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The interaction between asthma and anxiety:

A systematic review of cognitive-behavioural therapies and a qualitative exploration of young people's experiences.

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Doctorate in Clinical Psychology

The University of Edinburgh

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Thesis Abstract

Aims: There is a well-established link between asthma and anxiety, leading to exacerbations for both conditions. National guidelines and policy documents recommend the provision of psychological interventions for this comorbidity, although evidence for their effectiveness is inconclusive. This thesis had two objectives: a) to evaluate cognitive-behavioural therapy (CBT) interventions for reducing anxiety in adults and/or children with asthma, given that CBT has a stronger evidence base for relevant respiratory and mental health conditions, b) to explore the lived experience of the interplay between childhood asthma and anxiety directly from the affected population in order to identify specific thinking and behaviour patterns that may maintain this comorbidity.

Method: The first journal article outlined a systematic review. Three major electronic databases and manual searches were used to find relevant published and unpublished research. Trials meeting inclusion criteria, primarily utilising validated anxiety measures and employing both cognitive and behavioural techniques, were evaluated using adapted quality criteria. The second empirical article implemented interpretative phenomenological analysis (IPA) to explore the mechanisms maintaining the interplay between asthma and anxiety as experienced by 11 young people (aged 11-15) living with the comorbidity.

Results: Fourteen trials met the inclusion criteria for the systematic review. The reviewed trials showed reasonable preliminary support for the effectiveness of CBT for anxiety in individuals with asthma across the age range. The favourable results were largely maintained long-term. The empirical article revealed three super-ordinate themes: *i*) '*the influence of asthma*' by inhibiting valued activities or developmental tasks, triggering catastrophic thinking and leading to a generalisation of asthma coping strategies to managing anxiety; *ii*) '*the influence of anxiety*' by affecting appropriate medication use and triggering hyperventilation-induced asthma exacerbations; and *iii*) '*the interaction between asthma and anxiety*' by forming an unhelpful positive feedback loop and triggering symptom confusion.

Conclusions: The systematic review discussed the moderate overall study quality and called for more methodologically robust research, examining CBT models tailored to this population and utilising clinically representative samples. The empirical article pointed to possible maintaining mechanisms identified, which lend themselves to a cognitive-behavioural framework, potentially including mindfulness-based interventions, and may be used to tailor psychological treatments.

I. SYSTEMATIC REVIEW[1]

Title:

Is CBT effective in improving anxiety symptoms for adults and/or children with co-morbid asthma and anxiety?

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[1] **This systematic review was written in accordance to the guidance of the *Journal of Anxiety Disorders*** (Impact factor 2013: 3.042; SCImago Journal Rank - Clinical Psychology 17/245; see Appendix A for author instructions). Adaptations were made due to this document being submitted as part of an academic thesis portfolio. Figures, flowcharts and tables were, thus, included in the main text, rather than separately in a different file or at the end of the main text; an appendix expanding on the systematic review quality criteria was also included.

Word Count: 5948 (excl. abstract, tables, figures, references)

Abstract

There is a well-established interplay between asthma and anxiety, leading to exacerbations for both conditions. This systematic review summarised evidence regarding the effectiveness of cognitive-behavioural therapy (CBT) in reducing anxiety in adults and/or children with asthma. Fourteen trials meeting inclusion criteria, primarily utilising validated anxiety measures and employing both cognitive and behavioural techniques, were evaluated with adapted quality criteria. Reasonable preliminary support for the use of CBT for anxiety in individuals with asthma was found across the age range. The quality ratings on the treatment integrity and sample representativeness criteria determined the review outcomes. The overall study quality was moderate, calling for more methodologically robust research, examining CBT models tailored to this population and setting recruitment criteria that justify the use of anxiety interventions. Future research and guidance need to consider closely defining targeted outcomes and treatments to facilitate greater clarity regarding the usefulness of psychological interventions in asthma populations.

Keywords: anxiety, asthma, cognitive-behavioural therapy, systematic review

Abstract word count: 150

Highlights

- The effectiveness of CBT in improving anxiety in individuals with asthma was reviewed
- Available evidence was summarised and evaluated with purposefully-designed criteria
- Sampling and intervention rationale were crucial, study quality was moderate
- Preliminary evidence favoured the use of CBT for anxiety in the context of asthma
- Results were applicable across the age range and largely maintained long-term

Character count per highlight: 85

1. Introduction

Asthma is an inflammatory condition of the airways, which restricts the air passage into the lungs, resulting in wheezing, shortness of breath, coughing and chest tightness (Rees, Kannabar, & Pattani, 2006). It is the most common chronic health condition (National Institute for Health and Care Excellence [NICE], 2013), affecting more than 300 million individuals worldwide (Bateman et al., 2008). Over 5.4 million individuals suffer from asthma in the UK, one fifth of which are children (NICE, 2013). It is further estimated that one patient is hospitalised every seven minutes due to complications related to the disease (Asthma UK, 2012).

Despite medical advances, asthma remains a major contributor to morbidity and mortality (Jones et al., 2008). There is a well-established link between asthma and mental health difficulties, especially anxiety (Blackman & Gurka, 2007). A review of 12 studies reported a prevalence of 6.5 - 24% of panic disorder amongst adults with asthma (Katon, Richardson, Lozano, & McCauley 2004). In a large community study of 4181 participants, Goodwin, Jacobi, & Thefeld (2003) illustrated that severe asthma symptoms were linked with a higher risk of any anxiety disorder and a four-fold higher likelihood of panic disorder (O.R. = 4.61). Although amongst adults with asthma, panic disorder seems to be the most prevalent mental health comorbidity (Hasler et al., 2005), children with asthma have substantially higher risk to develop any anxiety disorder, including separation anxiety, specific phobia, panic and generalised anxiety disorder (Gupta, Mitchell, Giuffre, & Crawford, 2001; Ortega, Huertas, , Ramirez, & Rubio-Stipec, 2002).

Despite indicating anxiety as asthma's most common psychological complication, many of the above prevalence studies are limited by recruitment from specialised respiratory clinics. This may overemphasize 'difficult to treat' asthma and its implications, whilst some studies

are further restricted by relying on secondary measures of asthma and self-reported symptoms of anxiety (Lehrer, Feldman, Giardino, Song, & Schmaling 2002). The relationship between asthma and anxiety, however, may not be surprising given the key role of breathing function in anxiety (Carr, 1998); although other factors are also important in this comorbidity.

To be more specific, asthma attacks are particularly aversive, which can reinforce anticipatory anxiety or avoidance (Carr, 1998), increase health-related fear and hypervigilance regarding threatening bodily symptoms (Feldman, Siddique, Thompson, & Lehrer, 2005; Lehrer et al., 2008). Such factors have all been identified by predominant psychological models to maintain health anxiety and panic (Clark, 1986; Warwick & Salkovskis, 1990). Individuals with asthma and anxiety, in turn, tend to overperceive symptoms of asthma and overreact during asthma episodes (De Peuter, Lemaigre, van Diest, & van den Bergh, 2008; Main, Moss-Morris, Booth, Kaptein, & Kolbe, 2003). Studies including adult samples have confirmed that anxiety predicts overuse of reliever medication and increased healthcare use, independently of objective pulmonary function (De Peuter et al., 2005; Feldman et al., 2005; Feldman, Siddique, Thompson, & Lehrer, 2009). This results in an over-prescription response from medical staff (Fernandes et al., 2010) and in enormous costs for the NHS due to unnecessary hospital admissions and primary care use (Hutter, Knecht, & Baumeister, 2011; Jones et al., 2008).

Identifying and treating anxiety in the context of asthma and other respiratory conditions is thus of crucial importance. Strategic planning and policy documents in the UK (Department of Health [DoH], 2011; 2014; Scottish Government, 2012) and SIGN guidelines (Scottish Intercollegiate Guidelines Network, 2012a) recommend the provision of psychological interventions for individuals with asthma experiencing complications related to anxiety. It is also, however, recognised within such reports that the evidence regarding the potential

usefulness of psychological interventions in this context is unclear (SIGN, 2012a).

Only a few reviews have examined the effectiveness of psychological interventions in improving anxiety in individuals with asthma. For example, Lehrer, Sargunaraj and Hochron (1992) conducted a narrative review on the effectiveness of psychological therapies (biofeedback, family therapy, relaxation) in improving psychological and asthma outcomes in this context, but have not examined the effect on anxiety. Devine (1996) and Smith and colleagues (2005) reviewed the usefulness of psycho-educational input alone in improving psychological morbidity for adults and children with asthma, but found limited positive results for anxiety.

More recently, two Cochrane reviews focusing on adults and children respectively (Yorke, Fleming, & Shuldham, 2009a; 2009b) examined the effectiveness of psychological interventions primarily in improving asthma outcomes, e.g., medication or healthcare use, and secondarily in improving psychological functioning, including anxiety. They concluded that no sufficient evidence exists for the role of psychological treatments in asthma populations (Yorke et al., 2009a; 2009b). It is possible that the reviews were inconclusive because of the wide variation of the interventions examined, including biofeedback, hypnosis, psycho-education, imaginal and muscle relaxation, or cognitive-behavioural therapy (Yorke et al., 2009a; 2009b). Evaluating psychological interventions as a cohesive single construct may result in potentially missing therapeutic components or modalities that are critical for improving effectiveness.

The majority of published psychological trials in the context of asthma are designed to enhance asthma care and thus aim to support patients manage breathlessness/hyperventilation though relaxation and breathing retraining exercises (Freitas et al., 2013; Huntley, White, & Ernst, 2002). Reviews on the usefulness of such interventions conclude that outcomes are

contradictory (Freitas et al., 2013; Huntley et al., 2002). Some studies show improvements in psychosocial functioning alone (Chiang, Ma, Huang, Tseng, & Hsueh, 2009), some report a reduction in medication use and an improvement in asthma management (Opat, Cohen, Bailey, & Abramson, 2000; Thomas et al., 2003), while others report no significant contribution of relaxation to asthma management altogether (Lehrer et al., 1994). Methodological differences between the above trials may partially account for the contradictory findings, although the inconclusive outcomes may also be linked to the prescriptive inclusion of psychological techniques without a clear theoretical framework.

Frequently, psychological interventions for asthma solely focus on improving the physiological symptoms of anxiety through relaxation and breathing techniques. Respectively, other available treatment protocols may solely focus on improving some cognitive aspects of the comorbidity, targeting health worries and aiming to change asthma illness perceptions (Kaptein, Klok, Moss-Morris, & Brand, 2010). Anxiety, however, is determined by an interaction of cognitive, emotional, physiological and behavioural factors (Seligman, Walker, & Rosenhan, 2001) and all need to be addressed in a comprehensive model in order to improve long-term outcomes.

Cognitive-behavioural therapies (CBT) appear suitable in this respect and a significant body of evidence supports their effectiveness in improving anxiety in individuals without a medical comorbidity (NICE, 2011; Scottish Government, 2011). There is also empirical support for the use of CBT in reducing anxiety within other chronic respiratory conditions, such as chronic obstructive pulmonary disease (Livermore, Sharpe, & McKenzie, 2010).

No review to date has been published examining the effectiveness of CBT alone for anxiety in individuals with asthma. Most studies included in the relevant Cochrane reviews (Yorke et al., 2009a; 2009b) involved broadly defined psychological techniques, such as biofeedback or

relaxation, to address the physiological symptoms of anxiety, without targeting other aspects of the phenomenology of anxiety and the factors that psychological research has identified to maintain it (e.g., cognitive or emotional factors or safety-seeking behaviours) (Seligman et al., 2001). Only three CBT trials met standards for inclusion in the relevant Cochrane review on adults and two on children (Yorke et al., 2009a; 2009b), with some positive outcomes, but not enough to evidence the effectiveness of this treatment mode for anxiety. These reviews did not include other study designs, such as non-randomised, quasi experimental studies, although given the limited number of good quality randomised controlled trials (RCTs) in this field, the inclusion of other study designs would help address whether CBT is effective with anxiety in asthma populations.

1.1. Aim

The present review aims to systematically evaluate available evidence regarding the effectiveness of cognitive-behavioural interventions alone in reducing anxiety in adults and/or children and adolescents with asthma.

2. Method

2.1. Search strategy

The systematic search was conducted in July 2014. Initially, the Cochrane database was searched to explore relevant systematic reviews in the field and ensure that no similar review was recently undertaken. Subsequently, the following databases were searched: Ovid Medline (1946-2014), PsychInfo (1806-2014) and Embase (1974-2014). The terms used to search for keywords in all fields included: CBT or cognit* therap* or behav* therap* or cognitive-behav* therap* or problem-solving therap* and anx* and asthma* (where *allowed the inclusion of variations in spellings and word endings). The search was focussed on work

published in English due to limited resources for translation.

Further to the initial search method, manual searches were also undertaken to reduce potential limitations associated with the selection of these keywords. All papers referenced in the originally identified studies and the relevant Cochrane reviews (Yorke et al., 2009a; 2009b) were examined. Moreover, subsequent publications which cited the included studies, as they appear in the Google Scholar search engine, were also screened. Key journals in the field were further searched, including the Journal of Anxiety Disorders, Psychosomatic Medicine, European Respiratory Journal and Respiratory Medicine. To address publication bias web searches and searches in citations of included papers for unpublished documents, conference presentations and dissertations were also conducted. Key authors (e.g., Lehrer, Grover) were contacted for suggesting relevant work.

2.2. Inclusion and exclusion criteria

Guidance from the Centre for Reviews and Dissemination (CRD, 2009) and the PRISMA statement (Liberati et al., 2009) was followed to conduct and report the current review. The inclusion and exclusion criteria were thus determined based on the 'PICOS' approach: population, interventions, comparators, outcomes and study design (CRD, 2009).

2.2.1. Population

Included studies had participants with a diagnosis of asthma. No limitations were set on the severity of asthma symptomatology or on the diagnostic method/criteria. All types and levels of severity of anxiety symptomatology at baseline were included. Larger scale studies involving populations with other chronic medical/respiratory/mental health conditions were eligible, if results for asthma and anxiety were presented separately. No age, gender or other limitations on the included population were stipulated.

2.2.2. Intervention

Included studies examined CBT interventions that involved both cognitive and behavioural components as outlined by Butler and colleagues in their review of the empirical status of CBT (Butler, Chapman, Forman, & Beck 2005). Therefore, studies examining the effectiveness of behavioural only interventions, e.g. progressive muscle relaxation, were not eligible for this review. Anxiety improvement was a primary or secondary treatment goal in all studies. All intervention formats were eligible (e.g. individual and group treatment protocols, computerised or self-help interventions). No exclusions were set based on the level of therapist input, length or number of sessions. Studies providing additional input to significant others (parents or partners) were also eligible.

2.2.3. Outcome

Studies were eligible only if severity of anxiety symptomatology was assessed at baseline and at post-treatment using a standardised measure (validated observation, interview protocol or self-report tool).

2.2.4. Study design and comparators

Despite the generally higher quality of empirical support provided by randomised controlled trials (Sibbald & Ronald, 1998), other study designs were also eligible due to the restricted number of high quality RCTs in this field. Thus, non-randomised controlled trials and observational repeated-measures designs without controls were also included. Case studies were excluded due to the presence of a sufficient number of studies meeting higher quality standards. No specifications were set for the comparative conditions eligible for inclusion, e.g., treatment as usual, wait-list, placebo controls.

2.3. Quality criteria

The methodological quality of the eligible studies was assessed using quality criteria developed for the purposes of this review (Table 1; see Appendix B for an operationalisation of the criteria). Existing quality criteria were reviewed but appeared unsuitable for the aims of the current review, mainly due to the methodological variation between the eligible studies, including non-randomised controlled trials or observational studies. In addition, the idiosyncrasies of the treatment protocols and participants' clinical characteristics required specifically designed criteria to address them. The absence of power calculations in the majority of the studies also suggested the need to calculate this as part of the quality criteria, especially after determining a realistic effect size and evaluating each study based on this.

Several authors suggest that available quality criteria may need to be adjusted to ensure that they address the requirements of specific review questions (Coull & Morris, 2011; Mayo-Wilson & Montgomery, 2007). Major and internationally recognised guidelines, however, were closely consulted to develop the present quality criteria to meet the aims of this systematic review: the SIGN 50 Checklist for RCTs (SIGN, 2012b), the Consolidated standards of reporting trials (Schulz, Altman & Moher, 2010) and guidance from the Centre for Reviews and Dissemination (2009).

SIGN guidance (2012b) was followed for the ratings of each quality criterion: well covered (3 points), adequately addressed (2), poorly addressed (1) and not addressed (0). The highest possible score was 36. Guidance on conducting and reporting systematic reviews (Liberati et al., 2009) suggests that summarising outcomes on multiple criteria in a single arithmetic value alone can be misleading, especially as the criteria are not truly equally weighted. Thus, the overall rating was also given with a quality classification of ++, + or - (SIGN, 2012b), based on whether the overall rating ranged above the 75% (27-36), above 50% (18-26) or

below 50% (0-17) of the highest possible rating.

Table 1. Quality Criteria used to rate Reviewed Studies

	Quality criteria
1.	Study design provides sufficient evidence that the anxiety outcomes are due to the intervention
2.	Recruitment method and inclusion criteria are appropriate to ensure a representative and suitable sample
3.	Sample size (power) is sufficient for analysis relating to pre and post anxiety outcomes
4.	Allocation process is appropriate to address allocation bias
5.	Groups are comparable at baseline on key variables (i.e., asthma or anxiety severity, age, gender)
6.	Measures of anxiety are robust, appropriately administered and well-validated
7.	Follow-up measures are administered to evaluate if effects are maintained long-term
8.	Treatment protocol is suitable for improving anxiety outcomes in the context of asthma
9.	Intervention is appropriately conducted and adherence to protocol is suitably assessed
10.	Analysis is appropriate for the study aims, measures or design and outcomes are appropriately reported
11.	Attrition rates are low or comparable to control group
12.	Method to address missing data is suitable

3. Results

3.1. Study inclusion

The electronic database search method yielded 1681 results. Duplicates were removed and the remaining papers were screened against the eligibility criteria. Figure 1 presents a flowchart of the search pathway, its outcomes and the reasons for exclusion of reviewed studies. One paper was irretrievable (Grover, Kumaraiah, Prasadrao, & D'Souza 2002), despite library requests and contacting the author. Manual search produced two more results. A total of 13 papers were identified to meet all the inclusion criteria for this review. One paper described two different trials, each one of which independently met the eligibility criteria; hence, a total of 14 studies were included.

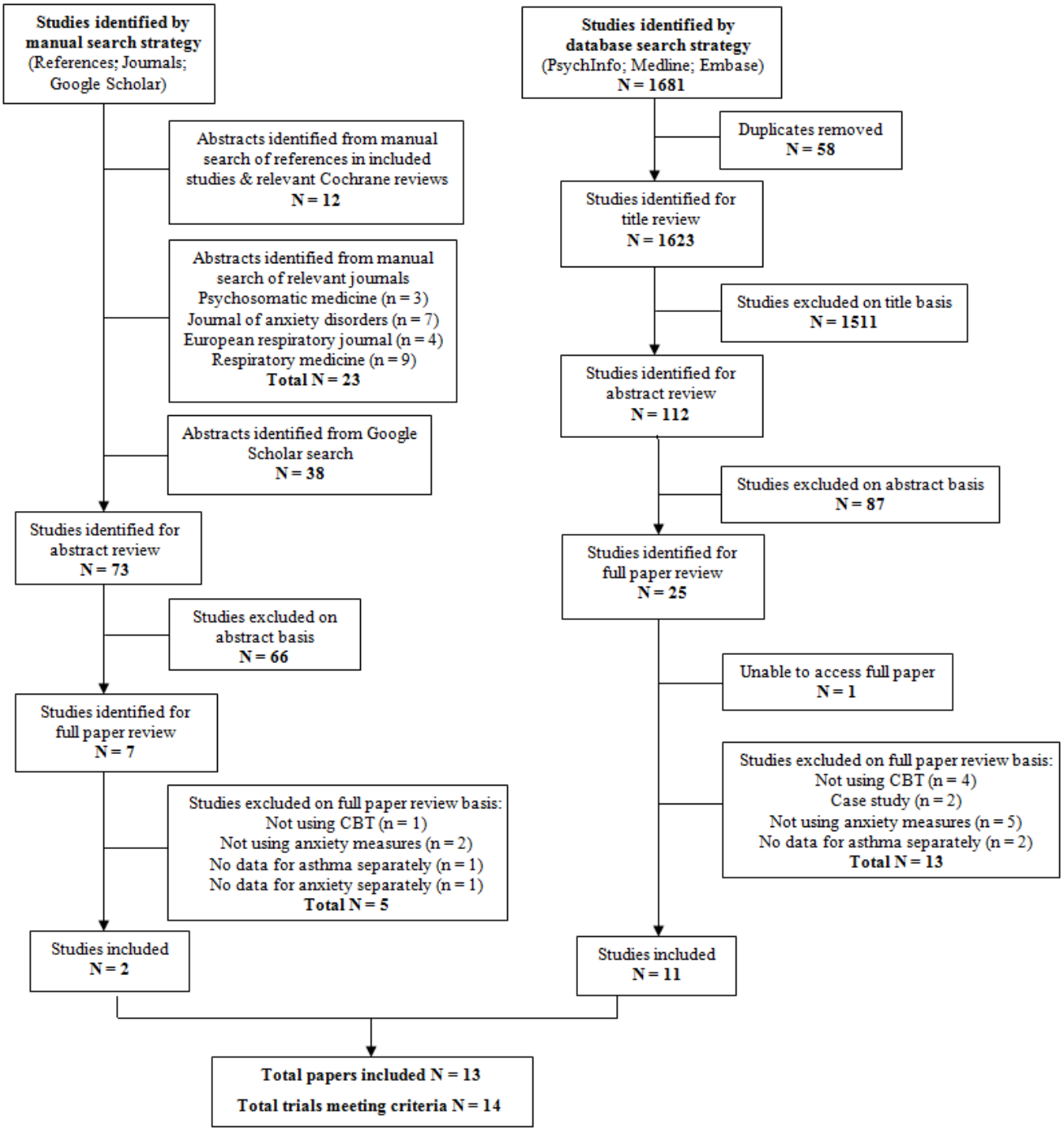

Figure 1. Flowchart of search strategy pathway and results

3.2. Quality assessment

All studies were rated based on the quality criteria purposefully developed for this review (Table 3). The second author independently evaluated the quality of a randomly selected third

(*n* = 5) of included studies using a randomised sequence generated by random.org. This yielded an agreement on 50/60 ratings (83.3%). Disagreement of more than one point was found in four ratings, with these discrepancies being discussed between both raters, and the criteria amended as necessary to increase clarity and consistency.

3.3. General characteristics of the studies

A summary of key characteristics of the studies included in this review is provided in Table 2. Ten studies recruited adult participants (aged 18 years or above) and these were presented and analysed separately from the four studies recruiting children and adolescents, as the treatment components are frequently different or adjusted for these age groups (Sauter, Heyne, & Westenberg, 2009). Overall, the study quality was moderate with significant variation amongst included trials. To answer the review question there were several aspects of the trials that were pertinent: the study design, the sample power and representativeness, the suitability of the intervention and the outcome measures used.

3.4. Adults

3.4.1. Study design

Of the 10 trials involving adult participants, six were RCTs, one was a non-randomised controlled trial and three uncontrolled repeated-measures designs (Table 2). Three of the RCTs were allocated the highest rating (++) (Campbell-Sills et al., 2013; Parry et al., 2012; Ross, Davis, & MacDonalds, 2005), with the rest of the controlled trials allocated the next highest rating (+) (Sommaruga et al., 1995; Put et al., 2003; and Maes & Schloser, 1988). Even amongst highly rated studies, there were poor ratings in specific quality criteria indicating some methodological limitation in relation to the current review question (Table 3).

Table 2. Characteristics and key findings of included studies

Study Reference	Design	Intervention description	Control condition	Treatment group	Control group	Anxiety outcome measures	Follow-up	Anxiety-specific key findings	Pre-post intervention effect sizes[a]	Limitations	Quality rating
Adults											
Parry et al. (2012) UK	RCT	CBT for asthma-specific fear 5-9 individual sessions with a clinical psychologist or a CBT therapist Treatment fidelity assessed through peer supervision & recordings of sessions	standard care	*n* = 50 Mean age = 47 Female = 61% severe asthma = 39%	*n* = 44 Mean age = 43.8 Female = 65% severe asthma = 38%	Anxiety subscale - ASC Anxiety subscale - HADS	6 months	A significantly greater improvement in asthma-specific anxiety was found for the CBT group as compared to controls at post-treatment, which increased at 6-months. No statistically significant differences between groups were found for the general anxiety levels (HADS).	ASC - anxiety *d* = 0.32	High drop-out in CBT group. 22% of the CBT group were still in the clinical range for asthma-specific fear at post-treatment	++ 32/36
Campbell-Sills et al. (2013) USA	RCT (part of larger scale trial)	Computerised CBT Minimum 10-12 individual sessions & minimum 1 intervention contact with an anxiety specialist	standard care	Not reported Total asthma participants in both groups *N* = 207	Not reported Total asthma participants in both groups *N* = 207	Anxiety subscale - BSI	6, 12, 18 months	Significant improvements on anxiety symptoms were found in both groups over time. There were no statistically significant differences on anxiety between groups.	BSI – anxiety *d* ≈ 0.70	No descriptive, demographic & clinical data reported between groups No reported therapist training & experience	++ 28/36
Ross et al. (2005) Canada	RCT	Asthma education & CBT for panic 12 group sessions with doctoral nurses Session-by-session protocol & treatment fidelity assessed by rating videotapes in relation to protocol checklists	wait-list delayed treatment	*n* = 15 Mean age = 37 Female = 100% self-rated asthma severity (1-10) Mean = 6.80	*n* = 10 Mean age = 40 Female = 100% self-rated asthma severity (1-10) Mean =3.89	SPRAS ASI Panic attack diary Agoraphobia subscale - FQ	6 months	Statistically greater improvements were found in panic frequency, general anxiety & anxiety sensitivity for the CBT group as compared to controls. Only the panic frequency results were maintained at 6-months. There was no difference between groups in agoraphobic avoidance.	SPRAS *d* = 1.86 ASI *d* = 1.43 FQ – agoraph. *d* = 0.52	Small sample size Sampling limited on women	++ 27/36
Sommaruga et al. (1995) Italy	RCT	Asthma education & CBT 3-6 individual CBT sessions with a psychologist	standard care	*n* = 20 Mean age = 44 Female = 45% asthma severity: inpatients	*n* = 20 Mean age = 51 Female = 55% asthma severity: inpatients	Anxiety subscale - ASC STAI - CBA 2.0 QPF – CBA 2.0	12 months	The CBT group showed statistically significant improvements in anxiety & psycho-physiological symptoms at 12 months, which were higher in comparison to the control group.	STAI trait anxiety *d* = 0.67 QPF *d* = 0.38	Convenience sampling No reported assessment of treatment fidelity Unclear therapist experience	+ 24/36

Study Reference	Design	Intervention description	Control condition	Treatment group	Control group	Anxiety outcome measures	Follow-up	Anxiety-specific key findings	Pre-post intervention effect sizes[a]	Limitations	Quality rating
Put et al. (2003) Belgium	RCT	Asthma-specific CBT facilitated by a workbook 6 individual sessions with psychology researchers	wait-list	*n* = 12 Mean age = 43 Female = 42% mild -moderate asthma	*n* = 11 Mean age = 48 Female = 62% mild - moderate asthma	Anxiety subscale - ASC	3 months	No statistically significant differences on the ASC anxiety subscale within the intervention group at post-treatment & follow-up and between groups.	ASC – anxiety *d* = 0.42	Small sample size No reported assessment of treatment fidelity Unclear therapist experience	+ 23/36
Hockemeyer & Smyth (2002) USA	RCT	Four weeks of self-help CBT with audio-taped relaxation tasks & 20min exercises writing about stressful events No therapist input	placebo self-help workbook	*n* = 27 Mean age = 21.7 Female = 56% self-rated health (0-6) Mean = 4.48	*n* = 27 Mean age = 19.67 Female = 52% self-rated health (0-6) Mean = 4.63	PSS	none	No statistically significant differences in PSS levels were found over time or between groups.	PSS *d* = 0.46	Convenience sampling PSS assessed stress levels over treatment period No therapist input No follow-up	+ 18/36
Maes & Schloser (1988) Netherlands	Controlled trial	Asthma education & CBT 8 weekly, 2-3h group sessions with patients & partners, facilitated by a health psychologist & other health professionals.	standard care	*n* = 10 no other information reported	*n* = 9 no other information reported	STAI	none	A statistically greater improvement in general anxiety was found for the CBT group as compared to controls, but not in state anxiety during an asthma attack.	STAI state anxiety *d* = 0.38 STAI trait anxiety *d* = 1.33	Small sample size Convenience sampling Participants not randomised in groups No follow-up or assessment of fidelity	+ 18/36
Lehrer et al. (2008) (study b) USA	Repeated measures design	Asthma education & CBT for panic 8 group sessions Session-by-session protocol	none	*n* = 12 Mean age = 31 Female = 67% moderate asthma	none	PDSS ASI ACQ BSQ BAI	1 & 2 months	Significant decreases were found on panic & general anxiety scores at post-treatment & follow-ups. PDSS effect sizes were large at post-treatment & follow-up, but in BAI were small to medium at post-treatment & follow-up.	PDSS *d* = 1.16 ASI *d* = 0.68 BAI *d* = 0.48 BSQ *d* = 0.60	Small sample size No control condition No reported assessment of treatment fidelity No reported therapist training & experience	- 16/36
Lehrer et al. (2008) (study a) USA	Repeated measures design	Asthma education & CBT for panic 14 group sessions Session-by-session protocol	none	*n* = 10 Mean age = 44.1 Female = 60% mild asthma	none	PDSS ASI ACQ BSQ BAI	1 & 2 months	Significant decreases were found on panic & general anxiety scores at post-treatment & follow-ups. PDSS and BAI effect sizes remained large at post-treatment & follow-up	PDSS *d* = 1.01 ASI *d* = 0.19 BAI *d* = 1.21 BSQ *d* = 0.72	Small sample size No control condition High drop-out (50%) No reported assessment of treatment fidelity No reported therapist training & experience	- 15/36
Spurgeon et al. (2005) UK	Repeated measures design (part of larger scale trial)	CBT focused on health perceptions & reactions 8 group sessions with qualified counsellors	none	*n* = 29 Mean age = 51.8 Female = 64% asthma severity not reported	none	Anxiety subscale - HADS	6 months	A statistically significant improvement in anxiety was found at post-treatment & 6-month follow-up.	HADS-anxiety *d* = 1.30	HADS not administered to control group available in study No reported assessment of treatment fidelity	- 14/36

Study Reference	Design	Intervention description	Control condition	Treatment group	Control group	Anxiety outcome measures	Follow-up	Anxiety-specific key findings	Pre-post intervention effect sizes[a]	Limitations	Quality rating
Children & Young People											
Colland (1993) Netherlands	RCT	Self-management asthma training & CBT with homework assisted by parents 10 group sessions with a behaviour therapist & a group psychotherapist	control group a: 1 information session control group b: no therapy	*n* = 48 Mean age = 10 Female = 39%	n_a = 34 n_b = 30 Mean age = $_{a\ \&\ b}$ 10 Females $_{a\ \&\ b}$=38.9%	STAI-children	1, 6, 12 months	Significantly greater reductions in general & asthma-specific anxiety were found at post-treatment in the CBT group versus controls. Only the difference on the asthma-specific anxiety remained significant at 6-month.	STAI *d* = 0.52	No reported assessment of treatment fidelity	++ 29/36
Papneja & Manassis (2006) Canada	Controlled trial (data from larger scale trial)	CBT for anxiety 12 group or individual sessions with psychiatrists or psychologists (potential parental involvement) Session-by-session protocol, audio-taped sessions independently rated for adherence	CBT for matched group without asthma	*n* = 36 8-12 years Asthma severity not reported Gender not reported	*n* = 36 8-12 years No history of asthma Gender not reported	RCMAS	none	A statistically significant reduction in anxiety was found in both groups at post treatment. A trend (not statistically significant) towards less improvement in total anxiety was found for children with asthma as compared to children without asthma. Physiological anxiety increased for the asthma group compared to the group without asthma.	RCMAS *d* ≈ 0.14	No follow-up measures No reported results separately for group or individual sessions Treatment not adjusted for asthma	++ 29/36
Long et al. (2011) USA	Repeated measures design (two combined trials)	Asthma education & CBT with physiological feedback & relaxation 6 individual sessions with graduate CBT therapists, MSc clinicians & research assistants Session-by-session protocol & weekly supervision	none	*n* = 22 (trial 1 *n*=14 trial 2 *n*=8) 7-12 years Female = 36% mild-moderate persistent asthma	none	PSS STAI-children Anxious mood - POMS	none	Statistically significant improvements were found in PSS & anxious mood at post-treatment, but not for the state-trait anxiety measure.	PSS *d* = 1.65 POMS - anxiety *d* = 0.59 STAI trait anxiety *d* = 0.40 STAI state anxiety *d* = 0.004	No follow-up measures No control condition Limited therapist clinical experience	- 17/36
Marriage & Henderson (2012) UK	Repeated measures design	Asthma education & CBT with mindfulness 6 group sessions with a respiratory nurse specialist trained in behavioural techniques	none	*n* = 17 Mean age = 14.2 Female = 50% mild-severe asthma	none	SCAS	3 & 6 months	A reduction of up to 30% on anxiety scores was found at post-treatment and at 6 months.	cannot be estimated	Descriptive statistics only High dropout, not addressed in analysis Convenience sample No reported assessment of treatment fidelity	- 14/36

Abbreviations: BSI: Brief Symptom Inventory; PSS: Perceived Stress Scale; PDSS: Panic disorder severity Scale; ASI: Anxiety Sensitivity Index; ACQ: Agoraphobic Cognitions Questionnaire; BSQ: Body Sensations Questionnaire; BAI: Beck Anxiety Inventory; STAI: State Trait Anxiety Inventory; ASC: Asthma Symptom Checklist; HADS: Hospital Anxiety & Depression Scale; FQ: Fear questionnaire; SPRAS: Sheehan Patient-Rated Anxiety Scale; CBA: Cognitive Behavioural Assessment Batteries; QPF: Psycho-physiological symptoms; POMS: Profile of mood states; SCAS: Spence Children's' Anxiety Scale; RCMAS: Revised Children's Manifest Anxiety Scale.

[a]Cohen (1988) suggested interpreting effect sizes as small *d* = .2, medium *d* = .5, and large *d* = .8.

Table 3. Quality ratings of methodological ability to address review question

		Sample representativeness		Allocation bias		Data collection		Treatment integrity			Attrition		
Authors	**Study design**	**Recruitment & inclusion criteria**	**Sample size / power**	**Allocation process**	**Groups similar at baseline**	**Robust measures**	**Follow-up measures**	**Suitable protocol**	**Treatment adherence**	**Appropriate analysis**	**Attrition rates low & comparable**	**Method to address missing data**	**Overall rating**
Adults													
Parry et al. (2012)	well covered	well covered	poorly addressed	well covered	well covered	well covered	adequately addressed	well covered	well covered	well covered	adequately addressed	well covered	++ 32/36
Campbell-Sills et al. (2013)	well covered	adequately addressed	well covered	well covered	poorly addressed	well covered	well covered	poorly addressed	adequately addressed	poorly addressed	well covered	well covered	++ 28/36
Ross et al. (2005)	well covered	well covered	poorly addressed	adequately addressed	adequately addressed	adequately addressed	adequately addressed	well covered	well covered	well covered	adequately addressed	poorly addressed	++ 27/36
Sommaruga et al. (1995)	well covered	poorly addressed	poorly addressed	adequately addressed	adequately addressed	adequately addressed	well covered	adequately addressed	not addressed	adequately addressed	well covered	well covered	+ 24/36
Put et al. (2003)	well covered	adequately addressed	poorly addressed	adequately addressed	adequately addressed	well covered	poorly addressed	poorly addressed	not addressed	well covered	well covered	adequately addressed	+ 23/36
Hockemeyer & Smyth (2002)	well covered	poorly addressed	adequately addressed	adequately addressed	well covered	not addressed	not addressed	poorly addressed	not addressed	poorly addressed	well covered	adequately addressed	+ 18/36
Maes & Schloser (1988)	adequately addressed	poorly addressed	poorly addressed	poorly addressed	adequately addressed	well covered	not addressed	adequately addressed	not addressed	well covered	not addressed	well covered	+ 18/36
Lehrer et al. (2008) b	poorly addressed	well covered	poorly addressed	not addressed	not addressed	well covered	poorly addressed	well covered	not addressed	well covered	poorly addressed	not addressed	- 16/36
Lehrer et al. (2008) a	poorly addressed	well covered	poorly addressed	not addressed	not addressed	well covered	poorly addressed	well covered	not addressed	adequately addressed	poorly addressed	not addressed	- 15/36
Spurgeon et al. (2005)	poorly addressed	poorly addressed	adequately addressed	not addressed	not addressed	well covered	adequately addressed	poorly addressed	not addressed	well covered	not addressed	poorly addressed	- 14/36
Children & Young People													
Colland (1993)	well covered	adequately addressed	well covered	adequately addressed	well covered	well covered	well covered	poorly addressed	not addressed	well covered	well covered	well covered	++ 29/36
Papneja & Manassis (2006)	adequately addressed	well covered	well covered	poorly addressed	well covered	well covered	not addressed	well covered	well covered	well covered	well covered	adequately addressed	++ 29/36
Long et al. (2011)	poorly addressed	poorly addressed	poorly addressed	not addressed	not addressed	well covered	not addressed	adequately addressed	adequately addressed	well covered	well covered	poorly addressed	- 17/36
Marriage & Henderson (2012)	poorly addressed	adequately addressed	poorly addressed	not addressed	not addressed	well covered	adequately addressed	well covered	not addressed	not addressed	poorly addressed	poorly addressed	- 14/36

3.4.2. Sample representativeness and power

Of the trials that reported descriptive statistics (Table 2), the mean age of participants ranged between 21.7 and 51.8 years. Sample sizes were generally low and for the intervention condition ranged between 10 and 50 participants. Attrition rates for the intervention groups were moderate overall (≤40%), but ranged between 0%-50%.

The majority of the trials (n = 9) adopted suitable analyses to examine effect over time and differences between conditions, but had not outlined a power calculation (n = 7). The first author computed a post-hoc power analysis for the pre-post results of the intervention group of each trial (for reasons of consistency across studies) using the G*power programme and estimating effect size to be medium (d = 0.5 for t-test; f = 0.25 for ANOVA) and alpha 0.05. Most of the reviewed studies (n = 9) achieved power of less than 0.8. Campbell-Sills and colleagues (2013) were rated higher in terms of sample power for their analysis. The sample representativeness in this study, however, was only adequately rated due not examining asthma severity and not excluding mental health co-morbidities.

Recruitment methods and eligibility criteria varied substantially between the reviewed studies. Two studies used convenience samples of inpatients admitted in a single department at the time of the study (Sommaruga et al., 1995), or volunteer college students who were telephone screened for asthma (Hockemeyer & Smyth, 2002), without applying any other specific criteria that would allow to generalise conclusions based on their outcomes. The remaining studies were based on representative respiratory populations recruited by multiple specialist services, chronic disease registers, or primary care services, who had a physician-confirmed asthma diagnosis. However, out of these eight trials, only five recruited participants, who were also screened for the presence of anxiety symptomatology (Campbell-Sills et al., 2013; Lehrer et al., 2008a; 2008b; Parry et al., 2012; Ross et al., 2005) using

validated methods and who would benefit from an anxiety psychological intervention. These were rated higher on sample representativeness. Maes and Schloser (1988) recruited participants that were asthma medication over-users and thus potentially suitable for anxiety management input, if over-use was triggered by anxiety (Feldman et al., 2009), although this was not examined.

3.4.3. Outcome measures

Hockemeyer and Smyth (2002) used a robust measure for anxiety, but it was rated poorly as the post-evaluation instructions referred to the treatment period - rather than the post-treatment period, during which anxiety would be expected to be similar to baseline or even elevated. All other studies used at least one well-validated and reliable anxiety measure and administered it appropriately. Four trials included the HADS (Zigmond & Snaith, 1983) and/or the anxiety subscale of the ASC (Kinsman, Luparello, O'Banion, & Spector, 1973), which are arguably particularly well-suited to measuring psychological functioning in the context of chronic respiratory conditions. Most studies (n = 8) followed outcomes long term.

3.4.4. Interventions

Five interventions were delivered in a group and three in an individual format (Table 2), offering from 3 to 14 therapist sessions. Two studies offered a minimum number of either one (Campbell-Sills et al., 2013) or no therapist sessions (Hockemeyer & Smyth, 2002). Significant variation existed between the background training and clinical experience of therapists, which was only reported in six of the trials. This ranged from clinical or health psychologists and CBT therapists (Maes & Schloser, 1988; Parry et al., 2012) to doctoral nurses (Ross et al., 2005), psychologists and psychology researchers (Put et al., 2003; Sommaruga et al., 1995) or counsellors (Spurgeon et al., 2005). Examination of adherence to treatment protocol was sufficiently addressed only by Parry and colleagues (2012) and Ross

and colleagues (2005).

Six of the interventions were designed to reduce anxiety as one of their primary aims (Campbell-Sills et al., 2013; Lehrer et al., 2008a; 2008b; Parry et al., 2012; Ross et al., 2005; Sommaruga et al., 1995). Three of the included trials provided minimum or no asthma-related education (Campbell-Sills et al., 2013; Hockemeyer & Smyth, 2002; Spurgeon et al., 2005). Two of the trials were rated lower regarding the suitability of the protocol for improving anxiety outcomes, as they mainly focused on improving asthma knowledge or management and addressing asthma health perceptions (Put et al., 2003; Spurgeon et al., 2005). Of the 10 trials, four were highly rated regarding the level of CBT input provided and the suitability of the protocol in improving anxiety (Lehrer et al., 2008a; 2008b; Parry et al., 2012; Ross et al., 2005), and two were only adequately rated for offering brief or low intensity CBT input for anxiety complicated by asthma (Campbell-Sills et al., 2013; Sommaruga et al., 1995).

3.4.5. Key findings

Seven out of 10 trials included in this review reported favourable results for the CBT intervention in terms of reducing anxiety (Lehrer et al., 2008a; 2008b; Maes & Schloser, 1988; Parry et al., 2012; Ross et al., 2005; Sommaruga et al., 1995; Spurgeon et al., 2005), with these benefits largely maintained at follow-up.

Of the three studies whose overall methodology was best suited to address the review question, two found that CBT reduced anxiety relative to controls (Parry et al., 2012; Ross et al., 2005), whereas Campbell-Sills and colleagues (2013) found no significant differences between treatment as usual and computer-assisted CBT. This difference may be due to the lack of asthma-related input in their intervention or the lower intensity of the computerised CBT provided, which may have been insufficient to enable improvements for anxiety complicated by asthma; especially as mental health comorbidity was not excluded in this

study. In addition, the treatment groups' demographic data and baseline clinical characteristics in this study were not reported (Campbell-Sills et al., 2013), thus hindering the evaluation of potential bias in allocation between trial arms, which may also explain this outcome.

Intervention integrity was also a significant limitation in the additional two studies, which reported no favourable results for CBT for anxiety (Hockemeyer & Smyth, 2002; Put et al., 2003). Put and colleagues (2003) only aimed to improve anxiety as a secondary goal, such that their protocol was primarily focused on using CBT to change illness-specific perceptions (self-monitoring for asthma-related stimuli, modifying irrational cognitions about asthma and asthma therapy). This protocol may not be expected to change generalised anxiety or panic disorder outcomes, which are the most frequent anxiety co-morbidities in the context asthma (Goodwin et al., 2003). Hockemeyer and Smyth (2002), focused on improving anxiety outcomes, but provided a low intensity 4-week workbook intervention without therapist input, which may be less sufficient for managing anxiety complicated by asthma. Perhaps, more importantly in this trial the post-evaluation instructions referred to the treatment period - rather than the post-treatment period, during which anxiety would be expected to be similar to baseline or elevated; results, therefore, did not accurately reflect post-treatment effectiveness.

Interestingly, two of the three trials providing minimum or no asthma-related education (Campbell-Sills et al., 2013; Hockemeyer & Smyth, 2002) found no significant differences on anxiety between the experimental groups, suggesting that asthma-related education may be important in enabling reductions in anxiety complicated by asthma. Studies with greater methodological rigour would be required to confirm this. Spurgeon and colleagues (2005) although not providing asthma-specific education, still included health-related input in their

protocol, which may account for the positive effects of CBT on anxiety in their study.

3.5. Children and young people

3.5.1. Study design

Four trials involving children or adolescent participants met criteria for inclusion in this systematic review, of which only one was an RCT (Colland, 1993), one was a non-randomised controlled trial (Papneja & Manassis, 2006), and two utilised repeated-measures designs (Long et al., 2011; Marriage & Henderson, 2012). The evidence from the later two was rated as significantly more limited, in relation to the RCT and controlled trial, which were rated as providing similarly strong evidence in relation to the review question (Table 3).

3.5.2. Sample representativeness and power

The age of participants ranged between 7 to 14.2 years, with sample sizes for the intervention condition of between 17 and 48 participants (Table 2). Aside from Marriage and Henderson (2012), all other studies had relatively low attrition rates (0%-20%) for the treatment group and adopted suitable analyses in relation to addressing the review question. The first author computed a post-hoc power analysis for the pre-post results of the intervention group of each trial using the G*power programme. Colland (1993) and Papneja and Manassis (2006) were rated high for achieving a power of at least 0.8 estimating effect size to be medium and using an alpha of 0.05.

Recruitment methods and eligibility criteria varied substantially between studies. Despite the overall high rating, sample representativeness in Colland (1993) was only adequately addressed because of recruitment criteria evaluating coping skills rather than anxiety symptomatology. Long and colleagues (2011) utilised a representative respiratory sample, but did not assess clinical need to undergo an anxiety intervention at the recruitment stage. In

contrast, Marriage & Henderson (2012) included clinically relevant participants that had both asthma and anxiety symptoms, although representativeness was limited by unclear screening methods for anxiety and recruitment from a single respiratory clinic. Papneja and Manassis (2006) utilised data from a large scale anxiety RCT, analysing data for participants with co-morbid anxiety and asthma and was, thus, rated higher on this criterion.

3.5.3. Outcome measures

All studies on younger participants used primary anxiety measures that were well-validated and reliable (SCAS; Spence, 1998, RCMAS; Reynolds & Richmond, 1985 and STAIC; Spielberger, Edwards, Lushene, Montuori, & Platzek, 1973). Two studies assessed the outcomes of the intervention up to 6 and 12 months later (Table 2).

3.5.4. Interventions

Two trials examined CBT in group formats and one in individual format (Table 2). One study provided the intervention in both formats, but reported their combined results, due to their outcomes not being significantly different between conditions (Papneja & Manassis, 2006). Half of the trials involved some level of participation of significant others in treatment (Colland, 1993; Papneja & Manassis, 2006). The number of offered sessions ranged between 6 and 12. All interventions were facilitated by therapists of varied training and experience, from psychologists, psychiatrists and psychotherapists (Colland, 1993; Papneja & Manassis, 2006) to graduate therapists, MSc clinicians or research assistants (Long et al., 2011), and a respiratory nurse (Marriage & Henderson, 2012). Only one study recorded sessions and rated them independently to ensure adherence to treatment protocol (Papneja & Manassis, 2006).

Three studies (Long et al., 2011; Marriage & Henderson, 2012; Papneja & Manassis, 2006) were designed to reduce anxiety as one of their primary aims. Two of the trials were rated

lower on the treatment suitability for improving anxiety outcomes, as their protocol content focused mainly on improving asthma knowledge and perceptions (Colland, 1993; Long et al., 2011). Papneja & Manassis (2006) was the only trial not providing asthma-related education.

3.5.5. Key findings

All four trials reported significant reductions in the general anxiety outcomes following a CBT intervention on children with asthma, which were maintained at the follow-up evaluations. Of the two methodologically stronger studies, Colland (1993) found that asthma training and CBT led to significantly greater improvements in anxiety compared to a single information session for families or to no treatment. Papneja and Manassis (2006) compared the relative effectiveness of a CBT intervention protocol for anxious children with and without asthma. A statistically significant improvement in general anxiety scores across time was found for the anxious group with asthma, but the intervention was slightly less effective amongst children in this group as compared to anxious controls without asthma. In addition, the physiological anxiety subscale scores actually slightly increased at post-treatment for the co-morbid asthma and anxiety group, but not for the anxious controls without asthma. Several reasons may account for this, including the increased complexity of the experimental group and the absence of input regarding asthma in a group that is likely to additionally experience asthma-related anxiety complications.

Interestingly, Colland (1993) found favourable anxiety outcomes after their CBT intervention, despite having been rated poorly on the suitability of the applied protocol for improving anxiety due to mainly focusing on asthma knowledge and management. Closer examination shows, however, that only the asthma-specific, as opposed to the general, anxiety results were maintained at the six and 12 month follow-up. Long and colleagues (2011), also found mixed results with no improvement on one of the primary anxiety

inventories (STAIC), but limited conclusions can be drawn given that the sample was not selected to be clinically anxious, and the intervention protocol or therapists' experience were only adequately appropriate to improve anxiety outcomes.

4. Discussion

This systematic review aimed to explore the effectiveness of CBT interventions for anxiety in individuals with co-morbid asthma and anxiety. The 14 reviewed trials presented reasonable preliminary evidence to support the use of CBT for anxiety in the context of asthma both for adults and for children/young people (7-14 years).

The intervention protocol appeared important in addressing the review question. The majority of reviewed studies used a generic CBT approach, with some focusing on modifying health perceptions and asthma knowledge as a way to reduce anxiety in the context of asthma, rather than applying a specific empirically-validated CBT model for anxiety disorders (e.g., for panic or health anxiety; Clark, 1986; Warwick & Salkovskis, 1990). In the six studies where ratings suggested that a suitable treatment protocol was used to improve anxiety outcomes, the findings indicated CBT as an effective treatment.

Prevalence studies highlight the increased comorbidity of panic, generalised anxiety disorder or even social anxiety amongst individuals with asthma (Goodwin et al., 2003; Hasler et al., 2005; Vila et al., 2000). Some of the reviewed trials successfully used a panic/health anxiety focus in their CBT intervention (e.g., Parry et al., 2012; Ross et al., 2005). Although health anxiety is less frequently cited in literature as an asthma complication, this is likely to be due to most prevalence studies not administering measures designed to identify health anxiety. More recently, this field has shifted towards adapting anxiety CBT models for asthma and exploring cognitions, which may maintain the high comorbidity between asthma and anxiety (De Peuter et al., 2008; Deshmukh, Toelle, Usherwood, O'Grady, & Jenkins, 2007). This shift

may be further validated by evidence in this review showing that interventions which provided minimum or no asthma-related input found no significant differences on anxiety between the experimental groups (Campbell-Sills et al., 2013; Hockemeyer & Smyth, 2002), or were only partially successful in improving anxiety, with levels of physiological anxiety remaining high at post-treatment (Papneja & Manassis, 2006).

Another factor important in addressing the review question was the clinical relevance of the samples. Only half of the reviewed studies screened for anxiety as part of their eligibility criteria. In studies where the recruitment method and inclusion criteria were rated higher to indicate a clinically representative anxious sample with asthma the results favoured the use of CBT for anxiety.

4.1. Limitations of reviewed articles and future research

Many of the included studies did not have control groups, with the remaining studies usually having only non-active groups (e.g. waitlist or standard asthma care). Future studies may consider comparing CBT with other psychological therapies.

Significant heterogeneity existed between the applied outcome measures, limiting potential for comparisons between studies in the current review. Comparisons were also limited as a result of the substantial diversity between the CBT protocols employed, many of which primarily focused on modification of asthma behaviours or knowledge as means to reduce anxiety rather than directly on specific anxiety beliefs. The present review aimed to include all CBT studies targeting anxiety as an outcome in an asthma sample, which subsequently revealed the importance of the intervention rationale and content. To increase effectiveness perhaps future trials need to consider more thoroughly tailoring the treatment protocol, using existing evidence regarding this comorbidity and the mechanisms that may maintain it.

Future studies would also benefit from giving greater consideration to protocol adherence and the training of therapists as these aspects of methodology were often not well addressed in the reviewed studies, despite having consistently been found to impact on psychotherapy research findings (Huppert et al., 2001; Rakovshik & McManus, 2010).

Sample representativeness was of variable quality across studies, with most employing small samples that would not enable sufficient power for analyses. In half of the reviewed studies, anxiety was not a criterion for inclusion, but was assumed, e.g., by the medication overuse. This is likely to impact on the outcomes and effect sizes, as inclusion of individuals without anxiety naturally reduces the potential to deliver reductions in anxiety. Attrition rates were also significant amongst studies, reaching up to 50%; although they were lower in most studies involving children and adolescents, potentially due to parental involvement in supporting attendance. Of the trials that had attritions, with the exception of two, others did not consider how to manage missing data in the analysis, which may increase bias in the final conclusions (Azar, 2002).

4.2. Implications for clinical practice and policy

The complications of the interplay between asthma and anxiety have extensively been discussed in the literature (Lehrer et al., 2002), including overperception of asthma symptoms and overreaction during episodes (De Peuter et al., 2008; Main et al., 2003), overuse of reliever medications and increased healthcare use, independently of pulmonary function (De Peuter et al., 2005; Feldman et al., 2009; 2005) or asthma severity (Rietvield et al., 2005), unnecessary hospital admissions and pharmacological prescriptions (Fernandes et al., 2010), and enormous costs for the healthcare providers (Hutter et al., 2011; Jones et al., 2008). Strategic planning reports and national guidelines (DoH, 2011; 2014; Scottish Government, 2012; SIGN, 2012a) have long called for appropriate interventions to manage this co-

morbidity, whilst highlighting that evidence is inconclusive.

The current systematic review endeavoured to delineate the outcomes of diverse and inconclusive research in this field (Yorke et al., 2009a; 2009b) by solely focusing on anxiety, given that it is the most common mental health comorbidity of asthma (Hasler et al., 2005) and on CBT interventions only, given that it comprises the treatment of choice for anxiety in general (NICE, 2011; Scottish Government, 2011) and in other respiratory conditions (Livermore et al., 2010). In such a framework, findings become less inconsistent and inform clinical practice by offering some preliminary support for the use of an anxiety-focused model combining cognitive and behavioural interventions, potentially including asthma-related input. Future guidance about the usefulness of psychological interventions in the context of asthma may, thus, benefit from closely defining targeted outcomes (asthma management or anxiety) and thus interventions and reflect more fully on issues of clinical representativeness in an attempt to facilitate greater clarity.

4.3. Strengths and limitations of review

This systematic review benefits from the use of quality criteria purposefully developed to address this review question. Existing quality criteria (e.g., SIGN, 2012b) were consulted, but needed adaptation. This was mainly due to the methodological variation between the reviewed studies, including non-randomised controlled trials or observational studies, in addition to the heterogeneity of the treatment protocols, the participants' clinical characteristics and comparators. All of these factors required specifically operationalised criteria to address them and ensure high consistency between raters. However, limitations may be identified in relation to the quality rating system. As criteria were not truly equally weighted, differentially rating them could potentially be considered fairer. Similarly the numerical cut-offs for the quality characterisation of studies from poorly to well-addressed

may be viewed as arbitrary.

The included studies were published in peer-reviewed journals, which may lead to publication bias. Efforts to address this were conducted by contacting key authors, and searches in the web or in citations of included papers for unpublished documents, conference presentations or dissertations. Due to limited resources search was restricted to work in English. Specific and closely defined search terms were employed and three major databases were only explored, all of which could potentially omit further eligible trials. Multiple manual searches in relevant journals and references were employed to mitigate such limitations.

4.4. Conclusions

The current systematic review offers some positive preliminary evidence for the effectiveness of CBT in reducing anxiety amongst adults and children/young people with asthma. The overall quality of reviewed studies was moderate and further methodologically robust studies evaluating CBT interventions that are specifically tailored to treat anxiety in the context of asthma are necessary.

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Empirical study hypothesis and aims

There is a well-established link between asthma and anxiety, leading to exacerbations for both conditions. The preceding systematic review summarised the evidence regarding the effectiveness of cognitive-behavioural therapy (CBT) in improving anxiety in adults and/or children with asthma. The reviewed papers presented reasonable preliminary support for the use of CBT for anxiety in the context of asthma across the age range. However, the overall trial quality was moderate, calling for more methodologically robust research. The rationale and content of the intervention protocol appeared critically important in determining the effectiveness of CBT for anxiety in the context of asthma. Consistent with other work in this field (Deshmukh *et al*., 2007; Nardi, 2005; Papneja & Manassis, 2006), the systematic review highlighted the importance of adapting anxiety treatment protocols and designing tailored interventions to the needs of this specific population. To tailor interventions to the needs of a particular population, however, it is first necessary to understand the perceptions and subjective experiences of the people in question.

The following empirical study seeks to investigate the interplay between childhood asthma and anxiety from the perspective of children and adolescents through in-depth semi-structured interviews. Qualitative data may shed light on the mechanisms that link these factors and may perpetuate this strong comorbidity, e.g., the attributions young people make regarding the experience of this relationship, problem-solving processes during symptom confusion and unhelpful management strategies. The findings are expected to inform clinical assessments, contribute to the development of a conceptual model and in the adaptation of psychological interventions.

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Reflective prologue

Qualitative research evaluative criteria (Yardley, 2000) and interpretative phenomenological analysis (IPA) quality assessment recommendations (Smith, 2011) were followed to ensure credibility and rigour in the following empirical study. Within this framework, a clear audit trail of each stage of the analysis and the pathway that led to the final report was kept. A reflective log prior to and throughout the process, demonstrating thoughts, decisions, prior expectations and consideration of potential bias further promoted reflexivity and transparency. This reflective prologue aims to elucidate some of this process, outlining the study context and the researcher's role, experience and prior expectations to enable the consideration of potential bias in the analysis and choice of data for presentation.

Characteristics of the research context

This study was undertaken within an NHS paediatric psychology service operating in close (physical and organisational) proximity to the medical teams that initiate most of its referrals, including the paediatric asthma service. Three specialist respiratory teams in equivalent NHS Boards were approached and two participated in the study allowing access to their patient database. As with other common physical health conditions, the tertiary services involved tend to follow up the most complex cases, which for multiple reasons may not be suitable for monitoring in the community. These services are based within urban hospitals, cover wide geographical regions and follow up children and adolescents aged 0-16 years. The specialist asthma nurses facilitating the contact with the potential participants are in close and regular contact with the families. Within this context, the involvement of the asthma treatment team in the present research by initially inviting potential participants to support the study and the interview venues in clinical health settings were likely to have influenced the information respondents chose to share, despite having been informed that their participation would

remain anonymous to the respiratory specialists.

Characteristics of the researcher

As this section focuses on the personal reflections of the main researcher regarding the influence of their role and prior conceptions on the findings, it is written in the first person.

> I previously worked as a child and adolescent therapist in a paediatric psychology and neuropsychology service for 2½ years. Within this role, I was exposed to the impact and potential sequelae of chronic physical health conditions, including respiratory conditions, on children and young people. This experience shaped my interest in paediatric clinical health and I thus looked to develop a thesis within this field when undertaking my doctoral training in clinical psychology. Liaison with my subsequent field research supervisor drew my attention to anxiety in the context of asthma and the increased number of referrals the service receives about reliever medication overuse.
>
> I consequently researched this area further and my interest was fuelled when discovering that, unlike my initial hypothesis, hyperventilation is only one of the multiple factors that are significant in the interplay between asthma and anxiety. It was also intriguing to discover that despite the availability of effective treatments for anxiety in general, these appear neither suitable nor particularly successful in the context of asthma. This exploration naturally led to the formulation of this thesis aims regarding evaluating available treatment programmes for anxiety amongst individuals with asthma and exploring the mechanisms that maintain the comorbidity from the perspective of young people, to allow an empirically supported adaptation of psychological

interventions and improve their effectiveness.

Aware of my prior clinical experience in working with young people with asthma, the service's high rates of referrals for asthma reliever medication overuse and my developing knowledge of research findings in this field, I kept a reflective log to report my pre-conceptions and own attributions so as to promote transparency in the interpretation of the findings. This included my expectation that a large part of the participants' narratives would focus on anxiety-induced hyperventilation, confusing symptoms with asthma and responding by inappropriately using medication. It further included reflections on the influence of my expectation and study objective to use the qualitative outcomes to adapt psychological interventions and self-help material, which were likely to have a cognitive-behavioural treatment (CBT) perspective due to this modality appearing more effective in managing anxiety without physical health co-morbidities. Indeed, upon reflection this influenced even the design of the interview schedule used, directing questions in such manner that would allow the surfacing of participant's thoughts, feelings, bodily responses and coping behaviours. Being aware of this predisposition, but also my knowledge in psychological theory, when analysing the transcripts I was mindful that I would be more likely to recognise cognitive-behavioural mechanisms known to maintain anxiety, such as avoidance, which may have been less likely to have been picked out by other professionals, should they have conducted the analysis. This may be viewed as a limitation, but it may also be one example of why in IPA the researchers' existing knowledge and prior experience could potentially be a strength and is considered integral within the double hermeneutic process.

However, to reduce the effects of confirmation bias I purposefully tried to look for patterns that could have fitted in different modalities or disproved such interpretations of the findings. Additionally, I thoroughly discussed such predispositions in supervision, as a novel qualitative researcher, and actively looked to increase the credibility of the findings by having transcripts second-coded and interpretations validated by respondents and other important stakeholders (e.g., parents, nurse specialists).

Within this log, I also reflected on my own worries regarding interviewing children and adolescents and how this may influence the process. From my clinical background, I was aware of the difficulties this age group may have in verbalising their experiences, but also the challenges in engaging them at times. Such worries account for the development of an interview guide that included prompts about areas adolescents may wish to consider. This was also consistent with recommendations about interviewing younger aged participants.

Finally, my anxiety about undertaking qualitative research with limited prior experience in this methodology covered a significant part of my reflections. To increase my confidence, I closely followed IPA guide books and quality measures and constantly tried to gain an understanding of the rationale behind each recommended step of the analysis, in addition to utilising supervision.

This brief prologue regarding the first author's predispositions aimed to promote transparency and allow the reader to evaluate bias in the research process, analysis and presentation.

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II. EMPIRICAL STUDY[2]

Title:

The interaction between childhood asthma and anxiety: Exploring young people's perspectives and attributions.

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[2] **This empirical study was written in accordance to the guidance of the *Journal of Anxiety Disorders*** (Impact factor 2013: 3.042; SCImago Journal Rank - Clinical Psychology 17/245; see Appendix A for author instructions). Adaptations were made due to this document being submitted as part of an academic thesis portfolio. Figures and tables were, thus, included in the main text, rather than separately in a different file or at the end of the main text; an extended method chapter and appendices expanding on aspects of the study were also included.

Word Count: 8946 (excl. abstract, references, tables, figures)

Abstract

The current study examined the lived experience of childhood asthma and anxiety directly from the affected population, to explore the specific thinking and behaviour patterns maintaining this strong comorbidity. Interpretative phenomenological analysis (IPA) was used to analyse eleven in-depth semi-structured interviews with young people (aged 11-15) living with the comorbidity. Well-established qualitative research recommendations were followed to promote credibility and rigour in the findings. Three super-ordinate themes emerged: i) *the influence of asthma* by inhibiting coping activities or developmental tasks, triggering catastrophic thinking and leading to an over-generalisation of asthma coping strategies to managing anxiety; ii) *the influence of anxiety* by affecting appropriate use of medication and triggering hyperventilation-induced asthma exacerbations; iii) *the interaction between asthma and anxiety* by forming an unhelpful positive feedback loop and triggering symptom confusion. The proposed mechanisms lend themselves to a cognitive-behavioural framework, potentially including mindfulness-based interventions, and may be used to tailor psychological treatments.

Keywords: anxiety, asthma, children, IPA, CBT, qualitative

Abstract word count: 150

Highlights

- The experience of asthma and anxiety was explored directly from the affected population
- Eleven interviews with young people living with the comorbidity were analysed using IPA
- Eight subthemes emerged outlining possible maintaining mechanisms for the comorbidity
- The proposed subthemes can be used to adapt cognitive-behavioural interventions

Character count per highlight: 85

1. Introduction

Asthma is the most common chronic childhood condition (Goodwin, Ferguson, & Horwood, 2004). It is estimated that over 1.1 million children in the UK suffer from asthma (National Institute for Health and Care Excellence [NICE], 2013), whilst worldwide prevalence rates range from 5.6% to 26.7% (Pearce et al., 2007).

In recent years a large body of evidence has confirmed that individuals with asthma present with greater mental health comorbidity, notably anxiety, when compared to their general population counterparts or even with populations with other chronic health conditions, such as arthritis (Di Marco, Santus & Centanni, 2011). Childhood asthma is associated with a higher risk of experiencing any anxiety disorder, including separation anxiety, specific phobia, panic and generalised anxiety disorder (Gupta, Mitchell, Giuffre, & Crawford, 2001; Ortega, Huertas, Canino, Ramirez, & Rubio-Stipec, 2002). Vila and colleagues (2000) compared 82 children with moderate/severe asthma with matched healthy controls. They found that children with asthma were substantially more likely to experience anxiety, with a third of their asthma sample meeting criteria for an anxiety diagnosis, primarily generalised anxiety disorder (Vila, Nollet-Clemencon, de Blic, Mouren-Simeoni, & Scheinmann 2000). In a cross-sectional epidemiological study of 1285 youth (9-17 years) in the US, Goodwin, Pine and Hoven (2003b) showed that self-reported asthma was linked with a twofold higher risk of panic attacks (O.R.=2.2), even after controlling for demographic and psychological comorbidity factors.

1.1. Understanding the mechanisms linking asthma and anxiety

The mechanisms explaining this comorbidity are largely unclear, but it is currently widely acknowledged that there is an interplay between anxiety and asthma, leading to greater exacerbations for both conditions (Lehrer, Feldman, Giardino, Song, & Schmaling, 2002).

Studies on the relationship between asthma and anxiety in children are scarce, but research on adult populations can be informative. Anxiety may exacerbate asthma symptoms by increasing hyperventilation, which may cause bronchoconstriction (Meuret & Ritz, 2010). The release of cytokines and neuropeptides during an anxiety episode may further exacerbate asthma by triggering airway inflammations and allergic reactions (Chiang, Ma, Huang, Tseng, & Hsueh, 2009; Frieri, 2003). Asthma attacks, in turn, can be particularly aversive, which may reinforce anticipatory anxiety and avoidance (Carr, 1998), and may increase health-related fear or hypervigilance regarding threatening bodily symptoms (Feldman, Siddique, Thompson, & Lehrer, 2005; Lehrer et al., 2008). Hypervigilance and selective attention on somatic symptoms are identified by predominant psychological models on panic and health anxiety as key factors for maintaining such difficulties (Clark, 1986; Warwick & Salkovskis, 1990). Interestingly, asthma illness severity, as measured by pulmonary tests, is not a significant predictor of anxiety symptoms (Rietvield, Van Beest, & Prins, 2005).

Research has shown that individuals with asthma and anxiety tend to overperceive symptoms of asthma and overreact during asthma episodes (De Peuter, Lemaigre, van Diest, & van den Bergh 2008; Main, Moss-Morris, Booth, Kaptein, & Kolbe, 2003). For example, Chen, Hermann, Rodgers, Oliver-Welker, & Strunk (2006), measured pulmonary function and subjective symptom perception in 86 children with asthma during a bronchial challenge test. They showed that children with increased anxiety at baseline reported greater asthma symptoms than suggested by the pulmonary function measures, especially when symptoms were mild or ambiguous (Chen et al., 2006). Studies with adults have confirmed that anxiety predicts overuse of medication and increased healthcare use, independently of objective pulmonary function (Feldman et al., 2009; Feldman, Lehrer, Borson, Hallstrand, & Siddique, 2005). This results in enormous costs for the NHS due to unnecessary hospital admissions and increased primary care use, as well as an over-prescribing response from medical staff

(Fernandes et al., 2010; Hutter, Knecht, & Baumeister, 2011; Jones et al., 2008). In relation to medication use, in particular, it has been shown that at least one third of asthma patients overuse their reliever medication independently of their lung function (Hand & Bradley, 1996). Increased reliever inhaler use, however, has been linked with several medical complications, including cardiovascular symptoms (Newhouse et al., 1996) and tolerance effects (Taylor, Sears, & Cockroft, 1996), resulting in implications for their effectiveness.

The interplay between anxiety and asthma is also complicated because of the overlap of symptoms creating confusion regarding the cause of symptoms (e.g., chest tightness versus throat tightness, shortness of breath versus hyperventilation) and, therefore, leading to inappropriate care in cases of misinterpretion (Lehrer, 1998; Schmaling & Bell, 1997). This may be more evident amongst children and young people who are developmentally less able to make such fine distinctions. In addition, the suggested management strategies for the two conditions alone are often contradictory (Lehrer et al., 2002). For example, although for panic and anxiety, distress tolerance and gradual habituation to the symptoms would be recommended (Carr, 1999); for asthma, increased sensitivity to symptoms is suggested and an appropriate level of anxiety about exacerbations is reinforced in order to trigger prompt action during an episode (Lehrer et al., 2002).

The provision of effective anxiety treatments in the context of asthma is, therefore, of crucial importance. SIGN guidelines (Scottish Intercollegiate Guidelines Network, 2012), strategic planning and policy documents in the UK (Department of Health [DoH], 2011; 2014; Scottish Government, 2012) emphasise the significance of identifying anxiety early amongst individuals with respiratory conditions and developing suitable psychological interventions.

1.2. Developing treatments for anxiety in the context of asthma

Research initially turned to the development of asthma care programmes enhanced with

psychological techniques to manage co-morbid anxiety; primarily relaxation and breathing retraining exercises. The outcomes of systematic reviews on such studies are contradictory (Freitas et al., 2013) with some reporting no significant results (Huntley, White, & Ernst, 2002). Apart from the methodological differences amongst these studies, the inconclusive outcomes may be linked to some of such interventions solely targeting the physiological symptoms of anxiety, possibly hypothesising that this is the single mechanism linking asthma and anxiety. Respectively, other available treatments solely focus on some cognitive aspects of the interplay targeting health worries and aiming to change asthma illness perceptions only (Kaptein, Klok, Moss-Morris, & Brand, 2010), despite prevalence surveys indicating generalised anxiety and panic as the most frequent co-morbidities (Goodwin, Jacobi, & Thefeld, 2003a; Vila et al., 2000). Perhaps more importantly, the multifaceted nature of anxiety is not acknowledged in such programmes, involving cognitive, emotional, behavioural and bodily factors (Selingman, Walker, & Rosenhan, 2001) that need to be considered in a comprehensive model in order to promote long-term improvements.

Cognitive-behavioural treatment (CBT) approaches would appear appropriate in this respect and have strong empirical support in treating anxiety without physical health comorbidities (NICE, 2011; Scottish Government, 2011). Nine controlled trials have been published examining the effectiveness of adapted CBT interventions in improving anxiety and asthma outcomes in adults (Campbell-Sills et al., 2013; Grover, Kumaraiah, Prasadrao, & D'Souza 2007; Hockemeyer & Smyth, 2002; Maes & Schloser, 1988; Ross, Davis, & MacDonalds, 2005; Parry et al. 2012; Put, van den Bergh, Lemaigre, Demedts, & Verleden, 2003; Sommaruga et al., 1995; Spurgeon, Hicks, Barwell, Walton, & Spurgeon, 2005) and three in children and adolescents (Colland, 1993; Long et al., 2011; Papneja & Manassis, 2006). Their effectiveness ranged significantly, with some showing favourable findings, although they had considerable limitations, including: small N designs, high attrition rates, sampling limited to

one respiratory centre or non-clinically anxious participants, and significant variations in the CBT protocols. Interestingly, the single controlled trial comparing 36 children and young people with asthma and anxiety with matched anxious controls without asthma (Papneja & Manassis, 2006) found less favourable results in the general anxiety scores of the co-morbid group in relation to the non-asthmatic group, whilst noting an increase in their physiological anxiety. This may point to the importance of using a treatment that is adapted to consider the unique impact of this comorbidity on the experience of physiological states.

In addition, the poorer and inconsistent outcomes of the CBT interventions may be linked to our limited knowledge regarding the role of cognitive processes in maintaining this complex comorbidity (McLeish, Zvolensky, & Luberto, 2011), especially amongst children and adolescents. De Peuter and colleagues (2008) attempted to shed light on the role of catastrophic thinking in perpetuating anxiety in adult asthma by directly adapting the 'Pain Catastrophizing Scale' (Sullivan, Bishop, & Pivik, 1995) to the symptoms of asthma. Using this scale they found that catastrophic thinking predicted asthma symptom overperception in 72 adult patients both during asthma exacerbations and in general (De Peuter et al., 2008). Main and colleagues (2003) also used a mediation model to show that negative affect may lead to a misinterpretation of non-specific symptoms as symptoms of asthma, which may subsequently trigger symptom overperception and medication overuse.

McGrady and colleagues (2010) in their sample of 151 urban adolescents found that perceiving asthma as difficult to control and as significantly affecting life, mediated the relationship between asthma and anxiety. However, research to explore such cognitive vulnerabilities in young people is extremely limited, and generalising evidence from adult studies may fail to take into account developmental or family factors. In addition, no study to date has explored such cognitive processes directly from the perspective of children and

adolescents in order to extrapolate the specific unhelpful thinking and behavioural patterns that maintain their difficulties. Qualitative approaches would provide valuable information in this respect. For example, qualitative data on treatment adherence indicate that medication may be used as a safety-seeking strategy, e.g., "I always walk with my spray. If I discover I don't have my pump...you could feel the tightness, and I jump off the bus and go back home" (p. 411; in Choi, Westermann, Sayles, Mancuso, & Charlson, 2008).

1.3. Study aims

Several papers have highlighted the urgent need to design tailored interventions and adapt standard CBT protocols for the needs of this population (Deshmukh, Toelle, Usherwood, O'Grady, & Jenkins, 2007; Nardi, 2005; Papneja & Manassis, 2006). This may be particularly important in childhood asthma where evidence regarding effective treatments is limited and multiple factors, such as the role of significant others and developmental issues have not been explored (Vuillermin et al., 2010). To tailor interventions to the needs of a particular population, however, it is first necessary to understand the perceptions and subjective experiences of the people in question.

The current study seeks to investigate the interplay between asthma and anxiety from the perspective of children and adolescents. Qualitative data may shed light on the mechanisms that link these factors and maintain this comorbidity, e.g., the attributions young people make regarding the experience of this relationship, problem-solving processes during symptom confusion, unhelpful management strategies.

2. Method

2.1. Study design

Interpretative phenomenological analysis (IPA) was used to analyse 11 in-depth semi-

structured interviews with children and adolescents, who had both asthma and anxiety symptomatology. IPA is concerned with how individuals perceive their world and reflect on their lived experience (Smith & Osborn, 2003). It involves the individuals' attempt to make sense of their experience and the researcher's effort to make sense of the individuals' accounts, filtering them through their own perceptions, experiences and pre-existing beliefs (Smith, Flowers, & Larkin, 2009; Starks & Trinidad, 2007). In recent years, IPA has become the approach of choice in qualitative healthcare research (Reid, Flowers, & Larkin, 2005). It has been extensively used to derive service users' experiences of conditions or treatments and has substantially contributed in a number of areas, including genetics (Michie, Smith, Senior, & Marteau, 2003), cancer (Jarrett, Payne, Turner, & Hillier, 1999) and pain (Osborn & Smith, 1998). It benefits by its compatibility with current psychological models, such as CBT, as within its theoretical framework it assumes a connection between participants' talks, thoughts and affect (Smith & Osborn, 2003). It was, therefore, considered appropriate to address the current study objectives (see extended method chapter for details).

2.2. Research ethics review

Approvals were obtained from the NHS Research Ethics Service and the local Boards' Research and Development offices (Appendix C). Approved procedures were undertaken to secure anonymity and confidentiality of the initial data and interviews and to remove identifiable data from the transcripts. Issues regarding safeguarding participants' well-being and preventing distress were carefully considered. Participation was voluntary and confidential from the respiratory teams, informed consent and parental assent were obtained.

2.3. Recruitment

Consistent with IPA's idiographic approach, the sampling focused on recruiting a closely specified homogeneous group of young people for whom the research question was most

pertinent (Gavin, 2008), to allow for a clinically relevant in-depth case-by-case analysis (Smith & Osborn, 2003). To reduce bias in the selection of potential participants at the initial recruitment stage, a random sampling procedure was used. This ensured the approach of potential respondents that may have not been picked out by respiratory specialists; especially given the poor attendance rates in adolescent asthma clinics.

A consecutive series of 231 children and adolescents (aged 11-16) with a diagnosis of asthma, in accordance with the British Thoracic Society/Scottish Intercollegiate Guidelines Network (2008), were randomly-selected (using random.org) from the tertiary childhood asthma databases in NHS Lanarkshire and NHS Lothian and invited to participate in the study by post (see Appendix D). Thirty three (14.28%) returned completed their contact details and the screening information forms, including: a) a purposefully-designed form with questions exploring eligibility criteria, namely an asthma diagnosis of at least six months, fluency in English and no other mental health, learning, developmental or physical health condition (apart from asthma-related/atopic disorders, which are highly co-morbid) and b) the Screen for Child Anxiety Related Emotional Disorders (SCARED; Birmaher et al., 1999) to identify participants at high risk for anxiety.

In line with findings suggesting that children with asthma are at substantially higher risk of experiencing any anxiety disorder (Gupta et al., 2001; Ortega et al., 2002), a general measure of anxiety was selected. The SCARED is a self-reported 41-item measure, consisting of five subscales: panic disorder/significant somatic symptoms, generalised anxiety, separation anxiety, social anxiety and school anxiety (Verhulst & van der Ende, 2006). It has been shown to have satisfactory psychometric properties, including high test-retest and internal reliability (alpha co-efficient of 0.90) and good validity (Verhulst & van der Ende, 2006). For the current research, the recommended cut-off score of 22 or above was used (Desousa,

Salum, Isolan, & Manfro, 2013) to screen for participants that have increased anxiety symptoms.

2.4. Participant characteristics

Eleven respondents met inclusion criteria and all agreed to be interviewed. Participant characteristics are shown in Table 1. Names were replaced with pseudonyms to protect confidentiality and identifiable information was removed.

Table 1. Participant characteristics

Pseudonyms	Gender	Age	Asthma severity (duration)	SCARED score	Increased anxiety subscale scores[3]
John	M	11-13	mild (≥ 8years)	24	separation anxiety (5/5), school avoidance (4/3)
Lucas	M	14-15	moderate (≥ 8years)	23	generalised anxiety (9/9), separation anxiety (6/5)
Liz	F	11-13	moderate (≤ 7years)	22	generalised anxiety (11/9)
Clare	F	14-15	moderate (≥ 8years)	30	panic/somatic symptoms (8/7), separation anxiety (7/5)
Jennifer	F	11-13	severe (≤ 7years)	33	generalised anxiety (10/9), school avoidance (7/3)
Simon	M	14-15	severe (≤ 7years)	26	panic/somatic symptoms (7/7), generalised anxiety (11/9)
Amy	F	14-15	severe (≥ 8years)	38	panic/somatic symptoms (12/7), generalised anxiety (17/9), school avoidance (3/3)
Craig	M	14-15	mild (≥ 8years)	31	generalised anxiety (10/9), social anxiety (8/8), school avoidance (3/3)
Chris	M	14-15	mild (≥ 8years)	40	panic/somatic symptoms (10/7), generalised anxiety (13/9), separation anxiety (6/5), social anxiety (8/8), school avoidance (3/3)
Ben	M	11-13	moderate (≥ 8years)	27	panic/somatic symptoms (7/7), generalised anxiety (13/9)
Richard	M	11-13	moderate (≥ 8years)	52	panic/somatic symptoms (14/7), generalised anxiety (143/9), separation anxiety (10/5), social anxiety (10/8), school avoidance (4/3)

[3] Participants' scores on SCARED subscales on which they performed above the clinical cut-off as determined by the inventory's authors (Birmaher et al., 1999).

The mean age of participants was 13.09 years (*SD* = 1.37, range: 11-15). Seven were male (63.6%) and four female (36.4%). The majority of participants described their asthma as moderate at the point of the interview (on a 3-point self-report scale from mild to severe), with mean illness duration of 8.54 years (*SD* = 2.84, range: 2-12). The mean score on the SCARED was significantly above the clinical cut-off (*M* = 32.27, *SD* = 8.86). The SCARED subscales on which respondents scored in the clinical range as determined by the inventory's authors (Birmaher et al., 1999) are also presented to demonstrate the types of increased anxiety symptoms participants within this sample reported.

2.5. Data collection

Nine of the interviews took place in community child and adolescent mental health services, one in a medical practice and one in a hospital clinic. All interviews were conducted by the lead author, a female clinical psychology doctoral trainee with pre-existing experience in paediatric clinical health. They were audio-recorded and duration ranged between 27 and 35 minutes. The interviews were semi-structured, guided by a schedule (Table 2; extended version in Appendix H), which was developed to explore the experiences of living with asthma and anxiety, with probes relevant to empirical findings about this relationship. The schedule was piloted with three adults with childhood onset asthma using retrospective cognitive interviewing techniques (Haeger, Lambert, Kinzie, & Gieser, 2012; Willis, 1999).

In line with the research aims, particular attention was paid to examining all aspects of the experience of the asthma and anxiety interplay, including cognitions, personal attributions, emotions, physiological reactions, coping behaviours and management strategies. IPA principles (Smith & Eatough, 2007) guided the development of the schedule, with open-ended non-directive questions comprising the skeleton of the interview, whilst ensuring prompts were available to respond to potential developmental limitations in verbalising or

recalling for the young participants (Docherty & Sandelowski, 1999) (see extended method chapter for detail).

Table 2. Interview guide

Interview guide
Experience of asthma and anxiety separately
Can you talk to me about what is asthma like for you?
What has it meant for your life?
Can you talk to me about what is anxiety like for you?
What has it meant for your life?
Relationship between anxiety and asthma
Do asthma and anxiety influence or affect one another?
When are they more likely to influence one another/occur together?
How do you cope when asthma and anxiety influence one another /occur together?
What sort of worries do you have about your asthma?
How does worrying feel on your body; how is that different from an asthma attack?
How do you know when to get your medication?

2.6. Analysis

In line with IPA guidance regarding the process of analysis, the verbatim transcription of the interviews commenced after all interviews were completed (Smith & Osborn, 2003). As the focus in IPA heavily relies on the researcher's interpretative engagement with the participants' accounts, the lead author's previous experience, knowledge and expectations were logged *a priori* in a reflexive and open manner, not necessarily with the aim to withhold them, but rather to increase awareness of how these may influence the hermeneutic process.

The analysis was led by the first author and followed the stages described in Smith and colleagues (2009). The individual transcripts were read repeatedly, twice alongside the audio-recordings to encourage immersion with the data and sustain focus on each interview in its

own merits, in keeping with IPA's idiographic aspect. Descriptive, language and conceptual notes were made on the right-hand margin and these were subsequently overviewed to identify recurrent or particularly emotive points, associations and contradictions and allow the development of emerging themes within each interview (see Appendix K for an example of the initial coding). This process was repeated across all transcripts. When new themes emerged, previous interviews were re-visited to examine if such interpretations would be relevant.

All elicited themes from each participant were organised into multiple tables in a single document to allow examination of patterns across cases and themes that could be clustered together. Principles of abstraction, polarisation, contextualisation, numeration and function guided the grouping of emergent themes into subordinate themes (Smith et al., 2009). Particular attention was paid to analysis negotiating both convergence and divergence, thus pointing to how participants displayed the same theme in their individual ways (Smith, 2011). In keeping with IPA methodology, when the same themes appeared in at least one third of the participants (4/11) they were considered recurrent. These themes were subsequently integrated to establish super-ordinate themes and a table of 'master themes' with supporting extracts from each participant was created.

2.7. Quality assurance

Qualitative research evaluative criteria (Yardley, 2000; 2008) and IPA quality assessment recommendations (Smith, 2011) were considered to promote credibility and rigour in the present analysis. A clear audit trail of each stage of the analysis and the pathway that led to the final report was kept. A reflective log prior to and throughout the process, demonstrating thoughts, decisions, prior expectations and consideration of potential bias further promoted reflexivity and transparency. Homogeneous sampling and measures of subordinate theme

prevalence were utilised. Multiple sources were used to validate the findings, including drawing on multiple theoretical perspectives to interpret the data, and inviting important stakeholders (i.e., respiratory specialists and parents) to cross-check a summary of the initial findings and refine explanations. To assist in this process, respondent validation was also attained with over half of the participants (6/11) commenting on the initial interpretation of the findings. Feedback from important stakeholders and respondents was incorporated in the final analysis where appropriate (see extended method chapter). A random selection of three transcripts was independently coded by the second author, who is experienced in IPA methodology. High level of agreement was found in the emergent themes (87%, 70% and 81% of themes identified by the second rater in each interview respectively, were also noted by first author) and close supervision was utilised to reach consensus in the interpretation and development of master themes.

3. Results

The analysis produced three super-ordinate themes pertinent to the research question regarding how the mechanisms linking asthma and anxiety are perceived by young people. Participants described experiences of this comorbidity as a single directional relationship of one condition influencing the other, with fewer also discussing experiences of asthma and anxiety in patterns of interaction. Table 3 presents an overview of the themes revealed through the analysis and interpretation of the data and their prevalence across participants (see Appendix J for details). The extracts were selected based on their ability to present how themes could be manifested in brief, coherent, and meaningful ways (Smith, 2011).

3.1. The influence of asthma

The influence of asthma on participants' experience of anxiety was evident across everyone's accounts and appeared to have affected all aspects of their functioning, including

developmental milestones, cognitions, behaviours and coping strategies.

Table 3. Overview of the super-ordinate and subthemes with prevalence across participants

Super-ordinate themes	*Subthemes*	*Theme prevalence across participants*
The influence of asthma	Asthma as a threat to important developmental goals	10
	Asthma as a barrier to valued, potentially coping, activities	11
	Asthma triggers worries and anxiety-provoking thinking patterns	11
	Strategies to manage asthma over-generalise to managing anxiety	9
The influence of anxiety	Physical symptoms of anxiety and anxiety-related behaviours trigger asthma	6
	Anxiety inhibits good asthma care and medication adherence	6
The interaction between asthma and anxiety	Asthma and anxiety interact forming a positive feedback loop	5
	Confusion between symptoms of asthma and symptoms of anxiety	4

3.1.1. Asthma as a threat to important developmental goals

Ten participants referred to the impact of asthma on their efforts to achieve important developmental goals, such as making friendships, forming an identity and seeking autonomy.

Purposeful homogeneous sampling meant respondents were in early or middle adolescence and all but one spoke of their continuous efforts to minimise the consequences of asthma on their developmental goals or negotiate a balance between managing asthma and engaging in crucial tasks for their age. Their descriptions pointed to the additional stressors and conflicts such efforts place on them and how this may contribute to anxiety symptomatology.

To be more specific, in keeping with their developmental stage (Shaffer & Kipp, 2014), respondents made reference to their endeavour to form friendships and belong in a peer group

being hindered by asthma symptoms and how this affected not only their feelings, but also how they worried their future might be.

> *"It's like kind of like tough because... with my asthma I'm always in the house... and that is shortening my time with my friends... I think to myself "Oh no, if this keeps up I'm going to end up like, all my pals are going to end up thinking, they'll just not have nothing to do with me and that. And I'm going to have to sit about in the house myself, always taking my inhaler and that" (Richard)*

In this context, others highlighted concerns regarding how this endeavour to negotiate their place in their peer group, whilst having asthma, influenced how they viewed themselves as "different" or "odd", and as such affected another major adolescent task, the development of identity.

> *"You couldn't join in with stuff they [friends] were doing. You felt the odd one out" (Chris)*

Six participants presented a continuous identity negotiation between feeling strong versus vulnerable. One participant talked about viewing asthma as a drawback, keeping him from leading a normal life, but later reports investing all his efforts in maintaining his identity as a strong person, as an achiever, despite asthma.

> *"It [asthma] is a drawback. I struggle and, well I used to. I'm slowly getting better but... if it becomes dormant in the future, obviously that's good and I can really start to lead more of a normal unhindered life" (Lucas)*

> *"I just work through it because I can always reason with myself and say, "Oh yeah I was beaten because I've got asthma," but in the end I don't want people to say that. I want to be able to say, "Well I won them, sort of won against them, even though I've got asthma" (Lucas)*

Others also reflected on the impact of asthma on their identity and how this could drive their efforts, but could also place increased pressure on themselves to achieve despite their medical condition, potentially impacting on their anxiety.

> *"The way I view myself, I feel like I can't do as much as a normal person could because I've got limitations. It [asthma] holds me back" (Simon)*

> *"Whereas asthma, for me, it can pull you back but I'm not going to stop. Because just say I'm in a game, then if I get really out of breath I'll stop, take an inhaler, but then usually people will go sit out. I won't. I'll just take my inhaler, stop for maybe a minute or two and then go again. It doesn't stop me" (Liz)*

The young people in this sample also expressed concerns about asthma affecting their efforts in achieving age-appropriate autonomy. Six young people provided descriptions of experiencing a conflict between their need to maintain increased closeness and support from significant others to manage their condition, whilst wanting to feel more independent. A sense of frustration emerged in many of the participants, as they discussed efforts to manage such conflicts.

> *"I'd always be with someone... I don't know it's just in case anything happens... It's not that nice because if I go out it then feels as if I'm following my, them [parents] around the shops, I don't like the fact that I go out and can't do stuff myself"(Chris)*

Some participants' descriptions also depicted how significant others also had concerns about encouraging them in such developmental tasks, possibly maintaining anxiety-maintaining patterns of seeking safety and reassurance in others.

> *"My teacher always says to me, Take it easy just in case. Keep your inhaler with you" (Clare)*

> *"Mum's very over-protective and now if I have a cold or a snuffle she'll quite often say to me, I don't want you to go to school cause your asthma could flare up"(Lucas)*

3.1.2. Asthma as a barrier to valued, potentially coping, activities

Related to the aforementioned subtheme, but potentially relevant to wider age groups, all participants invariably referred to perceiving asthma as a barrier to activities which were valued to them. Respondents described asthma to place barriers in their efforts to remain

engaged in meaningful activities.

> *"Well obviously if it's bad then I can't go to school and I can't do like sport and everything. And it's quite, yeah, quite annoying not being able to kind of, yeah, breathe properly" (John)*

> *"when it was particularly bad..., it affected my entire life basically; my education; my fitness; everything... School life became, was awful, because I was off every second week and I had really bad attendance; and I struggled through primary school because obviously it affected my education and I had to catch up a lot" (Lucas)*

Such valued activities, from spending time with friends, to education and fitness, may in some respects be crucial in participants' efforts to cope with anxiety. Asthma may, thus, be perceived as a barrier to using such coping strategies.

> *"Like doing sports just takes me to another place really. It just takes me away from everything... before I had asthma... I used to be really sporty. I still love sports and my asthma pulls me back... and my friends might not invite me out to play or something like that because I have asthma" (Liz)*

> *"I can't concentrate and I'm too busy thinking about my asthma and school and worrying. It all just brings more.... my friends... like, sometimes I won't speak to them for days because I'll be kept in or things like that" (Jennifer)*

3.1.3. Asthma triggers worries and anxiety-provoking thinking patterns

All participants readily discussed this relationship outlining how asthma symptoms may directly trigger worries and anxiety-provoking thinking patterns, indicating its role in maintaining anxiety.

Some participants described asthma as an additional stressor in their lives, triggering worries or comprising another matter to worry about, rather than possibly causing their anxiety.

> *"Everyone else worries about something else, I worry about asthma" (Simon)*

> *"I just don't really want to have it [asthma] anymore, because it's like [sighs] something else to worry about" (Ben)*

Anxiety-provoking thinking regarding asthma symptoms was also evident in respondents' descriptions, with catastrophising during an episode being the most prominent.

> *"I'd probably get worried that... if I was on a bed and they would like put on the masks on me, in case I was going to actually die" (Ben)*
>
> *"It does...panic me, Oh, god, there's something really wrong with me" (Clare)*
>
> *"I just get really confused and worried and panicky. What do I do? What's going to happen? Am I going to be OK?... Is it going to get worse in the future? Is it going to get worse now?" (Liz)*

Five participants perceived anxiety about asthma to be moderated by illness severity and how well-controlled the medical condition was thought to be.

> *"I think if I have quite bad asthma then, yeah, I might start worrying about what's going to happen... but it's not unless it's really serious" (John)*
>
> *"if it's bad, like over a period of time, I will be worrying "why is this and what's gonna happen"... like will I have an asthma attack and have to go to hospital" (Amy)*

Participants not only noted worrying about the progress of asthma and the impact it may have on their bodies and future, but also referred to worrying about its impact on significant others.

> *"I feel a bit bad because I don't want my parents to worry about it more than necessary" (John)*
>
> *"I'm putting like pressure on other people who have to look after for me. I don't like it very much" (Richard)*

3.1.4. Strategies to manage asthma over-generalise to managing anxiety, producing safety behaviours that maintain anxiety

Respondents promptly pointed to a wide variety of coping strategies to manage asthma, including sitting down, focusing on their breathing, having their medication available,

keeping helpful others close, being vigilant of potential asthma triggers and avoiding them. With years of experience of living with asthma, such strategies were readily described by all participants and appeared engrained in their 'coping toolkit'. Nine of the respondents made reference to using such strategies in managing anxiety too, which may then represent safety behaviours that would be expected to be counterproductive, potentially perpetuating their worrying.

For example, vigilance about potential asthma triggers is promoted in self-management programmes (Lehrer et al., 2002), but amongst participants in this sample, it appears to reinforce a constant state of alert. Thinking processes, such as hypervigilance and a positive attitude towards worrying (e.g., it helps me cope/prevent disasters) became apparent in respondent reports and may be expected to contribute to anxiety, in line with generalised anxiety models (Wells & King, 2006; Dugas & Robichaud, 2007)

> *"I always have to worry, do I have my inhaler on me? Can I do that? If I have an asthma attack, will I be fine? Yeah, I just have to think of all the things that might happen and then almost prepare for them" (Simon)*

> *"I need to be a lot more careful than obviously other people would have to be... I suppose, because I am worrying about it [asthma], it is making me, like, more aware of what is actually happening, so I am trying to prevent it even more, I am not that relaxed about it" (Amy)*

Other participants also described asthma coping strategies that could evolve to be unhelpful when used in the context of anxiety. Crucial examples referred to medication, lying or sitting down and being close to helpful others. Such strategies are important for asthma, but may generalise to invariably seeking safety in them to feel reassured and calm amongst respondents in this sample.

> *"I make sure I've got, like, spare inhalers in case I lose one and I bring three or something in case… I get almost worried that I will use it and then I will run out of inhalers and then I will get, I will need an inhaler and then that will just be*

me worrying about having an asthma attack... I then worry about not having my inhaler and then it just gets worse from thereon" (Simon)

"That's why I start getting scared for that... it's usually when your people aren't here. Because if something happens to me I can just rely on them to help me... I feel like I've got no gas mask, not having my mum and dad with me" (Richard)

"I get headaches when I'm nervous...mostly in school...I would take paracetamol and then just like cope until I go home... then I just go to bed and lie down" (Amy)

3.2. The influence of anxiety

Eight participants endeavoured to also consider this comorbidity from an opposite perspective pointing to how anxiety may influence asthma symptoms. They referred to how they perceive their anxiety-related behaviours and symptoms directly triggering asthma symptoms and indirectly affecting appropriate asthma care and treatment adherence.

3.2.1. Physical symptoms of anxiety and anxiety-related behaviours trigger asthma

Six respondents described anxiety-related symptoms triggering asthma symptoms. Participants focused on hyperventilation in the context of anxiety impacting on their airway and chest functioning.

"you start breathing a bit faster and I think that's, it's not really the fright it's more the sudden faster breathing that kind of brings on the asthma" (John)

"the anxiety would mean my breathing would increase which then made me feel horrible in my chest. It would then start the asthma" (Chris)

Respondents also considered situations where anxiety-related behaviours brought on asthma symptoms.

"Like, sometimes I do find it quite hard to breathe if I start worrying about something, then I find it hard to catch my breath and I start crying and feeling really shaky. If I ... I run away and obviously running impacts it" (Clare)

> *"Sometimes if I start crying and stuff it'll affect my asthma because when I cry I can't breathe" (Jennifer)*

3.2.2. Anxiety inhibits good asthma care and medication adherence

Respondents made reference to experiences where anxiety may secondarily contribute to asthma complications though preventing appropriate use of inhalers. Participants frequently responded to anxiety-related symptoms with asthma medication, resulting in potentially overusing their reliever inhalers and making themselves vulnerable to side effects (NICE, 2008; Newhouse et al., 1996; Taylor et al., 1996).

> *"Then things like exams would make me nervous the same way, lightheaded and sick almost, but I could feel my breathing start to go...and I'd just panic. My deep breaths and take my inhaler, just control it and stay calm" (Chris)*

> *"In primary school, if we had to do something worrying... I would usually get quite chesty... And kind of finding it harder to breathe, so I took my inhaler and it was better" (Craig)*

In addition, during asthma episodes participants acknowledged that worrying about how their medical condition may evolve prevented appropriate problem-solving and, thus, asthma care.

> *"Because I always think of the worst. I can't make something good with my asthma because I'm too busy worrying" (Jennifer)*

> *"When I have an asthma attack... then I will get really worried and I'll get quite panicky and I won't just sit down and take a deep breath, I'll be like, "What do I do, what do I do?"... The times in the past that I've had an asthma attack or my asthma's been really bad, I hadn't taken my inhaler properly because I'd been that worried. I get confused, that kind of feeling" (Liz)*

Within this context, one participant also shed light on how anxiety regarding social situations may also affect medication adherence.

> *"It is more if I have to take my inhaler in front of people; I don't like doing that, cause they might think I'm on drugs or something" (Craig)*

3.3. The interaction between asthma and anxiety

The last super-ordinate theme refers to six participants' attempts to approach this comorbidity in non-linear terms of one leading to the other, but describing experiences of asthma and anxiety in patterns of interaction and acknowledging a more complex interplay between the two conditions.

3.3.1. Asthma and anxiety interact forming a positive feedback loop

Five participants provided descriptions of asthma and anxiety symptoms in a self-perpetuating feedback cycle, which may maintain this comorbidity. Participants provided examples where they experienced difficulties in identifying stages within this cycle where they could intervene and prevent it from escalating.

> *"If I feel out of breath, I might start to worry that I'm going to have an asthma attack, start breathing heavier and then that invokes my asthma more... but because I'm worrying about having an asthma attack while I'm a wee bit bad on asthma, then all of a sudden that might just trigger it and then I could actually have an asthma attack...then it will be that circle again and then I'll get worried and then it will get worse, worrying that I'm making it worse by worrying and then I just can't get out of it until it ends basically" (Simon)*

> *"my worrying is like it's trying to help my asthma beat me, beat like [sighs] beat me! It's like they'll help, try help each other like to beat me" (Richard)*

One participant explains that the trigger for this vicious interactive cycle may equally be asthma or anxiety symptoms.

> *"If I ever had an asthma attack it would make me nervous and anxious so and then I would get worked up and it would make the asthma worse. Then because the asthma would get worse I would get more anxious, it would keep going and both would get worse, and worse, and worse until my asthma was really bad and we would have to phone an ambulance and go to hospital... If I was anxious I would start breathing quickly which would then make my asthma come on if I started to get tight in my chest, and then it would be the other way about so then my asthma would get worse because of the anxiety. Again they would both get worse and worse because I was nervous" (Chris)*

Participants reported prioritising asthma management (i.e., medication/sitting down) when experiencing this interaction between asthma and anxiety, whilst acknowledging the importance of managing the panic symptoms, by seeking re-assurance from helpful others, using distraction, or trying to balance worrying thoughts.

> *"I just focus on the fact that, right, I'll deal with that asthma and then I'll think about other stuff later because, at the moment, the asthma is my number one priority, to make sure I get better" (Simon)*

> *"I have to try and keep things together so I will be able to breathe. I just try and think of the positive side of it and then I just try and take my inhaler more or take more of my medicine, whatever. I just have to calm myself down and try and do something else and watch TV to try and take it off my mind" (Jennifer)*

> *"Well, my inhalers obviously help me but my mum will be there for me if I want to talk about it" (Liz)*

Salbutamol use, however, is associated with common adverse effects, such as palpitations, anxiety and hyperventilation (NICE, 2008), all of which could further feed in to the vicious interactive cycle, making it almost impossible for young people to 'escape'.

3.3.2. Confusion between symptoms of asthma and symptoms of anxiety

Four participants made reference to situations where the distinction between the physical symptoms of anxiety and the asthma symptoms became less definite, aggravating decision-making regarding the appropriate reaction.

> *"I was, like, right, I need to take my inhaler. I don't have it, and then I started really worrying and then that caused me to actually have an asthma attack... That probably… if I realised I don't have asthma, I just sit down and make sure I breathe slower, then I would've been fine" (Simon)*

> *"I was sitting there. I think I was worrying, but then... I can just remember worrying and then taking my inhaler. So... I don't know if that was one of the two" (Liz)*

This theme is related to previous themes discussing inappropriate medication use in the context of anxiety symptoms. Participants in this sample may be particularly vulnerable, as managing asthma in situations where both symptoms co-occur appeared to be a priority for them; such priority is of course in keeping with asthma self-management guidance suggesting early intervention before symptoms deteriorate (Lehrer et al., 2002). However, the decision regarding the suitability, or not, of medication use in such ambiguous situations may not be as straightforward, especially in the context of reported experiences of physical symptoms of anxiety triggering actual airway obstruction symptoms.

4. Discussion

The current study offers an insight into the mechanisms linking asthma and anxiety as experienced by young people (11-15 years) living with symptoms of both conditions. Analysis endeavoured to consider factors that may maintain this relationship, approaching it both in linear terms, describing participants' experiences of one condition influencing the other, and as an interaction examining more complex ways in which this comorbidity may affect participants' lives. The study provides rich qualitative data to support previous findings in this field regarding the manifold links between the factors in question (DePeuter et al., 2008; Feldman et al., 2009; 2005; Lehrer, 1998; McGrady et al., 2010; Meuret & Ritz, 2010), whilst adding novel conceptions about the patterns that may maintain this comorbidity. It further provides good evidence regarding the increased awareness young people have about experiences that may perpetuate the comorbidity, indicating that such hypotheses can be tested directly by children and adolescents rather than by proxy through professionals and parents. However, participants appeared less able to recognise such experiences as maintaining mechanisms and consider strategies to prevent them. The present research suggests that this could be the specific focus of psychological treatment protocols tailored to

manage this comorbidity.

The first theme focused on the unilateral impact of asthma-related factors on anxiety symptoms. The findings confirmed that perceiving asthma as a barrier to meaningful and potentially anxiety-relieving, coping activities may play a crucial role amongst young people with asthma and anxiety, which is consistent with previous research indicating that viewing asthma as significantly affecting one's life and limiting activities mediated the asthma and anxiety comorbidity amongst adolescents (McCauley, Katon, Russo, Richardson, & Lozano, 2007; McGrady et al., 2010). The current study further suggests that asthma may be perceived as threatening not only to valued activities, but also to major developmental tasks for young people, placing additional stressors and conflicts on them, thus contributing to anxiety symptomatology. Respondents described continuous efforts to minimise or negotiate asthma's impact on developmental tasks, such as achieving age-appropriate autonomy, forming friendships, maintaining a sense of belonging and establishing an identity (Shaffer & Kipp, 2014). Such developmental conflicts, thoughts and perceptions regarding the impact of asthma may need to be defused or modified in a tailored psychological treatment in order to promote long-term improvements.

Within this super-ordinate theme, the present research confirms previous evidence highlighting the impact of catastrophic thinking regarding asthma symptoms, both in general and during an episode, on maintaining anxiety amongst individuals with asthma and anxiety (DePeuter et al., 2008). Contrary to quantitative research outcomes suggesting that the association between asthma and anxiety is independent of objective pulmonary function (Feldman et al., 2009; Rietvield et al., 2005), almost half of the respondents in this sample perceived illness severity as moderating the relationship between asthma symptoms and catastrophic thinking. Besides catastrophic thinking, this study further identified additional

unhelpful and anxiety-maintaining thinking and behaviour patterns. Effective asthma self-care strategies, reinforced over years of living with the condition (i.e., sitting down, focusing on respiratory function, having medication available and using them early when identifying symptoms, keeping helpful others close, being vigilant about potential asthma triggers and avoiding them), may over-generalise to being used for managing anxiety too, which would be expected to be counterproductive, potentially perpetuating worrying. Indeed, cognitive processes such as hypervigilance and holding positive beliefs about worrying (e.g., it helps me cope/prevent disasters, like exposure to asthma triggers) have been identified as maintaining factors in well-evidenced generalised anxiety models (Wells & King, 2006; Dugas & Robichaud, 2007) and may maintain anxiety in this context too. In addition, coping behaviours, such as medication or seeking re-assurance from significant others are likely to be effective with asthma symptoms, but when used with ambiguous or anxiety symptoms, they may prevent individuals from habituating to anxiety, experiencing that nothing catastrophic happens, and developing more suitable strategies (Clark, 1986; Warwick & Salkovskis, 1990), thus gaining mastery in managing anxiety. The present findings shed light to potential systemic factors further reinforcing such safety-seeking strategies with highly protective responses from family and school. Further quantitative research is warranted to confirm such anxiety-maintaining patterns in the context of asthma with larger samples, but their modification would appear critical in ensuring long-term positive outcomes.

The second super-ordinate theme was related to mechanisms explaining the reverse function of this comorbidity. Qualitative data in this study provide evidence to support original hypotheses within this field regarding the key role of breathing and physical symptoms of anxiety in exacerbating asthma symptoms (Carr, 1998). These are in keeping with outcomes linking hyperventilation with bronchoconstriction (Frieri, 2003; Meuret & Ritz, 2010), with participants in this study providing vivid examples of such processes. Such narratives

potentially point to designing interventions that promote awareness of these processes, potentially enriched with relaxation or mindfulness-based interventions to target physiological symptoms of anxiety.

In the third super-ordinate theme, respondents' experiences appeared to be consistent with the concept of an unhelpful feedback loop between asthma and anxiety symptoms, where either of which may activate a cycle of one condition exacerbating the other in a continuous process. Amongst participants in this sample, preventing this loop before escalating appeared more difficult, but at the peak of this self-perpetuating cycle respondents described asthma management as becoming a priority. This of course is complicated by experiences of symptom confusion, compromised care strategies and anxiety-triggering medication side-effects, as highlighted earlier in this study.

To be more specific, in line with previous research pointing to the complications of the symptom overlap between the two conditions, primarily symptom confusion and subsequently inappropriate care (Lehrer, 1998; Schmaling & Bell, 1997), the current analysis also revealed difficulties in the distinction between the physical symptoms of anxiety and the asthma symptoms amongst respondents, aggravating decision-making regarding appropriate reaction. However, the decision regarding the suitability, or not, of medication use in such ambiguous situations may not be as straightforward, especially in the context of reported experiences of physical symptoms of anxiety triggering actual airway obstruction symptoms and asthma management guidance suggesting early intervention before symptoms deteriorate (Lehrer et al., 2002). In addition, the current study further adds to these findings, showing within the second master theme that worrying during an asthma episode may also prevent effective problem-solving and appropriate inhaler application, which may also account for medication overuse (Feldman et al., 2009; 2005). Such experiences may further explain

outcomes of CBT trials resulting in a deterioration in physiological anxiety for children that also suffer from asthma (Papneja & Manassis, 2006). This indicates that potentially enriching standard anxiety treatments with techniques to train young people to differentiate between physiological states is likely to be crucial for this comorbidity.

Finally, it may be worth pointing to the fact that the emergent subthemes were supported by at least one third of the respondents, indicating that the majority experience multiple connections between asthma and anxiety symptoms, which may further increase complexity and strengthen this comorbidity. The cumulative impact of experiencing the symptoms of both conditions, and essentially the sequelae of a mental health and physical health comorbidity on respondents was evident throughout the analysis. This challenge has long been identified by researchers (Merikangas et al., 2007) and national policies (DoH, 2014; Scottish Government, 2012) and expedites the urgency of effectively treating such co-morbidities.

4.1. Implications for clinical practice, policy and future research

The present research was designed to respond to a clinical need regarding tailoring psychological interventions for the comorbidity between asthma and anxiety, a process which requires an increased understanding of the subjective experiences of the clinically relevant population.

Potential maintaining patterns discussed within this sample may be used as a guide to inform clinical assessments in paediatric psychology settings, working with respiratory patients. Findings may also be suitable to guide the development of a screening inventory to contribute to the initial assessment process. As items would directly emerge from the experiences of young people with similar difficulties, potentially using language from their extracts, this could raise its content and face validity. Such a measure may also assist in future studies that

are clearly indicated in order to test the applicability of the proposed mechanisms with larger samples, using quantitative methodology.

The proposed mechanisms lend themselves to a cognitive-behavioural approach and may be used to tailor psychological treatments for children and adolescents with asthma and anxiety. Analysis revealed explicit anxiety-maintaining thinking patterns relevant to this population, developmental conflicts, cognitive misinterpretations and counter-productive behaviours that can potentially be defused or modified utilising a specifically-designed CBT approach, informed by third wave CBT techniques. In relation to the third master theme, in particular, narratives point to difficulties in the differentiation between physiological states of asthma and anxiety and symptom confusion. Mindfulness-based interventions may prove valuable in allowing young people to identify and discriminate between elements of their experience, focusing less on reducing their symptoms directly and more on developing a non-judgemental and non-reactive awareness of these. Such an approach may potentially allow them to disengage from the unhelpful feedback loop of their symptom interaction and may also improve unnecessary medication use. Future research would be required to pilot such a treatment, potentially utilising multiple-baseline designs to evaluate its effectiveness across subjects; this would also correspond to national policies about prioritising the development of effective and suitable psychological treatments for individuals with mental health and physical health co-morbidities (DoH, 2014; Scottish Government, 2012).

In addition, as young people with asthma and anxiety often do not meet the threshold for referral to mental health services -although they still have a clinically significant need- the results could assist in the development of tailored self-help material to raise awareness regarding potential counterproductive thinking or behaviour patterns relevant to this comorbidity and techniques to manage them more effectively. Self-help interventions would

contribute to early intervention and health promotion targets in relevant national policies (Scottish Executive, 2005).

Finally, consistent with studies highlighting that anxiety is highly under-detected amongst patients with asthma (Chen et al., 2006), despite its manifold impact on the management of the condition and on well-being, the results once again draw attention to the effect of anxiety on childhood asthma. Findings may inform respiratory assessments, by pointing to anxiety mechanisms potentially complicating asthma care, which may need further exploration and input to resolve. In light of further evidence from this study, it appears essential that asthma policies and clinical practice guidelines stress the importance of early identification of anxiety by key workers in respiratory care and recommend subsequent referral for psychological input, where appropriate. This could, in turn, reduce anxiety-related asthma complications, promote suitable use of medication and, thus, enhance long-term outcomes and improve young people's quality of life. As noted previously, anxiety has also been linked with increased pressures on health care, i.e., longer hospitalisations and overtreatment medical responses (Fernandes et al., 2010), and it is therefore expected that empirically-based effective input from psychological services may benefit the health organisation long-term.

4.2. Strengths and limitations

The present research benefits from being the first to have explored the lived experience of the interaction between asthma and anxiety directly from the perspective of children and adolescents using qualitative methodology.

Qualitative research evaluative criteria (Yardley, 2000; 2008) and IPA quality assessment recommendations (Smith, 2011) were followed to increase the credibility and rigour of the analysis. The recruitment method benefited from the use of a randomly selected and homogeneous clinically representative sample, from multiple sites; although generalisability

is limited by the small number of participants and the lack of information regarding the characteristics of the high rate of the invited children and adolescents that chose not to respond (85.72%).

Only one participant had asthma duration of two years or less, which may have limited the emergence of issues of adjustment to new diagnosis in relation to the comorbidity. Illness severity in the current sample was variable and measured only by self-report at the time of the interview. This responded to evidence showing illness severity not predicting anxiety amongst individuals with asthma (Feldman et al., 2009; Rietvield et al., 2005). On retrospect, however, it may have been useful to have accessed an objective measure of asthma severity.

As with all qualitative studies, considerations arose in relation to the role of the researcher in the process and analysis, especially given the authors' familiarity with this domain. This was managed by having expectations logged *a priori* to increase awareness of potential confirmatory bias, having a random selection of the interviews second-coded and seeking validation of the initial interpretation of the findings through important stakeholders and respondents. In IPA, researchers' existing knowledge and prior experience is viewed as a strength within the double hermeneutic process of the later stages of the analysis (Smith et al., 2009). Furthermore, the availability and use of prompts during the semi-structured interviews, where appropriate (Appendix H), may also be viewed as increasing bias and leading responses. The provision of prompts was in line with IPA methodology (Smith et al., 2009) and guidelines regarding qualitative interviewing with young people (Docherty & Sandelowski, 1999). Finally, limitations exist in relation to the lack of a comprehensive assessment of data saturation. However, the relatively homogeneous sample and focused research question, in addition to the prevalence of each subtheme in at least one third of the transcripts, may increase the consistency and credibility of the reported subthemes.

4.3. Conclusions

This research contributes to existing knowledge regarding young people's experience of living with asthma and anxiety and adds novel conceptions regarding the mechanisms that may maintain this comorbidity via a more in depth analysis. Findings were summarised in three major themes: *i*) *the influence of asthma* by inhibiting valued coping activities or developmental tasks, triggering catastrophic thinking and leading to an over-generalisation of asthma coping strategies to managing anxiety; *ii*) *the influence of anxiety* via affecting appropriate use of medication and triggering hyperventilation-induced asthma exacerbations; and *iii*) *the interaction between asthma and anxiety* by forming an unhelpful positive feedback loop and triggering symptom confusion. This report outlines how findings could inform clinical practice guidelines, guide assessments, contribute to the development of a conceptual model and in the adaptation of psychological interventions.

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III. EXTENDED METHODOLOGY CHAPTER

This chapter expands on aspects of the methodology of the empirical study not outlined in the main journal article.

1. Additional ethics considerations

Approvals were sought and obtained by the West of Scotland Research Ethics Service and the local Boards' Research and Development (R&D) offices (Appendix C).

1.1. Protecting confidentiality

Steps were undertaken to safeguard confidentiality and anonymity. All questionnaires and contact information forms returned at the initial screening stage were stored in a lockable cabinet within secure NHS premises and were only accessible by the main author and the clinical supervisor. Digital recordings of the interviews were safely stored on an NHS network drive and were only accessible to the main author and clinical supervisor. Consent to retain anonymised data at the University of Edinburgh for research governance purposes and for use in future research was explicitly obtained. Each participant taking part in the interview was assigned a pseudonym and all data (questionnaires and transcripts) were labelled using this pseudonym and were cleared of any identifiable information. This was monitored by the main author's clinical supervisor.

1.2. Obtaining informed consent/assent

The information sheets inviting families to participate contained comprehensive information regarding all stages and aspects of the research project (Appendix D), including consent or assent to take part, ability to withdraw at any time without this affecting their treatment, and actions taken to protect confidentiality, safeguard participants and manage potential distress.

Explicit explanations were provided regarding the use of direct but anonymised quotes from the interviews in the presentation of the research outcomes. The information sheets were adapted to be understandable and engaging, excluding jargon and technical terms. In line with current practice, two information forms were available for young people, one with even more simplified language for participants below the age of 12.

Implicit consent to take part in the initial screening stage of the study was assumed by returning their contact details and the screening questionnaires. Families were invited to contact the main researcher for additional information and were provided with an opportunity to clarify aspects of the study during the telephone conversation to arrange the interview appointment for the main stage of the study.

Guidance from the Scottish Children's Research Network (ScotCRN, 2012) was followed regarding obtaining written consent. It is suggested that all children below the age of 16 are considered competent to provide informed consent for a study should they be facilitated to do so appropriately (ScotCRN, 2012). Consequently, during the initial part of the interview the main author discussed the purpose and stages of the study in accessible language and encouraged families to ask questions to help clarify potential misunderstandings. Subsequently, written consent was sought by all participants above the age of 12 years and written assent was obtained by all parents/guardians who accompanied participants. In keeping with guidance from local R&D departments, written assent was sought from young people below the age of 12 with parents/guardians providing written consent (Appendix E). Competency to provide informed consent was assessed by the main author during the initial part of the meeting. This assessment was in line with evaluations of competency to consent to treatment, which the main author has undertaken routinely in clinical practice. In consultation with the researcher's clinical supervisor, this included an evaluation of participants'

understanding of the nature of the project and ability to describe the stages it involved, possible implications, awareness of the right to withdraw at any time, and how their data could be used.

1.3. Safeguarding participants

Participants' GPs were notified by a letter regarding their participation (Appendix F). All parents or guardians of potential participants who scored above the recommended threshold on the anxiety questionnaire were sent a standard letter to advise them of this and to encourage them to explore it further with their GP. This letter also provided website links with age-appropriate self-help material (Appendix G).

Talking about a chronic medical condition and anxiety can potentially be difficult. In an attempt to ensure that the main author approached these issues sensitively and appropriately, the interview schedule was piloted with three adults with childhood onset asthma and their feedback was used to improve the style and manner of the interviewer. One pilot interview was also reviewed by the main author's clinical supervisor to facilitate this process.

Prior to the start of the interview all participants were informed that should issues arise, including risk disclosures, permission would be sought to contact their GP and additional psychological support by the aligned child and adolescent mental health services could also be offered. A plan was in place to discuss risk management with the main author's clinical supervisor, to agree the appropriate action in line with relevant NHS regulations. Although the interviews were not expected to cause distress, the main researcher monitored participants' affect throughout to ensure that immediate support would be offered if necessary. Regular academic and clinical supervision was utilised for any unforeseen issues. Families were provided with key contact information if they became concerned about any aspect of the study.

1.4. Issues related to the researcher

The interviews were all conducted in clinical settings, although participants were invited to select a venue that would make young people feel calm and relaxed, which could be outside NHS premises, e.g., family home. To manage associated risks, the main author would follow the local NHS lone working policy.

1.5. Ethics of interpretation

Another consideration referred to the debate regarding the ethics of interpretation in qualitative research, which highlights that such processes can potentially be distressing or harmful for participants when overanalysing or misreading their narratives (Willig, 2012). Methods adopted in the present study in order to preserve the idiographic aspect of IPA and to ensure quality in the analysis, also allowed to manage such considerations, i.e., respondent validation, second-rating of transcripts, actively looking for alternative interpretations, remaining close to respondents' "voice" and focused on the research aims (Willig, 2012).

2. Procedure

2.1. Recruitment

In qualitative research the number of participants required depends on the breadth of the questions, the homogeneity of the sample and the richness of the data (Smith & Eatough, 2007). A sample size of six to ten interviews was considered viable for this study, given the time constraints of a project undertaken for a clinical doctorate course (Smith et al., 2009). A sample size of this level was also considered suitable given the focused research question in one targeted aspect of participants' lived experience and the implementation of eligibility criteria that allowed the recruitment of a closely specified homogeneous group. However, given that young people participated, whose verbal skills were likely not to be fully

developed, more respondents were aimed to ensure adequate richness in the findings. The sampling procedure took place between April and October 2014. Within this time frame, eleven participants were recruited.

The local respiratory teams initiated the approach of potential participants registered in their clinics by post. At this stage the research team was not involved and as such the local Caldicott Guardian advised that specific approval was not necessary. NHS Lanarkshire, NHS Lothian and NHS Greater Glasgow and Clyde tertiary paediatric asthma services agreed to participate, with only the former two eventually disseminating the research invitation letters.

In order to ensure that no more families would be contacted than necessary, a random selection of 187 young people (using a randomised sequence generated by random.org) from the Lanarkshire and Lothian tertiary asthma registers were initially sent the information packs and screening questionnaires. As previous studies suggested that postal recruitment typically results in 20-25% return rate, it was expected that approximately 40-45 questionnaires would initially be returned. Out of those potential participants, based on published prevalence rates (Vila *et al*., 2000), it was expected that 1/3 would report increased anxiety symptomatology, resulting in approximately 14 children. These would be screened to evaluate if they meet the rest of the eligibility criteria and would subsequently be invited to the interviews. In practice, as at this stage only nine young people were recruited, a random selection of a further 44 information packs were sent, resulting in a total of eleven participants meeting eligibility criteria and attending the interviews.

2.2. Eligibility criteria

Inclusion criteria

- Young people aged 11-16 years to ensure that participants had sufficiently developed

verbal skills to articulate their views and experiences.

- Young people with a diagnosis of asthma in accordance with the British Thoracic Society/Scottish Intercollegiate Guidelines Network (2008). As research suggested illness severity is independent of the association between asthma and anxiety (Rietvield *et al*., 2005), the level of asthma impairment was not set as an inclusion factor.

- Young people whose total score on the SCARED anxiety screening questionnaire was equal to or above the cut-off score of 22 (Desousa *et al*., 2013).

Exclusion criteria

- Young people with a recent diagnosis of childhood asthma were excluded. Recent diagnosis is commonly associated with increased parental and child anxiety as part of the adjustment process to the condition and its challenges (Gupta *et al*., 2001). Although the length of the period needed to adjust to a chronic condition may vary dependent on a range of factors (Christie & Khatun, 2012), a minimum of six months since diagnosis was considered adequate in consultation with the paediatric psychology and the respiratory team.

- Young people with other physical health conditions, not related to asthma. Other atopic conditions (e.g., allergies or eczema) were not excluded as these are highly co-morbid with asthma (Rees *et al*., 2006) and affect a large percentage of the asthma population.

- Young people with severe mental health difficulties (e.g., psychosis), pervasive developmental disorders or learning disability that would affect their ability to communicate their views and capacity to provide informed consent.

- Non-English speakers. The interviews required sufficient verbal fluency. In addition,

the anxiety questionnaire was standardised in the English language and its translation could compromise consistency and the validity of using the suggested cut-off score.

3. Data collection

3.1. Developing the interview guide

An interview schedule was developed to ensure the process focused on the research aims. In line with guidance in IPA, this schedule was used in a semi-structured, non-prescriptive and non-rigid manner (Smith *et al*., 2009). It was developed in consultation between the research team and designed following the principles published by Smith and Eatough (2007), i.e., initial questions were open and reflective to allow participants to express their own perceptions and experiences, with probes available to ensure that the interview covers all areas relevant to the research objectives. Although particular consideration was paid to ensuring that the questions were not leading, specific prompts about areas to consider were thought necessary for young people in this study. This was in keeping with methodological considerations about interviewing children and adolescents, and managing developmental limitations in recalling or verbalising (Docherty & Sandelowski, 1999). Although, researchers previously queried the validity or efficiency of qualitative interviews with younger people, sufficient evidence currently exist that qualitative methods with children and adolescents can be extremely informative, allowing us to step outside the boundaries of our adult perspectives, and may be less directive than using inventories or scales that inevitably cue responses (Eiser & Morse, 2001; Mishna *et al*., 2004).

In line with the objectives of the study, the interview schedule aimed to examine all aspects of the experience of living with asthma and anxiety, including cognitions, personal attributions, emotions, physiological reactions and coping behaviours or management strategies. The guide was piloted with three adult volunteers with childhood onset asthma.

Their comments were used to amend the wording and approaching of questions, with feedback elicited by employing cognitive interviewing techniques at the end of the pilot interviews (Haeger *et al*., 2012). In particular, the retrospective verbal probing techniques included comprehension probes ("what does this term mean to you?"), paraphrasing probes ("how else would you express this question?") and general or recalling probes ("what was difficult in answering this question?", "what did you recall to respond to this question?") (Willis, 1999). The pilot interviews were audio-recorded and the final interview was reviewed by the clinical supervisor in order to revise the schedule and refine the main researcher's interview style and technique.

4. Analysis

4.1. The underpinnings of IPA

IPA is informed by three philosophical strands, namely phenomenology, hermeneutics and idiography (Smith *et al*., 2009). It is phenomenological as it is concerned with how individuals perceive their world and reflect on their lived experience (Smith & Osborn, 2003). It involves a 'double hermeneutic' approach, referring to the individuals' attempt to make sense of their experience and the researcher's effort to make sense of the individuals' accounts (Smith *et al*., 2009). As the researcher's approach is filtered by their own perceptions, experiences and pre-existing beliefs, it guides the researcher to engage in the analysis adopting an open, reflexive position (Starks & Trinidad, 2007). IPA also adopts an idiographic approach in that the inquiry is not focused on the population level, but it examines the individual's particular accounts of their experience and efforts for meaning making as they cope with aspects of their lives (Starks & Trinidad, 2007).

4.2. Choosing a qualitative research method

IPA is the approach of choice in qualitative healthcare research (Reid *et al*., 2005) and is therefore extensively tested for its ability to contribute to this field. To date it has had a substantial impact in deriving patients' experiences of conditions or treatments in a number of areas, including genetics (Michie *et al*., 2003), cancer (Jarrett *et al*, 1999) and pain (Osborn & Smith, 1998), leading to improvements and developments in the provision of care and treatment, which was consistent with the aims of this project. IPA is also extremely detailed as a framework and, thus, sufficiently accessible for a novice researcher. In addition, it is compatible with current psychological models, such as CBT, as it takes a theoretical stance of assuming a connection between participants' talks, thoughts and affect (Smith & Eatough, 2007). IPA also places increased emphasis on the researcher's subjective stance and predispositions. Although a reflexive approach to pre-existing assumptions and knowledge is inherent in most qualitative methods, including IPA, such preconceptions and understandings are also integrated in the analytic process of IPA; they are acknowledged and become transparent in the interpretations within the double hermeneutic approach (Smith *et al*., 2009), which resonated better with the main researcher. The principles of IPA were, therefore, considered to fit appropriately with the aims of the study. Alternative established methodologies were also examined, namely discourse analysis and grounded theory. While these approaches have some commonalities and could have differentially informed the research question, when all factors were weighed, IPA was selected for the present study.

To be more specific, discourse analysis is concerned with how the individuals use language to construct identities or realities and accomplish activities (Starks & Trinidad, 2007). Although some consideration of the impact of discourses on self was important in the analysis, overall this method's aims and theoretical framework were felt to be less relevant to

the study aims. It was therefore deemed that the impact of language alone was less efficient in describing participants' realities and experiences in this context and in facilitating the study objectives.

Grounded theory, on the other hand, is concerned with developing a theory to explain social processes and the method is designed to allow concepts to become evident from the data (Starks & Trinidad, 2007). This focus extended beyond the aims of this study, which was seeking to understand a phenomenon by exploring an aspect of participants' individual experience. Less emphasis is placed in grounded theory on the analysts' predispositions and subjective stance, and Glasser (1998) discourages early reading in the topic to ensure an open position. In the present project, this would have been challenging given the lead author's prior clinical experience. The limited resources and time of the researcher would also potentially challenge the ability to achieve a sufficient number of participants for theoretical saturation, which is pertinent in grounded theory and this was also accounted for in the decision-making regarding the most appropriate method.

4.3. Transcription

In line with Yardley's (2000) recommendations to improve commitment and rigour in the analysis, the transcription was undertaken by the main researcher. As IPA focuses more on interpreting the content of the respondent's narrative, rather than on a detailed linguistic analysis, utterances, pauses or laughter were recorded, but without extensive details and exact lengths, in keeping with this method's suggestions (Smith *et al*., 2009). In addition, guidance was also followed in relation to initiating transcription after all interviews were completed (Smith & Eatough, 2007). This was to ensure that the main author remains true to the method's idiographic focus and does not impose informal interpretations emerging at transcription stage with respect to the manner the final interviews were conducted.

4.4. Respondent and stakeholder validation

Participants and their parents, as important stakeholders, were invited to feedback on the initial interpretation of the findings either through telephone contact or written response (Appendix I). Six of the eleven participants contributed to this stage of the study, all by phone.

Overall, young people reported that the themes largely provided a good representation of their perceptions and attributions regarding their experience of the interplay between asthma and anxiety. In order to ensure that they were provided enough space to express their personal and potentially alternative views, young people were purposefully asked questions such as: "are these in any way different to your experience of living with asthma?", "have I covered all the areas that were important to you?", "was there another way of viewing the results?", "was there any theme that surprised you, or was unexpected, or you felt was less relevant to you?". Such questions prompted young people to discuss aspects of the master themes that were less representative of how they would describe or interpret their experiences.

The themes that young people reported to be relevant to them were in agreement to the themes attributed to them in the initial analysis (see Appendix J for details). This demonstrated rigour in the findings and increased the credibility and trustworthiness of the interpretation. Three participants reported identification with more subthemes than initially revealed in their individual transcripts and provided examples of such experiences. Consequently, their original transcripts were revisited to check if they contain evidence of these additional themes; if not, then these additional subthemes would not be attributed to them. In any case, such reports increased confidence that the identified themes covered a wide range of experiences of living with asthma and anxiety. Similarly, one participant reported that the third theme was not relevant to them, despite this theme having been

identified in their interview. Their transcript was revisited with the supervisor and it was agreed that the relevant quotes clearly described the relevent subtheme and that this may be an issue of limited awareness.

The same process was followed with parents, who were asked similar questions. Parents also identified more subthemes to be relevant to their experience of bringing up a child with asthma, than initially revealed within their children's transcripts, which further increased confidence in the credibility of the findings. They reflected on how complex this comorbidity appeared to be and provided examples how the initial themes informed the way they interpreted some of the behaviours they had previously observed at home. Interestingly, two were able to progress this interpretation further by starting to consider strengths and protective factors in their children and it was agreed that the interview was not sufficiently geared towards exploring what protects young people from further deteriorations in their asthma or anxiety.

Finally, the specialist nurses involved in the recruitment process were invited to review the initial results of the analysis and assist in the final interpretation. They added to the interpretation by encouraging the lead author to consider the side effects of reliever medication, including palpitation, anxiety and tremor, which were subsequently incorporated as factors within the second and third super-ordinate themes. They further indicated that it was unexpected to see the impact asthma has on young people's lives and how this influences their anxiety (first theme), given that the respondents' asthma was monitored by the medical team and was, therefore, controlled. Such feedback allowed for reflections suggesting that the themes revealed herein emerged from young people with asthma who were also anxious, and may, thus, somewhat demonstrate their perception of the impact of asthma rather than the consequences of objective pulmonary function. This is consistent with evidence regarding

symptom overperception amongst highly anxious children and adolescents with asthma (Chen *et al.,* 2006). Finally, they indicated that it was encouraging to see the subthemes regarding the 'medicalised' ways of managing with anxiety and the over-generalisation of asthma strategies to coping with anxiety. They reported that they often observe such behaviours in clinics and not enough consideration has been given in their practice to the possibility that this may be counterproductive for anxiety, potentially maintaining it.

Discussions with the nurses and some of the parents, also pointed to the unclear distinctions between the subthemes referring to the interaction between asthma and anxiety, as initially presented to respondents and important stakeholders (see Appendix I for details). Supervision facilitated reflection on how the second subtheme ("working together to make things worse", which was referring to the cumulative impact of experiencing any comorbidity -in this case asthma and anxiety) was less directly relevant to the research question and was, therefore, not included in the final report.

4.5. Quality assurance

The principles outlined by Yardley (2000; 2008) were followed to promote quality and rigour in the research. *Sensitivity to context* was attained by extensively engaging with available evidence within this field and reflecting on the lead author's pre-existing clinical experience in respiratory health and treatment of anxiety. In addition, reflexivity (as briefly outlined in the prologue) allowed a consideration of the influence of the setting of the study and the main researcher's assumptions and role on the data participants chose to share.

Commitment was endeavoured by ensuring a prolonged immersion in the data. This was demonstrated by undertaking 11 in-depth interviews with a narrowly defined sample, which were transcribed and repeatedly read for the analysis, twice alongside audio-recordings, in addition to conducting three pilot interviews. *Rigour* was attempted by applying a random

recruitment procedure to reduce bias in the initial selection process, implementing strict empirically-based eligibility criteria to ensure a highly homogeneous representative sample and focusing the research question in a closely defined aspect of participants' experience. Furthermore, a random selection of transcripts were second-coded independently by the main researcher's clinical supervisor, who is experienced in the clinical field and IPA methodology. High level of agreement in the emergent themes was achieved and a consensus was reached in the super-ordinate themes through supervision. Respondent validation and important stakeholder validation was also sought, by posting an initial summary of the results to families and carefully considering how these cover, or not, young people's and their parents' experiences and understandings of the phenomenon. This included seeking validation of the original findings through the specialist respiratory nurses involved in this project and incorporating everyone's feedback and interpretations in the final report, where appropriate.

Coherence was displayed by thoroughly considering the choice of qualitative methodology to fit with the study aims, by following the standardised procedures recommended (Smith *et al*., 2009) and narrating findings in a manner that informed existing knowledge in this field. *Transparency* was demonstrated by detailing the stages of recruitment, data collection and analysis, including summary tables, theme prevalence across and within participants and samples of analysis (Appendix J), and maintaining an audit trail of decisions, reflections and pathway that led to the final report.

Impact and importance may be demonstrated by reviewing the rationale that led to the design of this study, as outlined in the introduction of the main journal article, which was effectively to respond to a specific gap in existing knowledge as highlighted by key researchers and national guidelines in this field. The multiple potential clinical implications of the findings as

described in the discussion of the journal article also responded to this evaluative criterion.

Other guidance to increase the credibility and trustworthiness of the data was also considered. For example, careful consideration was paid to the IPA evaluative criteria as specified by Smith (2011); in particular on the factors not emphasised in Yardley's (2000) main recommendations, i.e., maintaining a balanced consideration between patterns of divergence and convergence in the data, pre-setting measures of minimum prevalence of reported themes amongst participants (in at least 1/3), and ensuring enough extracts were presented to support each theme.

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APPENDIX A

Author guidelines for the Journal of Anxiety Disorders

Editorial guidance

The Journal of Anxiety Disorders publishes articles of relevance to the epidemiology, psychopathology, etiology, assessment, treatment, and prevention of the anxiety disorders in both child and adult populations. The format of the articles includes randomized controlled trials, single case clinical outcome studies, theoretical expositions, epidemiological studies, early mechanisms of risk, genetic and biomarker studies, neuroimaging studies, critical literature reviews, meta-analyses, and dissemination and implementation studies. We are also interested in evaluations of novel treatment delivery strategies, including the use of information technologies. Authors are encouraged to use methodologically rigorous sampling, structured or semistructured diagnostic interviews, randomization, therapist fidelity, and inter-rater reliability procedures where appropriate. With the exponential increase in the number of submissions to the journal over the last several years, there has been a need to make difficult decisions regarding the type of manuscripts that we believe are most relevant and useful to JAD readers. Although analogue studies and studies using non-clinical samples often are excellent approaches to controlled research, particularly in the area of etiology, others represent only very minor variations on repetitive themes, failing to advance the field in any meaningful way. Therefore, given limited journal space, we will no longer accept studies based on analogue samples unless they use a tightly controlled experimental design in order to enhance our understanding of etiology.

Language (usage and editing services)

Please write your text in good English (American or British usage is accepted, but not a mixture of these). Authors who feel their English language manuscript may require editing to eliminate possible grammatical or spelling errors and to conform to correct scientific English may wish to use the English Language Editing service available from Elsevier's WebShop (http://webshop.elsevier.com/languageediting/) or visit our customer support site (http://support.elsevier.com) for more information.

References

There are no strict requirements on reference formatting at submission. References can be in any style or format as long as the style is consistent. Where applicable, author(s) name(s), journal title/book title, chapter title/article title, year of publication, volume number/book chapter and the pagination must be present. Use of DOI is highly encouraged. The reference style used by the journal will be applied to the accepted article by Elsevier at the proof stage. Note that missing data will be highlighted at proof stage for the author to correct.

Formatting requirements

There are no strict formatting requirements but all manuscripts must contain the essential elements needed to convey your manuscript, for example Abstract, Keywords, Introduction, Materials and Methods, Results, Conclusions, Artwork and Tables with Captions. If your article includes any Videos and/or other Supplementary material, this should be included in your initial submission for peer review purposes.

Divide the article into clearly defined sections.

Article structure

Subdivision - numbered sections

Divide your article into clearly defined and numbered sections. Subsections should be numbered 1.1 (then

1.1.1, 1.1.2, ...), 1.2, etc. (the abstract is not included in section numbering). Use this numbering also for internal cross-referencing: do not just refer to 'the text'. Any subsection may be given a brief heading. Each heading should appear on its own separate line.

Introduction

State the objectives of the work and provide an adequate background, avoiding a detailed literature survey or a summary of the results.

Material and methods

Provide sufficient detail to allow the work to be reproduced. Methods already published should be indicated by a reference: only relevant modifications should be described.

Theory/calculation

A Theory section should extend, not repeat, the background to the article already dealt with in the Introduction and lay the foundation for further work. In contrast, a Calculation section represents a practical development from a theoretical basis.

Results

Results should be clear and concise.

Discussion

This should explore the significance of the results of the work, not repeat them. A combined Results and Discussion section is often appropriate. Avoid extensive citations and discussion of published literature.

Conclusions

The main conclusions of the study may be presented in a short Conclusions section, which may stand alone or form a subsection of a Discussion or Results and Discussion section.

Abstract

A concise and factual abstract is required. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separately from the article, so it must be able to stand alone. For this reason, References should be avoided, but if essential, then cite the author(s) and year(s). Also, non-standard or uncommon abbreviations should be avoided, but if essential they must be defined at their first mention in the abstract itself. The abstract should not exceed 150 words in length and should be submitted on a separate page following the title page.

Highlights

Highlights are mandatory for this journal. They consist of a short collection of bullet points that convey the core findings of the article and should be submitted in a separate editable file in the online submission system. Please use 'Highlights' in the file name and include 3 to 5 bullet points (maximum 85 characters, including spaces, per bullet point). See http://www.elsevier.com/highlights for examples.

Keywords

Include a list of four to six keywords following the Abstract. Keywords should be selected from the APA list of index descriptors unless otherwise approved by the Editor.

APPENDIX B

Operationalisation of the systematic review quality criteria

1. Study design provides sufficient evidence that the anxiety outcomes are due to the intervention	
Well covered (3)	Experimental - randomised controlled trial
Adequately addressed (2)	Quasi experimental - non randomised controlled trial / multiple baseline
Poorly addressed (1)	Observational - repeated measures design / uncontrolled trial
Not addressed (0)	Observational - single-case design
2. Recruitment method and inclusion criteria are appropriate to ensure a representative and suitable sample	
Well covered (3)	A representative recruitment procedure (e.g., random sampling) is applied to reduce selection bias & appropriate sample eligibility criteria are applied to address the review aims (e.g., asthma, anxiety levels).
Adequately addressed (2)	A convenience recruitment procedure is applied, but appropriate attempts have been made to address sample representativeness or participants' inclusion criteria are only adequately appropriate to address the review aims.
Poorly addressed (1)	Convenience recruitment procedure without sufficient attempts to reduce bias in sample selection or participants inappropriate to address the review aims.
Not addressed (0)	Recruitment method inappropriate or poorly described & no attempt to apply eligibility criteria or address participants' characteristics.
3. Sample size (power) is sufficient for analysis relating to pre and post anxiety outcomes	
Well covered (3)	Number of participants who completed both pre & post measures in the intervention group is sufficient to achieve Power of at least 0.8, where effect size is anticipated to be medium & alpha is 0.05.
Adequately addressed (2)	Number of participants who completed both pre & post measures in the intervention group is sufficient to achieve Power of at least 0.7, where effect size is anticipated to be medium & alpha is 0.05.
Poorly addressed (1)	Number of participants who completed both pre & post measures in the intervention group is sufficient to achieve Power of less than 0.7, where effect size is anticipated to be medium & alpha is 0.05.
Not addressed (0)	Sample size not reported.
4. Allocation process is appropriate to address allocation bias	
Well covered (3)	Appropriate process of allocation to treatment groups is applied to address bias & investigator(s) are blinded (e.g., random allocation).
Adequately addressed (2)	Only adequate process of allocation to groups is used to address bias (i.e., poor randomisation method).
Poorly addressed (1)	Control group not randomised.
Not addressed (0)	No control group.
5. Groups are comparable at baseline on key variables (i.e., asthma or anxiety severity, age, gender)	
Well covered (3)	The treatment & control groups comparable at baseline or sufficient attempts have been made to statistically control for the differences.
Adequately addressed (2)	The treatment & control groups only adequately comparable at baseline or only adequate attempts have been made to control for the differences.
Poorly addressed (1)	The treatment & control groups are not comparable at baseline or no attempts have been made to address the differences.
Not addressed (0)	No control group.
6. Measures of anxiety are robust, appropriately administered and well-validated	
Well covered (3)	The primary anxiety measures are clearly suitable, valid, reliable, standardised & appropriately administered.
Adequately addressed (2)	Most primary anxiety measures are only adequately appropriate, valid, reliable, standardised or only

	adequately administered.
Poorly addressed (1)	Less than 50% of the primary anxiety measures are adequately appropriate, valid & reliable or adequately administered.
Not addressed (0)	Not appropriate primary anxiety measures are selected or these are inappropriately administered.
7. Follow-up measures are administered to evaluate if effects are maintained long-term	
Well covered (3)	Follow-up anxiety measures ≥ 12 months
Adequately addressed (2)	Follow-up anxiety measures ≥ 6 months
Poorly addressed (1)	Follow-up anxiety measures < 6 months.
Not addressed (0)	No follow-up anxiety measures administered.
8. Treatment protocol is suitable for improving anxiety outcomes in the context of asthma	
Well covered (3)	A sufficiently detailed CBT treatment protocol is used & this is appropriate to improve anxiety outcomes (e.g., sufficient number of sessions, clear & valid protocol rationale/content, sufficient level of therapist input).
Adequately addressed (2)	An adequately detailed CBT protocol is used or this is only partially appropriate to improve anxiety outcomes (number of sessions, protocol rationale/content, level of therapist input).
Poorly addressed (1)	The CBT protocol is not sufficient to ensure reliability or it is not adequate to improve anxiety outcomes (number of sessions, protocol rationale/content, level of therapist input).
Not addressed (0)	No treatment protocol is used.
9. Intervention is appropriately conducted and adherence to protocol is suitably assessed	
Well covered (3)	Intervention is carried out by experienced therapists in CBT, & sufficient procedures are available to ensure treatment is applied accurately & consistently (e.g. standardised measure to assess adherence, or recording & close supervision).
Adequately addressed (2)	Intervention is carried out by adequately trained therapists or only adequate procedures to ensure adherence to treatment are used.
Poorly addressed (1)	Intervention is not carried out by suitably trained therapists or not appropriate procedures to ensure treatment fidelity are used.
Not addressed (0)	No information about the therapists' background or procedure to assess treatment fidelity.
10. Analysis is appropriate for the study aims, measures or design and outcomes are appropriately reported	
Well covered (3)	An appropriate statistical analysis is conducted (excl. missing data analysis) & the outcomes are appropriately reported.
Adequately addressed (2)	An adequately appropriate statistical analysis is conducted (excl. missing data analysis) or the outcomes are only adequately reported.
Poorly addressed (1)	Inappropriate or poorly conducted statistical analysis is used or the outcomes are poorly reported.
Not addressed (0)	Statistical analysis not carried out or not reported.
11. Attrition rates are low or comparable to control group	
Well covered (3)	Attrition rates are low (≤20%) or equivalent to control group at post-treatment & follow-up.
Adequately addressed (2)	Attrition rates are moderate (≤40%) or moderately different from control group at post-treatment & follow-up.
Poorly addressed (1)	Attrition rates are high or differ substantially from control group at post-treatment & follow-up.
Not addressed (0)	Attrition rates not reported or considered.
12. Method to address missing data is suitable	
Well covered (3)	No missing data or a suitable method to address missing data is used (e.g., intention to treat analysis, maximum likelihood estimation).
Adequately addressed (2)	An adequate method to address missing data is used.
Poorly addressed (1)	Missing data are poorly addressed.
Not addressed (0)	No attempt to consider missing data in the analysis.

APPENDIX C

Ethical and R&D approvals

WoSRES
West of Scotland Research Ethics Service

NHS
Greater Glasgow and Clyde

Ms Eleni Pateraki
Trainee Clinical Psychologist
NHS Lanarkshire
Paediatric Psychology Service (CAMHS)
Wishaw General Hospital
50 Netherton Street
Wishaw
ML2 0DP

West of Scotland REC 5
Ground Floor - Tennent Building
Western Infirmary
38 Church Street
Glasgow
G11 6NT

Date 23 December 2013

Direct line 0141 211 2102
E-mail WoSREC5@ggc.scot.nhs.uk

Dear Ms Pateraki

Study title: **Towards an understanding of the interaction between childhood asthma, anxiety and medication use: Exploring young people's perspectives and attributions.**
REC reference: **13/WS/0318**
Protocol number: **N/A**
IRAS project ID: **136165**

The Research Ethics Committee reviewed the above application at the meeting held on 18 December 2013. Thank you for attending to discuss the application with Dr Vance.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Mrs Sharon Macgregor, WoSREC5@ggc.scot.nhs.uk.

Ethical opinion

Ethical issues raised by the Committee in private discussion, together with responses given by the researcher when invited into the meeting

You were asked what the initials in the right hand column of the SCARED questionnaire meant and whether it was appropriate for the participants to see them. You confirmed that these stand for different types of anxiety disorders (eg PN is Panic disorder) and that this column would be removed before the questionnaire was given to participants.

It was noted that the participants will be asked to check an anonymous summary of all the interviews and you were asked to explain this process. You advised that this is to check that you have reflected the lived experiences of the participants.

The Committee asked why two digital recorders will be used during the interviews and you

advised that this is for back up only in case one recorder fails.

It was noted that the tests for criteria were very general and you were asked if you were concerned that there may be a chance that some potential participants could be lost. You advised that the test will pick up children with increased anxiety.

You also confirmed that that you will ask if the normal medication plan or use of inhalers changes when the child is more anxious.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

1. In the Young Person Consent Form and Assent form, the third statement should be changed to "I agree to my information being audio-recorded, listened to and written down".

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Evidence of insurance or indemnity		25 June 2013
Interview Schedules/Topic Guides	1.0	28 November 2013
Investigator CV		
Other: Contact Information Form	1.0	28 November 2013
Other: Parent/Guardian Assent Form	1.0	28 November 2013
Other: Young Person Assent Form	1.0	28 November 2013
Other: Letter to advise of increased score	1.0	28 November 2013
Other: GP letter	1.0	28 November 2013
Other: Academic Supervisor CV (Morris)		
Other: Clinical Supervisor CV (Vance)		
Participant Consent Form: Parent/Guardian	1.0	28 November 2013
Participant Consent Form: Young Person	1.0	28 November 2013
Participant Information Sheet: Parent/Guardian	1.0	28 November 2013
Participant Information Sheet: Young People	1.0	28 November 2013
Participant Information Sheet: Younger Children	1.0	28 November 2013
Protocol	1.0	28 November 2013
Questionnaire: SCARED		
Questionnaire: Screening	1.0	28 November 2013
REC application		02 December 2013

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

13/WS/0318	Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

Yours sincerely

SMacgregor

for
Dr Gregory Ofili
Chair

Enclosures:	List of names and professions of members who were present at the meeting and those who submitted written comments "After ethical review – guidance for researchers"
Copy to:	Professor Charlotte Clarke, The University of Edinburgh Raymond Hamill, NHS Lanarkshire

WoSRES
West of Scotland Research Ethics Service

NHS
Greater Glasgow and Clyde

Ms Eleni Pateraki
Trainee Clinical Psychologist
NHS Lanarkshire
Paediatric Psychology Service (CAMHS)
Wishaw General Hospital
50 Netherton Street
Wishaw
ML2 0DP

West of Scotland REC 5
Ground Floor - Tennent Building
Western Infirmary
38 Church Street
Glasgow
G11 6NT

Date 08 January 2014

Direct line 0141 211 2102
E-mail WoSREC5@ggc.scot.nhs.uk

Dear Ms Pateraki

Study title: **Towards an understanding of the interaction between childhood asthma, anxiety and medication use: Exploring young people's perspectives and attributions.**
REC reference: **13/WS/0318**
Protocol number: **N/A**
IRAS project ID: **136165**

Thank you for your email of 4 January 2014. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 23 December 2013.

Documents received

The documents received were as follows:

Document	*Version*	*Date*
Interview Schedules/Topic Guides	2.0	04 January 2014
Other: Young Person Assent form	2.0	04 January 2014
Participant Consent Form: Young Person	2.0	04 January 2014
Questionnaire: SCARED (revised)		

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	*Version*	*Date*
Evidence of insurance or indemnity		25 June 2013
Interview Schedules/Topic Guides	2.0	04 January 2014

Investigator CV		
Other: Contact Information Form	1.0	28 November 2013
Other: Parent/Guardian Assent Form	1.0	28 November 2013
Other: Letter to advise of increased score	1.0	28 November 2013
Other: GP letter	1.0	28 November 2013
Other: Academic Supervisor CV (Morris)		
Other: Clinical Supervisor CV (Vance)		
Other: Young Person Assent form	2.0	04 January 2014
Participant Consent Form: Parent/Guardian	1.0	28 November 2013
Participant Consent Form: Young Person	2.0	04 January 2014
Participant Information Sheet: Parent/Guardian	1.0	28 November 2013
Participant Information Sheet: Young People	1.0	28 November 2013
Participant Information Sheet: Younger Children	1.0	28 November 2013
Protocol	1.0	28 November 2013
Questionnaire: Screening	1.0	28 November 2013
Questionnaire: SCARED (revised)		
REC application		02 December 2013

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

13/WS/0318 **Please quote this number on all correspondence**

Yours sincerely

Mrs Sharon Macgregor
Committee Co-ordinator

Copy to: Professor Charlotte Clarke, The University of Edinburgh
Raymond Hamill, NHS Lanarkshire

Ms Eleni Pateraki
Trainee Clinical Psychologist
Paediatric Psychology Service (CAMHS)
Wishaw General Hospital
50 Netherton Street
Wishaw
ML2 0DP

R&D Department
Corporate Services Building
Monklands Hospital
Monkscourt Avenue
AIRDRIE
ML6 0JS

Date 31 January 2014
Enquiries to Lorraine Windsor,
R&D Facilitator
Direct Line 01236 712459
Email Lorraine.Windsor@lanarkshire.scot.nhs.uk

Dear Ms Pateraki

Project title: Towards an understanding of the interaction between childhood asthma, anxiety and medication use: Exploring young people's perspectives and attributions.

R&D ID: L13123_GE55

NRS ID Number: NRS13/PE74

I am writing to you as Chief Investigator of the above study to advise that R&D Management approval has been granted for the conduct of your study within NHS Lanarkshire as detailed below:

NAME	TITLE	ROLE	NHSL SITE TO WHICH APPROVAL APPLIES
Ms Eleni Pateraki	Trainee Clinical Psychologist	Principal Investigator	Paediatric Respiratory Unit, Wishaw General Hospital Paediatric Psychology Service, Wishaw General Hospital

For the study to be carried out you are subject to the following conditions:

Conditions

- You are required to comply with Good Clinical Practice, Ethics Guidelines, Health & Safety Act 1999 and the Data Protection Act 1998.
- The research is carried out in accordance with the Scottish Executive's Research Governance Framework for Health and Community Care (copy available via the Chief Scientist Office website: http://www.show.scot.nhs.uk/cso/ or the Research & Development Intranet site: http://firstport/sites/randd/default.aspx.

- You must ensure that all confidential information is maintained in secure storage. You are further obligated under this agreement to report to the NHS Lanarkshire Data Protection Office and the Research & Development Office infringements, either by accident or otherwise, which constitutes a breach of confidentiality.
- Clinical trial agreements (if applicable), or any other agreements in relation to the study, have been signed off by all relevant signatories.
- You must contact the R&D Department if/when the project is subject to any minor or substantial amendments so that these can be appropriately assessed, and approved, where necessary.
- You notify the R&D Department if any additional researchers become involved in the project within NHS Lanarkshire
- You notify the R&D Department when you have completed your research, or if you decide to terminate it prematurely.
- You must send brief annual reports followed by a final report and summary to the R&D office in hard copy and electronic formats as well as any publications.
- If the research involves any investigators who are not employed by NHS Lanarkshire, but who will be dealing with NHS Lanarkshire patients, there may be a requirement for an SCRO check and occupational health assessment. If this is the case then please contact the R&D Department to make arrangements for this to be undertaken and an honorary contract issued.

I trust these conditions are acceptable to you.

Yours sincerely,

Raymond Hamill – Corporate R&D Manager

cc.

NAME	TITLE	CONTACT ADDRESS	ROLE
Charlotte Clarke	Head of School	University of Edinburgh	Sponsor Contact
Margaret Johnston	Children's Services	Wishaw General Hospital	Named Contact

c.c – (email)
nhsg.nrscc@nhs.net

CC Paul Dearie, QA Manager,
Karen Maitland, Research Governance Manager,
Gavin Robertson, Research Governance Officer,
Fiona Mitchell, Director of Operations, Women and Childrens Associated Services

APPENDIX D

Parent/guardian and young people information sheets and forms

PART I: For parents/guardians

Information Sheet

Dear parent / guardian,

Your child is being invited to take part in a research study that is being conducted as part of my Doctorate degree in Clinical Psychology with the University of Edinburgh and the NHS.

Before you and your child agree to take part it is important that you understand what this research involves and why it is being done. Please take time to read the following information carefully. Please contact me (Eleni Pateraki, Trainee Clinical Psychologist), if there is anything that is not clear or if you would like more information.

Title of the project:

The interaction between childhood asthma, anxiety and medication use: Exploring children and young people's perspectives and attributions.

What is the purpose of the study?
The aim of the study is to help us understand children and young people's experiences and thoughts about asthma, anxiety and medication use. It appears that this issue has not been sufficiently explored and this research is expected to provide us with valuable information about how to improve the assessment and treatment of both difficulties when they occur together.

Why has my child been chosen?
Your child is invited because he/she has asthma and is aged between 10 and 16 years.

Does he/she have to take part?
No. Your child's participation in the study will be voluntary and their responses will remain confidential and anonymous. If you do decide to take part, you and your child will be asked to sign a consent forms.

As this study takes place within NHS, if you are invited to an interview, I will write to your GP to say that you have agreed to take part. Even if you agree to take part you are still free to withdraw at any time and without giving a reason. If you withdraw, your child's personal data will be securely destroyed. A decision to withdraw at any time will not interfere with your child's treatment or care or your relationship with staff in any way.

What will happen if my child takes part?
The research involves the following stages:

1) STAGE ONE: QUESTIONNAIRES

   If you agree to take part, you and your child will need to complete and sign the enclosed contact information form and complete the 'Screening Questionnaire'. The contact information is necessary so that I know how to contact you for the second stage of the research.

   Your child will also need to complete the enclosed anxiety questionnaire, which is designed to explore common childhood worries and fears.

   You will then need to return all the completed questionnaires and the contact information form in the enclosed freepost envelope. If you return these, then I will assume that you and your child have agreed to take part at least in this first part of the study.

2) STAGE TWO: INTERVIEW

   In the second stage of the study, I will contact a small proportion of parents/guardians who returned the questionnaires to invite their child to have an interview with me to discuss how they feel their asthma and worries or fears interact together. Before we start the interview, you can ask questions again about the study and I will ask you and your child to sign consent forms that you agree to take part in the study.

   The interview will take place in a venue of your choice (e.g. your home, hospital clinic or GP surgery, the local library). The length will depend on how much your child wishes to share, but I expect it will not be longer than 45-60 minutes. We can have breaks during the discussion if required. I do not expect that the questions are going to be upsetting or uncomfortable, but if your child feels so we will stop or have break.

   I will need to audio-record the interview using two digital recorders to allow me to recall the content and analyse the information that your child provides.

3) STAGE THREE: INTERPRETATION

   If you and your child agree, I will later ask you to read a brief summary of the analysis of all the interviews to help me with the interpretation based on your experience of living with asthma. This summary will be completely anonymised. This will happen through a telephone conversation at a later stage of the study, after I finish with all the interviews of the participants. When we meet for the interview, we can arrange a telephone appointment to do this. I do not expect this telephone conversation to last more than 10-15 minutes. As we talk I will take notes to make sure I remember the ideas and suggestions you made after reading the summary of the analysis.

What are the possible advantages/disadvantages of taking part?

The study is not intended to be of direct benefit to yourself or your child, but the results are expected to contribute in the improvement of NHS services.

In general, people who have taken part in similar studies have found it a positive experience to have a chance to feel listened to. In addition, if the score on the questionnaire suggests increased anxiety symptoms, I will write back to you to let you know, so that you consider if you want to seek support about this though your GP.

Will the information be kept confidential?
Yes, all information will be kept secure, confidential and anonymous. All audio-recordings and transcripts will be kept in a locked cabinet within NHS. Your child's name will be replaced by a pseudonym and it will not be possible for your family to be identified in the final reporting of the findings. Once the final results are reported, all recordings and transcripts will be securely deleted. Fully anonymised data from the study, from which your child could not be identified, may be kept in the University of Edinburgh to assist in future research, if you provide consent for this.

If during the interview information is disclosed that indicate that your child or others are at risk, then I will need to share this information with others outside the research team.

What will happen to the results of the study?
The results will be submitted to the University of Edinburgh for review and may be presented in scientific journals or conferences. Small quotes from the interviews will only be used after being made anonymous and any information that might identify your child will be removed.

Can I find out the results?
Yes. I will write back to you to provide an explanation of the results.

Did anyone else check that the study is ok to do?
Yes. The West of Scotland Research Ethics Committee, which has the responsibility to scrutinise proposals for research on humans, has examined and approved the proposal for this study. Data generated as a result of this study will also be available for inspection by regulation authorities.

What if there is a problem?
If you think that you or your child have been harmed by participating in this study, you have the right to make a complaint and ask for compensation from the University of Edinburgh, who is sponsoring this research. Details can be found by the research team. Also, as a patient of the NHS, you have the right to make a complaint through the NHS process. Details can be found through your GP.

What to do next?
If you are willing to take part in this study, please return the questionnaires and the signed contact information forms in the freepost envelope. Dependent on the responses on the questionnaires, I may subsequently contact you to arrange an interview.

Thank you for taking the time to read and consider the above information!

If you have any questions about the study, we would be happy to discuss it in more detail with you. Please contact:

Lead Researcher:
Eleni Pateraki, Trainee Clinical Psychologist
Address: **Paediatric Psychology Service, Wishaw General Hospital (Level 3), ML2 0DP**
Telephone: **01698 366 754**

Supervisors:
Dr Paul Graham Morris
Address: The University of Edinburgh, Medical Quad, Teviot Place, EH8 9AG
Telephone: 0131 651 3956

Dr Yvonne Vance
Address: Paediatric Psychology Service, Wishaw General Hospital (Level 3), ML2 0DP
Telephone: 01698 366754

PART II: For children aged 12 or above

Information Sheet
(Young People)

You are being invited to take part in a study that is being carried out as part of my Doctorate degree in Clinical Psychology with the University of Edinburgh and the NHS.

Before you take part it is important that you understand what this research involves and why it is being done. Please take time to read the following information carefully. Please contact me (Eleni Pateraki, Trainee Clinical Psychologist), if there is anything that is not clear or if you would like more information.

Title of the project:

The interaction between childhood asthma, anxiety and medication use: Exploring children and young people's perspectives and attributions.

What is this research about?
The research is about people's experiences with asthma, anxiety and medication use. We would like to hear what it's like for you, what thoughts you have around these issues and how do you cope with your condition.

Why have I been chosen?
You are being invited because you have asthma and you are between 10 and 16 years.

Do I have to take part?
No, you are free to decide if you want to take part. If you do decide to take part, you can change your mind anytime without explaining why. If you withdraw, your data will be securely destroyed. There will be no consequences for your treatment or your relationship with the staff in the asthma clinic.

What will happen if I take part?

If you decide to take part, the following steps will take place.

1) You and your parent/guardian will need to complete the contact information form. You will also need to complete the two questionnaires enclosed.

When you finish, please return all the forms to me in the freepost envelope.

2) In the second step, I will meet with some of the people who returned the completed questionnaires. I may meet with you to ask you what it's like to live with asthma, your worries and thoughts about this and how you decide to take your medication. This meeting will last less than 60 minutes and we can have a break or stop at any point. I will be audio-recording the interview so I can remember the information you provided. Before we start the interview, you can ask questions and I will ask you and your

parent to sign consent forms that you agree to take part in the study.

3) When I finish with all the interviews, I will analyse them and make a summary of the initial results. This summary will be completely anonymised and it will not be possible to identify you in the results. If you agree to help at this stage, I will ask you and your parent/guardian to read this brief summary and I will call you to tell me what you think and if there are other ways of explaining the findings.

Will I be asked difficult or upsetting questions?

I will be asking about your asthma, your worries and thoughts about it. Hopefully this won't be upsetting. You can decide not to answer a difficult question, to stop or have a break.

Will my information be kept private?

Yes, all information will be locked away and remain private. However, if you say something that makes me worried about you or someone else, I will have to say to your parent/guardian and your GP. Also, if the questionnaire shows you have many worries and fears, I will write back to your family to let you know and suggest what you can do to get help if you want.

What will happen to the results of the study?

The results will be submitted to the University of Edinburgh and may be presented in scientific journals or conferences. Small parts from the interviews will only be used after removing all the information that might identify you. If you agree to this, written manuscripts of the interviews may be used in future research, only after removing all the information that might identify you.

Can I find out the results?

Yes. I will send you an explanation of the results.

Did anyone else check that the study is ok to do?

Yes. The West of Scotland Research Ethics Committee, which has the responsibility to check over studies on humans, has checked this proposal and agreed to go ahead.

What if there is a problem?

If you feel that you have been harmed by this study, you have the right to make a complaint to the University of Edinburgh or the NHS. You can get details about how to do this from me or your GP.

Thank you for taking the time to read this information!

If you have any questions about the study, we would be happy to discuss these with you. Please contact:

Lead Researcher:
Eleni Pateraki, Trainee Clinical Psychologist
Address: Paediatric Psychology Service, Wishaw General Hospital (Level 3) ML2 0DP.
Telephone: 01698 366 754

Supervisors:
Dr Paul Graham Morris
Address: The University of Edinburgh, Medical Quad, Teviot Place, EH8 9AG
Telephone: 0131 651 3956

Dr Yvonne Vance
Address: Paediatric Psychology Service, Wishaw General Hospital (Level 3), ML2 0DP
Telephone: 01698 366754

PART III: For children below the age of 12

Information Sheet
(Younger Children)

You are being invited to take part in a study that is being carried out as part of my Doctorate degree in Clinical Psychology with the University of Edinburgh and the NHS.

Before you take part, please take the time to read why this research is being done and what it involves. Please contact Eleni Pateraki, who is the lead researcher, if there is anything that is not clear or if you would like more information.

Title of the project:

The interaction between childhood asthma, anxiety and medication use: Exploring children and young people's perspectives and attributions.

What is this research about?
The research is about people's experiences of asthma, anxiety and medication use. We would like to hear what it's like for you and how do you cope.

Why have I been chosen?
You are being invited because you have asthma and you are between 10 and 16 years.

Do I have to take part?
No, you are free to decide if you want to take part. If you do decide to take part, you can change your mind anytime without explaining why. If you decide to withdraw, this will not affect your treatment with the asthma team.

What will happen if I take part?

If you decide to take part, the steps below will take place.

1) You and your parent/guardian will need to sign the contact information form. You will also need to complete the enclosed questionnaires.

When you finish, please return all the forms to me in the freepost envelope.

2) In the second step, I may meet with you to ask you what it's like to live with asthma, your worries and thoughts about this and how you decide to take your medication.

This meeting will last less than 60 minutes and we can have a break or stop at any point. I will be audio-recording the interview so I can remember the information you provided. Before we start the interview, I will ask you and your parent/guardian to sign some forms that you agree to take part in this study.

3) When I finish with all interviews with all the participants, I will make a summary of the initial results. This summary will not have anything that might identify you. If you agree, I will ask you and your parent/guardian to read it and I will call you to tell me what you think and if you have more ideas to help me explain the findings.

Will I be asked difficult or upsetting questions?
I will be asking about your asthma and your worries about it. Hopefully this won't be upsetting. You can decide not to answer a difficult question, to stop or have a break.

Will my information be kept private?
Yes, all information will be locked away and kept private. However, if you say something that makes me worried about you or someone else, I will have to say to your parent/guardian and your GP. Also, if the questionnaire shows you have many worries and fears, I will say to your family and suggest what you can do to get help.

What will happen to the results of the study?
The results will be submitted to the University of Edinburgh for review and may be presented in scientific journals or conferences. Small parts from the interviews will only be used after removing anything that might identify you. If you agree for this, the interviews may be used in future research, only after removing anything that might identify you.

Can I find out the results?
Yes. I will send you an explanation of the results.

Did anyone else check that the study is ok to do?
Yes. The West of Scotland Research Ethics Committee, whose job is to check studies on humans, has checked this proposal and agreed to go ahead.

What if there is a problem?
If you feel that you have been harmed by this study, you have the right to make a complaint to the University of Edinburgh or the NHS. You can get details about how to do this from me or your GP.

Thank you for taking the time to read this information!

If you have any questions about the study, we would be happy to discuss these with you. Please contact:

Lead Researcher:
Eleni Pateraki, Trainee Clinical Psychologist
Address: Paediatric Psychology Service, Wishaw General Hospital (Level 3) ML2 0DP.
Telephone: 01698 366 754

Supervisors:
Dr Paul Graham Morris
Address: The University of Edinburgh, Medical Quad, Teviot Place, EH8 9AG
Telephone: 0131 651 3956

Dr Yvonne Vance
Address: Paediatric Psychology Service, Wishaw General Hospital (Level 3), ML2 0DP
Telephone: 01698 366754

The interaction between childhood asthma, anxiety and medication use: *Exploring children and young people's perspectives and attributions.*

SCREENING QUESTIONNAIRE

To be completed with help from parent(s) or guardian(s)

Please answer the questions below to the best of your knowledge.

What is your date of birth? ____/____/_____

What is your age? _____ years

You are being invited to this study because you suffer from childhood asthma.
How long has it been since you were diagnosed with asthma?
(please provide your answer in years and months) _____

Do you have other physical health conditions? Yes ☐ No ☐

If yes, what other condition do you suffer from?

_____

_____

_____

Have you been diagnosed with a learning disability or a developmental disorder? Yes ☐ No ☐

If yes, what is your diagnosis?

_____

Are you currently suffering from a mental health or emotional difficulty? Yes ☐ No ☐

If yes, what is your difficulty?

_____

Are you currently receiving help for anxiety? Yes ☐ No ☐

Are you fluent in English language? Yes ☐ No ☐

CONTACT INFORMATION FORM
(to be completed by parent/guardian and child/young person)

Title of the project: **The interaction between childhood asthma, anxiety and medication use: Exploring children and young people's perspectives and attributions.**

Name of Lead Researcher: **Eleni Pateraki, Trainee Clinical Psychologist**

I agree to Eleni Pateraki, Trainee Clinical Psychologist contacting me to discuss participation in the above research study.

Contact details:

Name of child/young person:_____
Name of parent or guardian: _____
Relationship to child: _____
Address:_____
_____
_____

PLEASE PROVIDE YOUR TELEPHONE NUMBER TO ALLOW ME TO CONTACT YOU TO ARRANGE A CONVENIENT TIME/PLACE FOR THE INTERVIEW.

Telephone number: _____
Mobile number: _____

If you have an answerphone, is it OK to leave a message? YES ☐ NO ☐

Please provide your child's GP details, so I can inform them regarding your child's participation in the research.

The child's or young person's GP details are:

Name: _____
Address:_____
_____
_____
Telephone number: _____

_____	_____	_____
Name of Parent/Guardian	Signature	Date
_____	_____	_____
Name of Young Person	Signature	Date

APPENDIX E

Consent/assent forms

PARENT/GUARDIAN CONSENT FORM

Title of the project: **The interaction between childhood asthma, anxiety and medication use: Exploring children and young people's perspectives and attributions.**

Name of Lead Researcher: **Eleni Pateraki, Trainee Clinical Psychologist**

Please Initial

I confirm that I have read and understand the information sheet for the above study. I have been offered the opportunity to ask questions and these have been answered satisfactorily. ☐

I understand that my child's participation is voluntary and we have the right to withdraw from the study at any stage without our medical care or rights being affected. ☐

I agree to my child's interview being digitally recorded and transcribed. ☐

I understand that small anonymised parts of my child's interview may be used for publication in reports. I understand that should this happen, my child will not be identified from any of the information provided. ☐

I consent to my son/daughter taking part in this study. ☐

I consent to fully anonymised and unidentifiable data from my child's participation to the study being kept in the University of Edinburgh to assist in future research. ☐

Name of Parent/Guardian	Signature	Date
Name of Researcher	Signature	Date

PARENT/GUARDIAN ASSENT FORM

Title of the project: **The interaction between childhood asthma, anxiety and medication use: Exploring children and young people's perspectives and attributions.**

Name of Lead Researcher: **Eleni Pateraki, Trainee Clinical Psychologist**

Please Initial

I confirm that I have read and understand the information sheet for the above study. I have been offered the opportunity to ask questions and these have been answered satisfactorily. ☐

I understand that my child's participation is voluntary and we have the right to withdraw from the study at any stage without our medical care or rights being affected. ☐

I agree to my child's interview being digitally recorded and transcribed. ☐

I understand that small anonymised parts of my child's interview may be used for publication in reports. I understand that should this happen, my child will not be identified from any of the information provided. ☐

I agree to my son/daughter taking part in this study. ☐

I agree to fully anonymised and unidentifiable data from my child's participation to the study being kept in the University of Edinburgh to assist in future research. ☐

Name of Parent/Guardian	Signature	Date
Name of Researcher	Signature	Date

YOUNG PERSON CONSENT FORM

Title of the project: **The interaction between childhood asthma, anxiety and medication use: Exploring children and young people's perspectives and attributions.**

Name of Lead Researcher: **Eleni Pateraki, Trainee Clinical Psychologist**

Please read the following statements carefully. If you are happy with each statement please tick the box.

I have read and I understand the information sheet for the above study. I have been given the opportunity to ask questions and these have been fully answered.	☐
I understand that I don't need to take part and I can withdraw from the study at any stage.	☐
I agree to my information being audio-recorded, listened to and written down.	☐
I understand that small parts of my interview may be used for reports. I understand that if this happens, all the information that might identify me will be kept private.	☐
I consent to take part in the study.	☐
I consent to my responses being kept in the University of Edinburgh to help with future studies, after all the information that might identify me are removed.	☐

Name of Child/Young Person	Signature	Date

Name of Researcher	Signature	Date

YOUNG PERSON ASSENT FORM

Title of the project: **The interaction between childhood asthma, anxiety and medication use: Exploring children and young people's perspectives and attributions.**

Name of Lead Researcher: **Eleni Pateraki, Trainee Clinical Psychologist**

Please read the following statements carefully. If you are happy with each statement please tick the box.

I have read and I understand the information sheet for the above study. I have been given the opportunity to ask questions and these have been answered.	☐
I understand that I don't need to take part and I can withdraw from the study at any stage.	☐
I agree to my information being audio-recorded, listened to and written down.	☐
I understand that small parts of my interview may be used for reports. I understand that if this happens, all the information that might identify me will be kept private.	☐
I agree to take part in the study.	☐
I agree to my answers being kept in the University of Edinburgh to help with future studies, after all the information that might identify me are removed.	☐

Name of Child/Young Person	Signature	Date

Name of Researcher	Signature	Date

APPENDIX F

Letter to advise GP of participation

Eleni Pateraki
Trainee Clinical Psychologist
Paediatric Psychology Service (CAMHS)
__Address of service__

Date: __/__/__

Name/address of GP

Dear Dr__(Name of GP)___

Re: ___(Patient name and date of birth)___

I am writing to advise that the above named young person and their parent/guardian have agreed to take part in the research project I am undertaking in part fulfilment of the requirements of the Doctorate degree in Clinical Psychology with the University of Edinburgh and the NHS.

Study title: The interaction between childhood asthma, anxiety and medication use: Exploring children and young people's perspectives and attributions.
REC reference: 13/WS/0318
R&D Project No: 2014/0051

The research will be adopting a qualitative methodology using a purposeful random sampling procedure. In-depth semi-structured individual interviews with children and young people will be used to gather data. The West of Scotland Research Ethics Committee has scrutinised and approved the proposal for this study.

Please find enclosed the information sheet sent to parents/guardians and children/young people for further information. Please do not hesitate to contact me, should you wish to discuss aspects of this research project further.

Yours sincerely

Eleni Pateraki
Trainee Clinical Psychologist

Supervised by **Dr Paul Graham Morris**
Lecturer in Health Psychology
and
Dr Yvonne Vance
Clinical Psychologist

APPENDIX G

Letter to families to advise of increased anxiety scores

Eleni Pateraki
Trainee Clinical Psychologist
__Address of Service__
Date: __/__/__

Parent/guardian of:
__(Name of potential participant)__
Address

Dear parent/guardian

Study title: The interaction between childhood asthma, anxiety and medication use: Exploring children and young people's perspectives and attributions.
REC reference: 13/WS/0318
R&D Project No: 2014/0051

Thank you for agreeing to support my research project. As discussed in my initial correspondence, I am writing back to all families of children and young people who scored higher on the anxiety questionnaire to advise them of this.

Although a high score on a single anxiety questionnaire cannot be the only source of information to make conclusions regarding the presence of an anxiety difficulty, it may suggest that the reported worries could require further exploration. If you think your child's fears or worries are troubling, here are some websites which may be of value:

www.kidshealth.org/ www.handsonscotland.co.uk/ www.moodjuice.scot.nhs.uk/

You can also discuss this with your GP if you feel that this is appropriate at this stage.

I hope you find the above information useful. In relation to the research process, I may still contact you to invite your child to the interview.

Thank you again for supporting this study.

Yours sincerely

Eleni Pateraki
Trainee Clinical Psychologist

Supervised by: Dr Paul Graham Morris
Lecturer in Health Psychology
and
Dr Yvonne Vance
Clinical Psychologist

APPENDIX H

Interview guide

- Discuss the information sheet and provide another opportunity for both parents/guardians and children/young people to ask questions.
- Discuss and sign consent/assent forms.
- Discuss the interview schedule to set the context of the interview.

  Prompts: If the word anxiety is difficult to comprehend, consider alternatives: feeling nervous, scared, worried, being apprehensive.

A. <u>Experience of conditions separately.</u>

- ***Can you talk to me about what is asthma like for you?***
  How does it affect your life?
- ***How do you feel about your asthma? What has it meant for your life?***
  Prompts: day-to-day functioning/activities, relationships, coping strategies, medication, role of parents.
- ***Can you talk to me about what is anxiety like for you?***
  How does anxiety affect your life?
- ***What do you think about your anxiety? What has it meant for your life?***
  Prompts: types of worries, examples of worrying situations, day-to-day functioning/activities, relationships, coping strategies, role of parents.

B. <u>Relationship between anxiety and asthma</u>

- ***Do asthma and anxiety sometimes influence or affect one another?***
  Prompts: consider alternatives, e.g. happen at the same time/occur together.
  When are they more likely to occur together? What happens before/after?
  Prompts: thoughts, feelings, behaviours, bodily symptoms.
- ***How do you cope when asthma and anxiety occur together?***
  How do you try to improve your symptoms then?
  What would make your anxiety and asthma better?
  Prompts: strategies, behaviours, role of parents, role of medication.
- ***Does your anxiety impact on your asthma? If yes, how?***
- ***Does your asthma impact on your anxiety? If yes, how?***
- ***What sort of worries do you have about your asthma?***
  When do you worry about your asthma?
  What sort of thoughts/worries do you have when you have an asthma episode?

What are your expectations about your asthma and anxiety in the future?

Prompts: explanations, predictions about the future, impact on functioning/relationships, identity/how others perceive them.

- ***How does worrying feel on your body? How is that different from asthma?***
  Do you ever confuse the two? If yes, please tell me about that.
- ***How do you know when to get your medication?***
  Prompts: asthma symptoms monitoring, role of parents, medication plan changes.

C. How was this interview for you?

Additional prompts:

- I'm interested in / Can you tell me more about that?
- What do you mean by that?
- Can you give me an example? / What did you do?
- How do you feel/think about that?

APPENDIX I

Respondent validation letter and summary of initial themes

PART I: letter

Eleni Pateraki
Trainee Clinical Psychologist
Paediatric Psychology Service (CAMHS)
Level 3, Wishaw General Hospital
50 Netherton Street
ML2 0DP
01698 366 754

Date: __/__/__

Parent/guardian of:
__name of the child__

Dear *name of the child* and parent/guardian

Study title: The interaction between childhood asthma, anxiety and medication use: Exploring children and young people's perspectives and attributions.
REC reference: 13/WS/0318
R&D Project No: 2014/0051

Thank you for recently participating in my study exploring the relationship between asthma and anxiety. I have now completed the initial analysis of all the interviews with young people with similar difficulties.

As discussed during our appointment, I am writing back to provide you with a brief summary of the most common themes that came up from the analysis with examples directly taken from the interviews. This summary refers to all the interviews and some of the themes may not be relevant to __name of the child__.

If you still wish to participate in this third stage of the study, please read the enclosed summary. I will call you in approximately 10 days to discuss your and __name of the child__ thoughts on these initial results.

I will be asking you questions such as: Are these similar or different to your experience of living with asthma or bringing up a child with asthma? Have I covered all the areas that are important to you? Is there another way of viewing the results?

I do not expect this telephone conversation to last more than 10-15 minutes. As we talk I will take notes to make sure I remember the ideas and suggestions you made after reading the summary of the analysis. If I cannot reach you by the phone, please feel free to post any comments to me. Your feedback will be greatly appreciated.

Once again, thank you for supporting this study.

Yours sincerely

Eleni Pateraki
Trainee Clinical Psychologist

Supervised by: **Dr Paul G. Morris**
Lecturer in Health Psychology
and
Dr Yvonne Vance
Clinical Psychologist

PART II: Summary of initial themes

Key themes from the interviews:

THE IMPACT OF ASTHMA ON ANXIETY SYMPTOMS

1. Asthma as a threat to important goals of development in adolescence.
    - Influencing the development of identity: *"you couldn't join in with stuff... you felt the odd one out"*
    - Achieving age-appropriate independence: *"I'd always be with someone... just in case anything happens... I don't like the fact that I go out and can't do stuff myself"*
    - Forming friendships: *"Very upsetting because all my friends are always with each other and sometimes I can't be with them and then I start drifting away from them and I don't get to see them"*
2. Asthma triggers worrying thoughts
    - Asthma as a theme to worries: *"It's just something that goes on, like, everyone else worries about something else, I worry about asthma."*
    - Predicting disasters, catastrophising: *"I just get really... panicky (when experiencing asthma symptoms) What do I do? What's going to happen? Am I going to be OK? Is it going to get worse now?"*
    - Worrying about impact on important others: *"I'm putting like pressure on other people who have to look after for me. I don't like it very much"*
3. Strategies to manage asthma may generalise to managing anxiety and may maintain anxiety
    - Being vigilant for asthma triggers may generalise to being constantly vigilant about anything unsettling, hindering relaxation: *"Well, the asthma affects ...just almost everything I do, because I always have to worry... I just have to think of all the things that might happen and then almost prepare for them"*
    - Medication and being around helpful others is important for asthma, but may generalise to constantly seeking safety in them to feel safe and relaxed: *"I make sure I've got, like, spare inhalers in case I lose one and I bring three... I will never need three... but I get almost worried that I will use it and then I will run out of inhalers and then I will get an asthma attack"*
    - Coping with anxiety may become very medical: *"I get headaches... when I'm nervous... I would then take Paracetamol and then just like cope until I go home... go to bed and lie down"*
4. Asthma acts as a barrier to activities that are valued and possibly stress-relieving
    - Asthma hinders engagement in activities that are valued: *"I miss a lot of learning in school";"That's when it was particularly bad, when I was much younger it affected my entire life basically; my education; my fitness; everything"*

- Asthma hinders engagement in activities that help to cope with anxiety: *"like doing sports just takes me to another place really. It just takes me away from everything... before I had asthma... I used to be really sporty. I still love sports and my asthma pulls me back";*

THE IMPACT OF ANXIETY ON ASTHMA SYMPTOMS

1. Physical symptoms of anxiety and anxiety-related behaviours trigger asthma symptoms

   "it's not really the fright it's more the sudden faster breathing that kind of brings on the asthma"

   "Sometimes if I start crying and stuff it'll affect my asthma because when I cry I can't breathe"

2. Anxiety inhibits good asthma care and medication adherence

   "When I have an asthma attack... I won't just sit down and take a deep breath, I'll be like, "What do I do, what do I do?" stuff like that. And then usually when I'm worried... The times in the past that I've had an asthma attack or my asthma's been really bad, I hadn't taken my inhaler properly because I'd been that worried..."

   "It is more if I have to take my inhaler in front of people; I don't like doing that, 'cos they might think I'm on drugs or something"

THE INTERACTION BETWEEN ASTHMA AND ANXIETY

1. Asthma and anxiety interact forming a vicious cycle of one leading to the other

   "Scary, it was…Whenever I had the asthma attack it would then turn into a panic attack and make that worse because I was scared of it, so then my breathing would get worse, my hands and feet I couldn't feel them and I just couldn't breathe"

   "If I ever had an asthma attack it would make me nervous and anxious so and then I would get worked up and it would make the asthma worse. Then because the asthma would get worse I would get more anxious, it would keep going and both would get worse, and worse, and worse until my asthma was really bad and we would have to phone an ambulance and go to hospital"

2. Asthma and anxiety work together to make things worse

   "I feel they're interacting because like, it feels like if [pause] say like my worrying is like it's trying to help my asthma beat me…beat like…[sighs] beat me!...It's like they'll help, try help each other like to beat me up"

3. Confusion between symptoms of asthma and symptoms of anxiety

   "Well, I was playing football and ... I was running around quite a lot and then I was, like right, I need to take my inhaler. I don't have it, and then I started really worrying and then that caused me to actually have an asthma attack. So I needed to go and get an inhaler. That probably… if I realised I don't have asthma, I just sit down and make sure I breathe slower, then I would be fine"

   "I was sitting there – I think I was worrying, but then... I can just remember worrying and then taking my inhaler. So then I don't know if that was one of the two."

APPENDIX J

Prevalence of themes across participants[4]

Subthemes	Jennifer	John	Ben	Amy	Craig	Clare	Simon	Lucas	Richard	Liz	Chris
The influence of asthma											
Asthma as a threat to important developmental goals	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓
Asthma as a barrier to valued, potentially coping, activities	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Asthma triggers worries and anxiety-provoking thinking patterns	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Strategies to manage asthma over-generalise to managing anxiety	✓	✓		✓	✓	✓	✓		✓	✓	✓
The influence of anxiety											
Physical symptoms of anxiety and anxiety-related behaviours trigger asthma	✓	✓			✓	✓			✓		✓
Anxiety inhibits good asthma care and medication adherence	✓	✓			✓		✓			✓	✓
The interaction between asthma and anxiety											
Asthma and anxiety interact forming a positive feedback loop	✓						✓		✓	✓	✓
Confusion between symptoms of asthma and symptoms of anxiety					✓		✓		✓	✓	

[4] Participants' names were replaced with pseudonyms to protect confidentiality.

APPENDIX K

Example of initial coding process

Emergent themes	Original Transcript	Exploratory comments
	I: Right. So you've told me a little bit about what is worrying and anxiety like for you and you explained what asthma is like for you, and medication, etc. Do asthma and anxiety sometimes affect one another?	
	P: Yeah.	
	I: In what way?	
Anxiety impacts on asthma – taking over and thus affecting medication use	P: When I have an asthma attack I'm just saying, for example, then I will get really worried and I'll get quite panicky and I won't just sit down and take a deep breath, I'll be like, "What do I do, what do I do?" stuff like that. And then usually when I'm worried... The times in the past that I've had an asthma attack or my asthma's been really bad, I hadn't taken my inhaler properly because I'd been that worried. I get confused, that kind of feeling. Then my mum would need to give me my inhaler just because I'd be too worried and too unsettled.	*Anxiety impacting on asthma treatment – appropriate medication use* *Asthma triggering worries* *Role of important others to guide when anxiety is overwhelming - takes over*
	I: So what you're saying is when asthma and anxiety kind of occur together, for example in an asthma attack, then you get a bit confused about how to use medication and you get...	
Asthma triggers anxiety during an episode	P: Uh-huh, I just get really confused and worried and panicky. "What do I do? What's going to happen? Am I going to be OK?" That kind of a....	*Asthma triggering catastrophic thinking about condition*
	I: Yeah. And how do you manage when these thoughts go through your mind? "What do I do? What's going to happen?"	
Reliance on significant others	P: I don't manage it, my mum does. My mum gets me sat down, gets me calm again, gets me to take my inhaler...	*Role of parents – reliance on mother* *Important others help - take the lead in treatment*
	I: Right. And how about when mum is not around?	
Asthma triggers anxiety during an	P: Then I just go in a complete panic. If I'm with anyone, then they'll... we'll both try and calm down. But if I'm not with anyone then I just try and do my	*Others crucial in managing during an asthma episode.*

episode – resolved with medication	best to take my inhaler, just calm down, take a deep breath.	*Aware of management plan - helpful others as a safety strategy?*
	I: OK. And can you tell me the sort of situation when you are more likely to get panicky, during an asthma attack, for example?	
Asthma triggering anxiety – resolved with medication use	P: When I have an asthma attack I get out of breath and I cough and I just wheeze or whatever happens at that time then I'll get quite worried. Then, because I'm worried I'll start thinking about, "Where's my inhaler? What do I do now? Am I going to be OK? What's going to happen? Is this going to affect me even more?" And then I'll be even more worried. So it's like one stage after another.	*Catastrophising during an asthma episode - 'what if(s)'* *Worrying about the long-term impact of asthma and how the episode will develop*
	I: And then does worrying affect your asthma?	
	P: Yeah, yeah.	
	I: In what way? Can you explain a little bit more about that?	*Anxiety triggers breathlessness – does this lead to asthma symptoms?*
Anxiety about non-asthma related issues leading to breathlessness, which in turn triggers asthma symptoms? – reliance on medication to manage this	P: As I say, I'm just sitting thinking about if people like me or what's going to happen in the future, then obviously I'll just get over the top basically and I'll think about it too deep in and then I won't get it out of my head, basically. It'll just stay in there. I won't maybe think about it but then I'll start thinking about it, it'll stay at that position so I'll still be quite worried and then I'll get out of breath. I might need my inhaler just because... I might be talking to myself or something about it and then I just get really worried and panicky. When I worry about things like that I just start to get panicky and when it's quite panicky then my asthma kicks in and that's when I need an inhaler or I need to sit down or something like that.	*Anxiety triggering asthma exacerbations* *Anxiety and asthma in a vicious cycle? Would that lead to worry about the asthma symptoms as described earlier? Inhalers help stop this chain – asthma improves, does anxiety then improve?*
	I: And how do you manage when these kind of things happen?	*Role of medication*
Reliance on medication	P: I honestly don't know. I guess I just kind of take my inhaler and then just try to calm down and stuff like that, but that only happens when a big problem is on my mind.	*Cycle only triggered when anxiety is increased – problem is severe*