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Running Head: Young people's experiences of living with asthma and anxiety

Title:

**The interaction between asthma and anxiety: An interpretative
phenomenological analysis of young people's experiences.**

Eleni Pateraki^{1*}, Yvonne Vance² and Paul Graham Morris³

Conflicts of Interest

Eleni Pateraki, Yvonne Vance and Paul Graham Morris declare that they have no conflict of interest.

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¹ *Corresponding author:

Eleni Pateraki, Paediatric Psychology Service, Level 2, Wishaw General Hospital, NHS Lanarkshire, Wishaw, UK, ML2 0DP; email: eleni.pateraki@nhs.net ; Tel. 0141 201 0123

² Yvonne Vance, Paediatric Psychology Service, Wishaw General Hospital, NHS Lanarkshire, UK

³ Paul Graham Morris, Clinical and Health Psychology Department, University of Edinburgh, UK

The interaction between asthma and anxiety: An interpretative phenomenological analysis of young people's experiences.

Abstract

Asthma and anxiety are highly co-morbid, and their interaction leads to exacerbations for both conditions. This study explored the interplay between these two conditions from the perspective of children and adolescents. The objective was to identify potential mechanisms of interaction between asthma and anxiety, and to derive improvements for prevention and treatment. Eleven semi-structured interviews of young people (aged 11-15), who met criteria for both asthma and anxiety, were analysed using interpretative phenomenological analysis. Well-established qualitative research recommendations were followed to promote credibility and rigour in the findings. Eight themes emerged, that were organised in three domains: i) asthma affecting anxiety by inhibiting coping activities or developmental tasks and by triggering unhelpful thinking and behaviour; ii) anxiety affecting asthma by impairing self-care and triggering hyperventilation; iii) interactions between asthma and anxiety, including self-perpetuating feedback cycles and symptom confusion. The proposed mechanisms could help tailor cognitive-behavioural interventions to reduce anxiety and asthma complications.

Keywords: anxiety, asthma, children and adolescents, interpretative phenomenological analysis, cognitive-behaviour therapy

Introduction

Asthma is the most common chronic childhood condition worldwide (Lazarus, 2010). It is highly co-morbid with anxiety disorders, primarily generalised anxiety disorder, but also separation anxiety, specific phobia and panic (Lu et al., 2012; Vuillermin et al., 2010) and up to a third of children with asthma meet criteria for an anxiety diagnosis (Katon et al., 2007). In a 20-year prospective cohort study of 591 young people, Hasler and colleagues (2005) showed that asthma was associated with a fourfold higher risk of panic disorder, even after controlling for demographic and mental health factors. Whilst mechanisms explaining this comorbidity are unclear, the interplay between anxiety and asthma can exacerbate both conditions (Thomas, Bruton, Moffat, & Cleland, 2011).

Anxiety may exacerbate asthma symptoms by increasing hyperventilation, which may cause bronchoconstriction (Ritz, Meuret, Trueba, Fritzsche, & von Leupoldt, 2013). 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; Theoharides et al., 2012). Conversely, asthma attacks may exacerbate anxiety by increasing health-related fear or hypervigilance regarding threatening bodily symptoms (Lehrer et al., 2008), which are key maintaining factors in predominant psychological models of panic and health anxiety (Clark and Beck, 2012).

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; Janssens, Verleden, De Peuter, van Diest, & van den Bergh, 2009). For example, Chen and colleagues (Chen, Rodgers, Oliver-Welker, & Strunk, 2006)

showed that asthmatic children with increased anxiety at baseline reported greater asthma symptoms than was indicated by the pulmonary function measures, especially when symptoms were mild or ambiguous. Correspondingly, anxiety is associated with overuse of medication and increased healthcare use, independently of objective pulmonary function (Feldman Siddique, Thompson, & Lehrer, 2009; 2013). This results in elevated healthcare costs and potential health complications associated with the overuse of reliever medication, such as cardiovascular symptoms and tolerance effects that could reduce medication effectiveness (Bozzola, Bozzola, Barberi, Cutlera, & Villani, 2013).

Developing treatments for anxiety in the context of asthma

Clinical guidelines and policy documents emphasise the importance of identifying anxiety early amongst individuals with respiratory conditions and developing suitable psychological interventions (Department of Health, 2011, 2014; National Institutes of Health, 2007; SIGN, 2012). Cognitive-behavioural treatment (CBT) approaches appear appropriate in this respect, as they have strong empirical support in treating anxiety in other clinical health populations (Halford & Brown, 2009; NICE, 2011). In a recent systematic review, reasonable preliminary support was reported for CBT interventions in improving anxiety amongst adults with asthma, with the evidence-base for interventions with children and adolescents looking promising, but as yet under-developed (Pateraki & Morris, 2017). Outcomes were often inconsistent for both adults and children, but trials were more likely to indicate beneficial effects when asthma-related education was provided alongside or within an anxiety-focused CBT intervention (Pateraki & Morris, 2017).

Some of the inconsistent outcomes on the effectiveness of CBT may be linked

to our limited understanding of processes maintaining this complex comorbidity between asthma and anxiety (McLeish, Zvolensky, & Luberto, 2011), especially amongst children and adolescents. A few studies propose a role for cognitive processes (Deshmukh, Toelle, Usherwood, O'Grady, Jenkins, 2007; Fellows et al., 2015). For example, De Peuter and colleagues (2008) found that catastrophic thinking predicted asthma symptom over-perception in adult patients. McGrady and colleagues (2010) found that perceiving asthma as difficult to control and/or as significantly affecting life, mediated the relationship between asthma and anxiety in adolescents. However, research exploring potential maintainers or triggers underpinning interactions between asthma and anxiety in young people is extremely limited. No study to date has explored such cognitive processes directly from the perspective of children and adolescents.

Study aims

The current study sought to investigate the interplay between asthma and anxiety as experienced by young people, in order to identify specific thinking and behavioural patterns that may maintain their difficulties, and which could inform tailored CBT interventions.

Methods

Study design

Interpretative phenomenological analysis (IPA) was used to analyse 11 in-depth semi-structured interviews with youth in their early to middle adolescent years who had both asthma and anxiety symptomatology. Consistent with the aims of this study, IPA has been extensively tested for its ability to contribute in qualitative

healthcare research on narrowly defined samples of patients who describe their lived experiences of medical conditions, or of treatments, leading to improvements in provision of care for those conditions (Reid, Flowers, & Larkin, 2005). IPA's double hermeneutic approach (Smith, Flowers, & Larkin, 2009) focuses on how the researcher is making sense of participants' attempts to interpret their experiences, while allowing for the investigators' pre-existing knowledge and understandings to be integrated into the analytic process, in a reflexive manner, i.e., in a way that encourages both the participant and the researcher to reflect upon their own personal experience. The approach therefore fits well with psychological therapy models.

Research ethics review

All procedures were approved by the NHS Research Ethics Service and the local Boards' Research and Development offices. Participation was voluntary and confidential from participants' respiratory health provider teams. No financial or other incentives were offered. Informed consent was obtained from young people and their parents prior to the interviews.

Recruitment

Consistent with IPA's idiographic approach (Smith, 2011), sampling focused on recruiting a closely specified homogeneous group of young people for whom the research question was most pertinent. Therefore, recruitment focused on youth of early to middle adolescence (aged 11-16). To reduce potential for bias, a random sampling procedure was used based on a sequence generated from random.org, an Internet service (<https://www.random.org/>) that provides access to random number series. A consecutive series of 231 young people with a diagnosis of asthma (from a pool of 329), were randomly-selected from two hospital childhood asthma databases,

covering two National Health Service (NHS) Boards, which together provide health services for approximately 1.5 million people. Potential participants were invited to participate in the study by post. The databases only included patients actively attending hospital asthma clinics and, therefore, had a physician confirmed asthma diagnosis, in accordance with the British Thoracic Society/Scottish Intercollegiate Guidelines Network (2008). All prospective participants' asthma symptomatology was complex enough to warrant monitoring by hospital-based respiratory teams, rather than solely by community general practitioners. Asthma nurse specialists managed the databases and posted the initial research invitations.

Initial letters were addressed to the parents, but included a simplified version addressed to young people. They explained that the purpose of the study was to explore experiences of asthma and anxiety: "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". The research invitations described the stages of the study (screening questionnaires, interview, contacting parents for validating outcomes): "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. 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, and how do you cope", "when I finish with all the interviews, I will analyse them and make a summary of the initial 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 your parent/guardian to tell me what you think and if there are other ways of explaining the findings". The letters also explained information around anonymity, voluntary participation, publication of

outcomes, and contact information for additional details or concerns.

Implicit consent to participate in the first stage of the study (screening) was assumed by returning the eligibility screening forms and signing the included contact information form that they agree to be called to arrange an interview. An extended discussion around the study took place at the meeting prior to commencing the interviews. Parents and young people were informed about the type of questions participants will be asked, the expected length of the interview, the audio-recording, the inclusion of anonymised quotes in the final report, the right to stop, have a break or withdraw at any time without consequences. Informed consent to participate in the interview and the validation of findings was obtained at that stage by both parents and young people.

Thirty-three (14.28%) returned the eligibility screening forms, including:

a) The Screen for Child Anxiety Related Emotional Disorders (SCARED; Birmaher et al., 1999), is a 41-item screen for anxiety disorders with total scores ranging between 0 and 82. Respondents are invited to circle the response that best describes them “*for the last 3 months.*” Scales range from: 0 = *not true or hardly ever true* to 2 = *very true or often true*. The SCARED consists of five subscales: panic disorder/somatic symptoms (13 items; range 0-26), generalised anxiety (9 items; range 0-18), social anxiety (7 items; range 0-21), separation anxiety (8 items; range: 0-16) and school avoidance (4 items; range 0-8). Typical panic disorder/somatic symptoms subscale items are “when I feel frightened, it is hard to breathe” and “I get shaky.” Typical generalised anxiety subscale items are “people tell me that I worry too much” and “I am nervous.” Typical social anxiety subscale items are “it is hard for me to talk with people I don’t know well” and “I am shy.” Typical separation

anxiety subscale items are “I worry that something bad might happen to my parents” and “I don’t like to be away from my family.” Typical school avoidance subscale items are “I get stomachaches at school” and “I worry about going to school.” Higher scores on the total scale or each of the subscales suggest the potential presence of an anxiety disorder. A total score of 22 or above is indicative of clinically significant anxiety (Desousa, Salum, Isolan, & Manfro, 2013) and this threshold was utilised as the inclusion criteria to ensure that respondents had high levels of anxiety. The SCARED has been shown to have satisfactory psychometric properties, including high test-retest reliability and good internal consistency (alpha co-efficient of .90 for the total scale and $\alpha = .74$ to $.93$ for each of the subscales) and good validity (Birmaher et al., 1999; Verhulst & van der Ende, 2006);

b) A purposefully-designed questionnaire to identify whether individuals met other inclusion criteria.

At the time of the face-to-face interview, participants were asked to rate their perceived severity of their asthma. The following question was asked: “How would you describe your asthma severity during the past few weeks?” They were invited to indicate their response on a 3-point self-report scale with the following response options, which were presented verbally: “mild, moderate, or severe.”

Inclusion criteria

Inclusion criteria included an asthma diagnosis of at least six months, a total score of 22 or higher on the SCARED, fluency in English and no other mental health, developmental or physical health condition (apart from asthma-related/atopic disorders, which are highly co-morbid).

Participant characteristics

Eleven respondents met all asthma and anxiety inclusion criteria and agreed to be interviewed within the timeframe of the study. Participant characteristics are shown in Table 1. Names were replaced with pseudonyms and identifiable information was removed. The mean age of participants was 13.09 years ($SD = 1.37$, range: 11-15). The majority 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 ($M = 32.27$, $SD = 8.86$), with most respondents reporting symptoms consistent with generalised anxiety disorder (9 of 11). Symptoms consistent with panic disorder (6 of 11), school avoidance (6 of 11) and separation anxiety (5 of 11) were also highly prevalent amongst the respondents (Table 1). None of the participants was actively receiving psychological treatment or prescribed medication for their anxiety difficulties at the time of the study.

[Table 1 INSERT HERE]

Data collection

Data collection was conducted by the lead author from April to November 2014 and interviews took place at the nearest available clinic sites, local to the families' homes (e.g., family doctor's practice, hospital sites, community health centres, mental health teams). Parents and young people attended solely for the interview and the process took place in private rooms booked for this purpose. The parent was present for the initial consent procedure, but was subsequently asked to remain in the waiting area during the interview. All interviews were audio-recorded and lasted approximately 45 minutes. Interviews were semi-structured, exploring

experiences of living with asthma and anxiety, with probes relating to areas that existing evidence indicates may be relevant to the relationship between asthma and anxiety, including cognitions, personal attributions, emotions, physiological reactions, coping behaviours and management strategies. The interview schedule is presented in Table 2. Questions initially focussed on the experiences of each condition alone (e.g., “What is asthma like for you?” and “What has anxiety meant for your life?”), which led to questions about experiences of the conditions occurring together and/or influencing one another (e.g., “Do they ever occur together?” or “When is it more likely to happen?” or “How do you cope on those situations?”). The schedule was piloted with three adults with childhood onset asthma using retrospective cognitive interviewing techniques (Miller, 2014).

[Table 2 INSERT HERE]

Analysis

In line with IPA guidance (Smith & Osborn, 2015), the verbatim transcription commenced after all interviews were completed. Individual transcripts were subsequently 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 margin, which were reviewed to identify recurrent or emotive points, associations and contradictions, so as to allow and facilitate the development of emerging themes within each interview. When new themes emerged, previous interviews were re-visited to determine whether the new interpretations might be relevant to interviews that had been previously been examined.

Elicited themes, and related supportive extracts from participants’ interviews,

were organised into multiple tables to allow examination of patterns across cases and to identify themes that could be clustered together. The grouping of themes was guided by concepts outlined by (Smith et al., 2009), which includes: abstraction (putting similar emergent themes together under a super-ordinate theme); polarisation (putting oppositional emergent themes about a particular aspect of the experience together under a super-ordinate theme, e.g., positive and negative effects of diagnosis); contextualisation (taking into account narrative and temporal aspects of the emergent themes, e.g., when my asthma gets worse); numeration (taking into account the frequency in which an emergent theme occurs); and function (taking into account the function of the emergent themes within interviews, e.g., presenting oneself as an outcast).

An audit trail was kept throughout the analysis. The lead author (a female doctoral trainee with pre-existing experience in clinical health psychology) logged *a priori*, in a reflexive manner, her previous experience, knowledge and expectations in order to increase her awareness of how these personal attributes might influence her hermeneutic process. Multiple sources were used to validate the findings, including drawing on multiple theoretical perspectives to interpret the data, and inviting relevant stakeholders (i.e., respiratory specialists and parents) to cross-check a summary of the initial findings. Parents and respiratory specialists validated initial interpretations and refined explanations. For example, parents reflected on the level of anxiety during an asthma episode and reiterated the difficulties in decision-making about appropriate use of healthcare and medication in such situations. The parents' comments and feedback led to re-examination of the interviews, which resulted in the enhancement of a theme that refers to how anxiety may inhibit asthma care.

The analysis of transcripts was undertaken by the lead author, but a random selection of three transcripts was independently coded by the second author, who has experience in IPA methodology. A high level of agreement was found in the emergent themes when comparing the coding of the three transcripts done by both authors. The first author's regular meetings with the second author allowed for further reflections on the interpretations of participants' experiences, facilitated discussions that reconciled differences, and shaped the development of the emergent and super-ordinate themes. Monthly meetings with the third author enriched the analysis and the reporting of the final themes.

Findings

The analysis produced eight themes, organised in three domains, pertinent to the research question regarding how mechanisms linking asthma and anxiety are perceived by young people. Consistent with IPA's quality criteria (Smith, 2011), particular attention was paid to prevalence and representativeness of final themes (which are shown in Table 3), and with a focus on how participants could display the same themes in their individual ways.

All participants described ways in which asthma affected their anxiety, with fewer discussing the effects of anxiety on asthma, or describing patterns of interaction between the two. The quotes presented below were selected based on whether they could independently manifest themes in brief, coherent and meaningful ways, whilst ensuring that all participants are represented in the final manuscript. Table 3 outlines major themes uncovered in the course of analysing transcripts of interviews as follows.

[Table 3 INSERT HERE]

1. Experiences of asthma affecting anxiety

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.

1a. Asthma as a threat to important developmental goals

Purposeful homogeneous sampling meant respondents with both asthma and anxiety were in early or middle adolescence. All but one spoke of their continuous efforts to minimise the consequences of asthma on developmental goals such as making friendships, forming an identity or seeking autonomy. Negotiating a balance between managing asthma and engaging in crucial tasks for their age, appeared to trigger worries about the future, peer relationships and becoming independent. The following quotations embody that theme.

“With my asthma I’m always in the house... 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 I’m going to have to sit about in the house myself, always taking my inhaler” (Richard)

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. As indicated by the following quotation, this ambivalence further maintained co-morbid anxiety symptoms.

“I’d always be with someone... I don’t know, [it’s] just in case anything happens... but if I go out it then feels as if I’m following them [my parents]

around the shops, I don't like the fact that I go out and can't do stuff myself" (Chris)

1b. Asthma as a barrier to valued, potentially coping, activities

All participants referred to perceiving asthma as a barrier to valued activities. Such restrictions in meaningful activities, from spending time with friends, to physical activity and uninterrupted education, may trigger anxiety and/or prevent such activities from helping participants to cope with their co-morbid anxiety. Asthma may, thus, be perceived as a barrier to using such coping strategies to ameliorate co-morbid anxiety.

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

"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)

1c. Asthma triggers worries and anxiety-provoking thinking patterns

All participants discussed how asthma triggers anxiety-provoking thinking patterns, indicating its role in maintaining anxiety. Five participants also described such effects in the context of a self-perpetuating feedback cycle, which is outlined as a separate theme. The others solely described the influence of asthma on anxiety.

“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 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)

“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)

1d. Strategies to manage asthma over-generalise to managing anxiety

Respondents noted a wide variety of coping strategies to manage asthma, including focusing on their breathing, ensuring medication was always available, keeping helpful others close, being vigilant of potential asthma triggers and avoiding them. Nine of the respondents mentioned also using such strategies to manage their anxiety, though some of these may serve as safety behaviours that could inadvertently maintain their worrying.

Participants reported thinking processes, such as hypervigilance and a positive attitude towards worrying (e.g., it helps me cope/prevent disasters), which may maintain anxiety, in line with generalised anxiety models (Clark & Beck, 2012; Wells, 2009).

“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... 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, such as being close to others or checking medication, that could evolve and become unhelpful when used to mitigate anxiety rather than just to adhere to medical advice concerning asthma.

“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)

“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)

Some participants’ descriptions also depicted how significant others may also influence anxiety-maintaining patterns.

“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)

2. Experiences of anxiety affecting asthma

Eight participants pointed to how they perceived their anxiety-related behaviours and symptoms directly triggering asthma symptoms and indirectly affecting appropriate asthma care and treatment adherence.

2a. Physical symptoms of anxiety and anxiety-related behaviours trigger asthma

Six respondents described anxiety-related symptoms triggering asthma symptoms, in particular, how hyperventilation in the context of anxiety affected their airway and chest functioning.

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

“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 thoughts and/or behaviours brought on asthma symptoms.

“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)

“if I start crying and stuff it’ll affect my asthma because when I cry I can’t breathe” (Jennifer)

2b. Anxiety inhibits good asthma care and medication adherence

Most respondents gave examples of anxiety symptoms impairing adherence, such as using inhalers in response to anxiety symptoms, with risks in relation to their asthma care together with other deleterious effects of medication overuse.

“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)

Participants indicated that anxiety induced by asthma attacks or social anxiety could also impair self-care of their asthma.

“When I have an asthma attack... 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” (Liz)

“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. Experiences of interactions between asthma and anxiety

Six participants described experiences of asthma and anxiety in patterns of interaction with a more complex interplay between the two conditions.

3a. Asthma and anxiety interact forming a self-perpetuating feedback cycle

Five participants described asthma and anxiety symptoms in a self-perpetuating feedback cycle, noting difficulties in identifying stages within this cycle where they might be able to 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)

One participant explained that the trigger for this vicious interactive cycle may equally be either asthma symptoms 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, 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” (Chris)

3b. Confusion between symptoms of asthma and symptoms of anxiety

Four participants referred to situations where the distinction between the physical symptoms of anxiety and the asthma symptoms was unclear, impairing

decision-making regarding the appropriate reaction and potentially leading to unnecessary use of asthma medication where symptoms are due to anxiety.

“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... 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)

The suitability of medication use in such ambiguous situations may be unclear, and not a straightforward decision, especially in the context of reported experiences of physical symptoms of anxiety triggering actual airway obstruction symptoms or anxious thoughts causing hyperventilation.

Discussion

The current study offers an insight into mechanisms linking asthma and anxiety, as experienced by young people, which may help to explain associations often reported between these two conditions (e.g., Feldman et al., 2013; Thomas et al., 2011), and could inform interventions to manage this comorbidity.

All participants readily discussed experiences of how asthma can restrict engagement in meaningful and potentially anxiety-relieving activities, such as socialising and exercise. This is consistent with previous research indicating that viewing asthma as significantly affecting one’s life and limiting activities mediated the relationship between asthma and anxiety amongst adolescents (McCauley, Katon,

Russo, Richardson, & Lozano, 2007; McGrady et al., 2010). The current analysis further highlighted that asthma may be perceived by young people as a barrier to major developmental tasks, placing additional stressors and conflicts on them, which may contribute to or perpetuate anxiety symptomatology. Respondents provided examples of 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 and Kipp, 2014).

Alongside examples of catastrophic thinking, the present analysis highlighted additional thinking and behaviour patterns that could trigger or maintain anxiety. Young people described utilising asthma self-care strategies, such as focusing on respiratory function, ensuring medication was always available, keeping helpful others close, being vigilant about potential illness triggers and avoiding them, when seeking to reduce their anxiety. However, when such strategies are used to reduce anxiety, this can be counterproductive and can potentially maintain anxiety. Indeed, cognitive processes such as hypervigilance and holding positive beliefs about worrying have been identified as maintaining factors in well-evidenced generalised anxiety models (Clark & Beck, 2012; Wells, 2009). Young people in this study noted systemic factors that may further reinforce such safety-seeking strategies, e.g., highly protective responses from family and teachers at school. Identifying and seeking to reduce such anxiety-specific safety behaviours could help individuals to gain greater control over their anxiety such that it might be less likely to trigger or exacerbate their asthma.

Previous research has indicated that symptom confusion between asthma and

anxiety can lead to inappropriate care (Favreau, Bacon, Labrecque, & Kim, 2014). Respondents reflected on difficulties in distinguishing between physical symptoms of anxiety and asthmatic symptoms. Narratives illustrated how such difficulties could lead to self-perpetuating feedback cycles, aggravating decision-making and potentially leading to overuse of reliever inhalers. This suggests the importance of training young people to make finer distinctions between physiological symptoms of anxiety and asthma, alongside strategies that enable them to self-manage anxiety so that it is less likely to trigger their asthma.

Implications for clinical practice, policy and future research

The current study highlights potential mechanisms of interaction between asthma and anxiety in young people, which could help inform assessment and interventions aimed at reducing the impact of both conditions. Participants described how asthma can reduce engagement in activities, such as socialising and exercise, that may otherwise help to prevent or reduce anxiety. Whilst some such activities may need to be limited due to constraints of asthma, discussions with young people may identify alternatives that serve a similar purpose.

Other findings, such as confusion between symptoms of anxiety and those of asthma, and examples of anxiety-provoking thinking patterns and safety-seeking behaviours, could be used to help tailor cognitive-behavioural interventions. Understanding the differing physiological symptoms of asthma and anxiety, the roles of cognitive misinterpretations and safety behaviours in triggering and maintaining anxiety, together with skills to reduce such cognitions and behaviours, could help young people manage their anxiety, and either prevent anxiety from triggering asthma attacks, or reduce its ability to exacerbate attacks when they do occur. Low-intensity

psychological interventions (e.g., guided self-help) focussing on identifying and managing symptoms of anxiety could be offered to all young people diagnosed with asthma and their families, alongside screening to identify individuals with more problematic anxiety that could then be targeted via group-based or individual CBT. Screening measures, including shorter versions of the SCARED that was utilised in this study, have been shown to be helpful in medical settings (Ramsawh, Chavira, & Stein, 2010). Their application would likely result in high volume of psychological therapy referrals, but may also allow the extent of the problem to surface and therefore justify the need for appropriately trained mental health practitioners. The costs involved in such screening and the provision of low and high-intensity psychological interventions would likely be counterbalanced by savings related to reductions in the frequency and length of hospitalisations and other complications that are otherwise high in young people with asthma and anxiety (Fernandes et al., 2010).

Mindfulness-based interventions may also have a role in assisting young people to discriminate between elements of their experience of anxiety and asthma; developing a non-judgmental and non-reactive awareness of their emotions and body sensations, which may reduce the likelihood of the escalating vicious cycles described above. Research on the effectiveness of mindfulness-based interventions with adults with asthma (Cheryl, Karen, Nilani, Melissa, Gabriel, & Marissa, 2017; Pbert et al., 2012) shows that such an approach may reduce unhelpful responses to symptoms and reduce risk of deleterious consequences, such as unnecessary medication use, or misinterpretations that feed into self-perpetuating cycles of anxiety and asthma.

Strengths and limitations

To the best of our knowledge, the present research is the first to have explored young people's experiences of interactions between asthma and anxiety. Qualitative research evaluative criteria (Yardley, 2008) and IPA quality assessment recommendations (Smith, 2011) were followed to increase the credibility and rigour of the analysis.

Recruitment benefited from the use of a randomly selected, closely-specified and clinically relevant sample, though representativeness and generalisability was limited by the small number of participants and lack of information regarding the characteristics of those that chose not to respond. The initial response rate (14.28%) was lower than most postal surveys (approximately 20%; Kelley, Clark, Brown, & Sitzia, 2003), which may be related to this study further asking participants and parents/carers to attend an interview. To improve response rates in future studies, it may be useful to employ personalised letters in advance of sending questionnaires, repeat postal reminders or incentives (Edwards et al., 2002; Nakash, Hutton, Jorstad-Stein, Gates & Lamb, 2006).

As with most qualitative studies generalisability cannot be applied in the traditional sense. Instead, the value of the findings from analytic approaches, such as IPA, is to recruit a sample which is homogeneous enough and to interview thoroughly enough so as to allow the interested reader to make evaluations about the applicability of findings and about the ability of the study to generate new hypotheses and broaden our understanding around the topic (Elliot & Timulak, 2005; Yardley, 2008). Whilst in depth exploration of the individual experience is the aim of IPA, limitations exist in this study from the lack of a comprehensive assessment of data saturation, although the number of new emergent themes had plateaued by the last few participants.

Asthma severity was measured only by self-report at the time of the interview. Self-perception of asthma severity may be important on its own in predicting outcomes, but it does not always accurately reflect lung function (Chen et al. 2006). Whilst illness severity has been shown not to be predictive of anxiety levels amongst individuals with asthma (Feldman et al., 2009; Rietveld, van Beest, & Prins, 2005), on retrospect it would have been advantageous to be able to describe the sample using an objective measure of asthma severity.

Conclusions

Young people's experiences of living with asthma and anxiety suggested the following mechanisms of interaction, with implications for prevention and treatment: *i) asthma affecting anxiety* by inhibiting valued coping activities or developmental tasks and by triggering unhelpful thinking and behaviour; *ii) anxiety affecting asthma* by impairing self-care and triggering hyperventilation; and *iii) symptoms of asthma and anxiety interacting*, and sometimes being so similar that participants were confused about what was happening within themselves. Also noteworthy were reports confirming the potential for comorbid asthma and anxiety to form self-perpetuating feedback cycles, in which each one triggered the other. This report outlines how these findings could help tailor cognitive-behavioural interventions to assist young people to identify and manage symptoms of anxiety in order to reduce ongoing exacerbations of the two conditions as a result of their interaction.

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broadly encouraging the publication of research.

Compliance with Ethical Standards

Conflict of Interest. Please see statement on Title page.

Human and Animal Rights and Informed Consent. All procedures followed were in accordance with ethical standards of the responsible committees on human experimentation (both institutional and national), and with the Helsinki Declaration of 1975 and its later amendments or comparable ethical standards. Informed consent was obtained from all participants and their parents for being included in the study.

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Table 1. Participant characteristics

Pseudonyms¹	Age	Self-reported asthma severity²	SCARED total score	SCARED subscale scores above cut-off point³
John	13	mild	24	separation anxiety = 5 (5), school avoidance = 4 (3)
Lucas	14	moderate	23	generalised anxiety = 9 (9), separation anxiety = 6 (5)
Liz	12	moderate	22	generalised anxiety = 11 (9)
Clare	14	moderate	30	panic/somatic symptoms = 8 (7), separation anxiety = 7 (5)
Jennifer	12	severe	33	generalised anxiety = 10 (9), school avoidance = 7 (3)
Simon	14	severe	26	panic/somatic symptoms = 7 (7), generalised anxiety = 11 (9)
Amy	14	severe	38	panic/somatic symptoms = 12 (7), generalised anxiety = 17 (9), school avoidance = 3 (3)
Craig	14	mild	31	generalised anxiety = 10 (9), social anxiety = 8 (8), school avoidance = 3 (3)
Chris	15	mild	40	panic/somatic symptoms = 10 (7), generalised anxiety = 13 (9), separation anxiety = 6 (5), social anxiety = 8 (8), school avoidance = 3 (3)
Ben	11	moderate	27	panic/somatic symptoms = 7 (7), generalised anxiety = 13 (9)
Richard	11	moderate	52	panic/somatic symptoms = 14 (7), generalised anxiety = 13 (9), separation anxiety = 10 (5), social anxiety = 10 (8), school avoidance = 4 (3)

¹ All participants were of white background, mainly Scottish, British or Irish. ² Participants' self-reported asthma severity at the point of the interview (on a 3-point self-report scale from mild to severe).

³ Participants' scores on the SCARED subscales on which they performed above the clinical cut-off point. The parentheses present the cut-off points of the respective subscales, as determined by the inventory's authors (Birmaher et al., 1999).

Table 2. Interview schedule

Interview guide

Experience of asthma and anxiety separately

What is asthma like for you?

What has it meant for your life?

- Prompts, if needed: Do you have any concerns about your asthma? How does asthma affect your day-to-day functioning/your relationships? What do you do to cope with your asthma? What is the role of your parents in coping with your asthma? What type of medication are you prescribed for your asthma? How do you decide when to take your medication?

What is anxiety like for you?

What has it meant for your life?

- Prompts, if needed: Do you have any concerns about your anxiety? Can you give me some examples of worrying situations for you? How does anxiety affect your day-to-day functioning/your relationships? What do you do to cope with your anxiety? What is the role of your parents in coping with your anxiety?

Relationship between anxiety and asthma

In your experience, do asthma and anxiety influence or affect one another?

- If yes, 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 are your expectations about your asthma and anxiety in the future?

How does worrying feel on your body; how is that different from asthma?

How do you know when to get your medication?

Table 3. Themes of how anxiety and asthma relate with prevalence across participants

<i>Overarching themes</i>	<i>Subordinate themes</i>	<i>Theme prevalence across participants</i>
1. Experiences of asthma affecting anxiety	a. Asthma as a threat to important developmental goals	10
	b. Asthma as a barrier to valued, potentially coping, activities	11
	c. Asthma triggers worries and anxiety-provoking thinking patterns	11
	d. Strategies to manage asthma over-generalise to managing anxiety	9
2. Experiences of anxiety affecting asthma	a. Physical symptoms of anxiety and anxiety-related behaviours trigger asthma	6
	b. Anxiety inhibits good asthma care and medication adherence	6
3. Experiences of interactions between asthma and anxiety	a. Asthma and anxiety interact forming a self-perpetuating feedback cycle	5
	b. Confusion between symptoms of asthma and symptoms of anxiety	4