How participants identified as a person with asthma	"So living with it, I don't really think about it, it's just part of who I am, you know." (P01)
	Management of asthma	Discussion of management techniques, including pharmacological and non-pharmacological therapy	"but it's just learning to accept and manage that I suppose… I don't do illness very well (laughs). I'm quite a healthy person" (P20)
	Multimorbidity	The impact of other conditions on asthma and asthma management	"if you're constantly worrying about your asthma, which I'm not, but I am constantly worrying about the tinnitus, so my mind is in this… in this loop of worry, that can have a detrimental effect on your life" (P04)
Quality of Life	Impact of asthma on QoL	How participants feel their life has been affected by living with asthma.	"It's not very pleasant at the time, it slows me down but it doesn't stop me from doing the things that I want to do. So… it's a nuisance really, rather than being seriously disabling" (P10)

	Meaning of QoL	Moslty answers to the question "what do you consider ideal quality of life?".	"I would like to be able to indulge in the sports that I enjoy, without having to worry about the asthma getting worse, I would like to be able to keep up with other people, climb flights of stairs without worrying or get through the winter without having to worry every time I go out that I would get a chest infection and it’s a worry every time.” (P12)
Interventions	Mindful Breathing	Thoughts on the breathing component of mindfulness and its value for people with asthma.	"it’s quite a good guide on how to control breathing, not to panic if anything does happen. So, I guess it was quite good like that" (P01)
	Dislikes about Headspace	Small dislikes or changes participants mentioned, mostly about the app itself rather than the concept of mindfulness.	"And also ahm… I’ve done a fair amount of yoga, breathing control and meditation, mainly in my youth, I found the tone of the app sort of condescending, so I didn’t really appreciate it… it didn’t have… I don’t respond well to someone telling me to be calm… "(P12)
	Asthma-specific benefits of Headspace	Discussion of how participants felt that Headspace helped specifically with their asthma	"I woudn’t say it has adjusted my asthma at all" (P11)
	General benefits of Headspace	Thoughts on how Headspace helped participants generally, such as with wellbeing, calmness etc.	"And doing the daily meditation it does clear your mind, you definitely feel calmer after the 10 minute session and then I found it works, which quite surprised me because I’m quite cynical about these kinds of things. But it’s made a difference." (P04)

	Uncertainty about the study aim (and use of Headspace)	Conceptions at the beginning of the trial about how Headspace might work, and confusion about the aims of the study.	"I don’t know, give them a bit more of a plan, but I was really, I didn’t really know what your outcome was." (P02)
	Patterns of Usage	Reports of how participants used Headspace, including frequency, associated behaviours and discussions about the habit of using it.	"I was trying to stick to a time, but my work and life balance kind of… it’s very fluid, so I try to get it first thing in the morning, if not, I’ll get it in the evening right before bed. And if I manage to sneak something in during the day, because I’m commuting or doing something else, then I’ll do that." (P13)
	Views on digital interventions	Participants' thoughts on Headspace being an app, as well as other digital interventions.	"I think the options are online or you go to one of these courses and I think if you went to a course, you would have to be very committed, whereas what I like about this is I can do it in my own time, nobody need know anything about it, and it was just… I just sit in this room here and it’s just an experiment that I’ve gone through, and from that point of view, I liked the fact that it’s online, I didn’t know you could do mindfulness online" (P04)

	Views on non-pharmacological interventions	Participants' thoughts on any potential non-drug intervention; it was discussed either as complementary to their medication or aiming to replace their medication.	"I think they have a value, because actually a lot of things, from my point of view, the worry about taking my inhalers out is just a worry, it’s no real evidence. If I look at this logically I’ve not had, you know, I don’t need to take my inhalers out every time I go out, because it’ll be fine, but actually my head’s, it’s the thoughts that my head processes and how it deals with that and goes << oh yeah, but, but >>, so actually having some ways just getting with things to help you overcome the other side, the medical bit you can treat with medicine, but actually the mind bit it’s much harder to treat with medicine" (P06)

Appendix F Interview script for Paper 3

The experience of living with and self-managing poorly-controlled asthma: a qualitative study of adherence, illness perceptions and multimorbidity

Interview Script

Start with : **Good morning/afternoon/evening, my name is Sabina, I am one of the researchers at the University of Southampton. Is this still a good time to have the interview?**

Just as a quick reminder, this interview is meant to explore your experience of living with asthma, but also generally about dealing with your other conditions. I just want to reassure you that there are no right or wrong answers; we would like to know about your views and experiences. **I will record our conversation and then transcribe it and use it as part of the research study. None of your personal information or identifying details will be used in the transcription, they will be deleted. Is that ok?** Also, you can change your mind about taking part at any point during the interview or choose to decline to answer a question. Are you happy with all this? And do you have any questions for me before I turn the recorder on?

1. To begin with, I know you have severe asthma. Could you please tell me a little about what it's like for you to live with [it]?
    a. How does having severe asthma affects your life?
        i. What is your ideal quality of life?
    b. What are some ways you prevent your asthma from affecting your life? (strategies, treatment strategies, coping)
    c. Treatment burden/ activities/ impact/ changes? How does taking your treatment affect your daily life?
2. Discuss adherence – what would make you remember to take your inhalers/pills etc?
    a. What other treatments do you take? How does taking [all of these] affect you?

3. Apart from asthma, do you have any other conditions that you live with?
    a. What is it like living with asthma and …[discuss conditions participant is living with]?
    b. How do you balance looking after your asthma and [conditions]?
    c. How do you feel your conditions affect your life?
    d. How do you feel your other conditions impact your asthma? (Or the other way around?)
    e. How do you deal with your conditions? How do you adjust your daily life tasks to take into account [conditions] How do you prioritise strategies?
4. What are your thoughts on non-drug programmes for people with asthma?
    a. What issues related to your asthma would you like to address with a non-drug intervention?
    b. Would you consider taking part in a study aimed at finding additional (non-medical) ways of helping people with asthma?

        What do you think might make it likely for you to take part? Is there anything that might stop you from taking part? What problems might we encounter when trying to recruit other people?
5. Physical Activity Questionnaire – discuss results?
    a. What is stopping you from doing more physical activity?
6. Is there anything you would like to add in order to help me understand your experience better?

Debrief

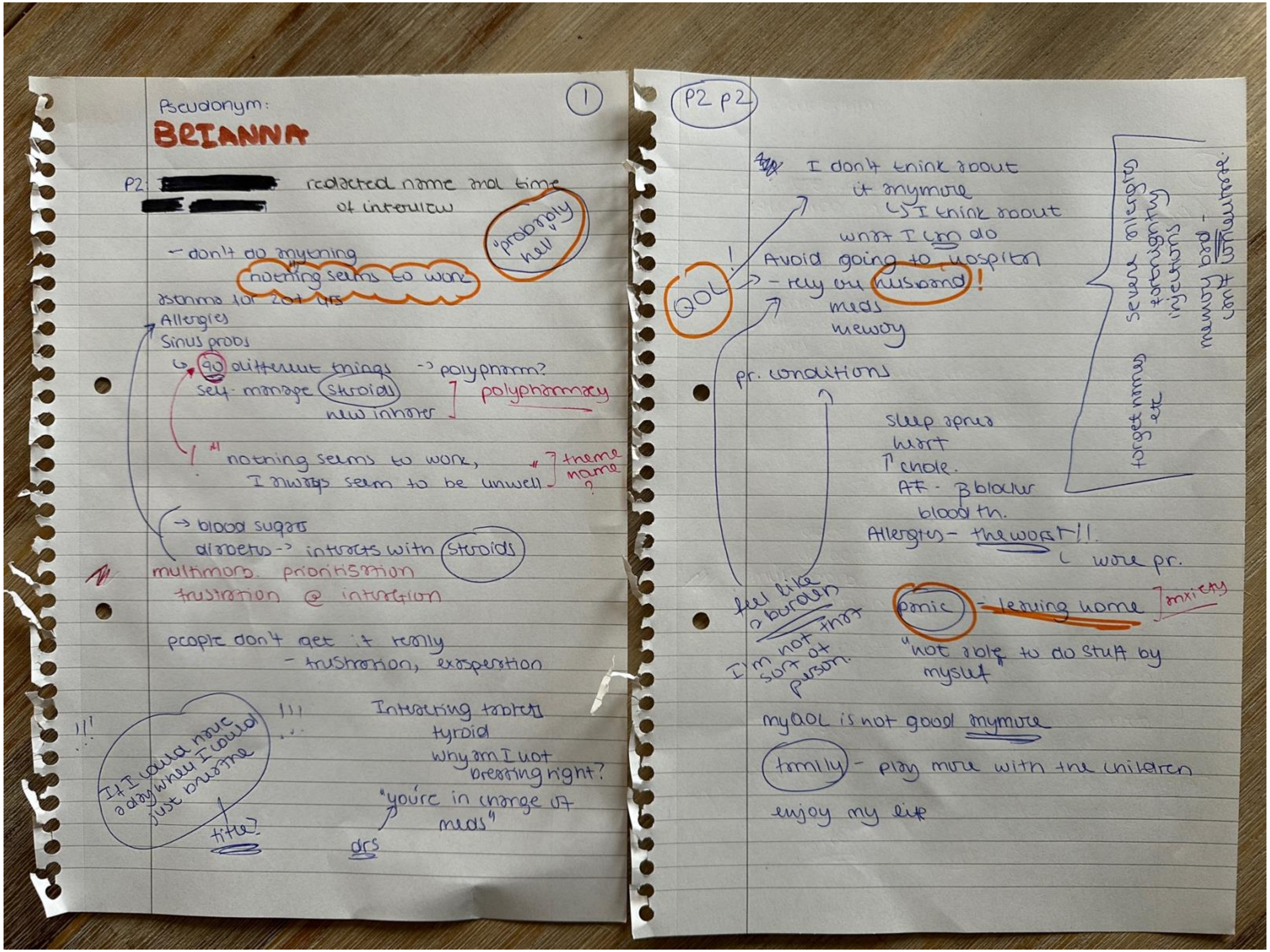
This is the end of the interview; the recorder is now switched off. Thank you very much for taking part in the study.

If you would like, we can send you a summary of the results when we have them, however this will not include any details that can identify you as an individual.

Do you have any questions? If you do remember any questions, please don't hesitate to email me!

Thank you again for taking part in the interview!

Appendix G Sample reflective diary taken during interviews for Paper 3



Pseudonym:
BRIANNA

①

P2: [redacted] redacted name and time of interview

"probably hell"

- don't do anything
"nothing seems to work"
asthma for 20+ yrs
Allergies
Sinus probs
↳ 90 different things -> polypharm?
self-manage steroids
new inhaler] polypharmacy

"nothing seems to work,
I always seem to be unwell"] theme name ?

→ blood sugar
diabetes -> interacts with steroids
multimorb. prioritisation
frustration @ interaction

people don't get it really
- frustration, exasperation

!!!

If I could have a day when I could just breathe

title?

Interesting factors
tyroid
why am I not breathing right?
"you're in charge of meds"
drs

P2 p2

I don't think about it anymore
↳ I think about what I can do

QOL !

Avoid going to hospital
- rely on husband !
meds
memory

pr. conditions

sleep apnea
heart
↑ chole.
AF - β blocker
blood th.
Allergies - the worst!!
↳ worse pr.

severe allergies
fortnightly injections
memory bad -
can't concentrate.
forget names etc

feel like a burden
I'm not that sort of person.

panic - leaving home] anxiety
"not able to do stuff by myself"

my QOL is not good anymore

family - play more with the children

enjoy my life

Appendix

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