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### "He's not fat, he just has asthma"

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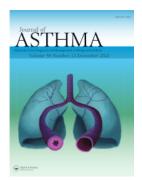
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## "He's not fat, he just has asthma": a qualitative study exploring weight management in families living with pediatric asthma

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## "He's not fat, he just has asthma": a qualitative study exploring weight management in families living with pediatric asthma

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#### **ABSTRACT**

**Objective:** Children and young people living with asthma have an increased risk of overweight/obesity, leading to increased severity of asthma symptoms. Weight management has been recommended to improve asthma symptoms, however, there is limited understanding of how this is experienced or how children and young people with asthma and their families wish to be supported. The aim of this study was to explore parents and children/young people's views and experiences of managing weight while living with asthma, and to identify acceptable strategies for support.

**Methods:** A qualitative methodological approach was taken to facilitate rich understanding of families' insights into weight management while living with asthma. In-depth interviews were conducted with nine families living with pediatric asthma (n=9 parents, 9 young people). Data were analyzed using a Framework approach.

**Results:** Findings indicated that family engagement with weight management behaviors was primarily influenced by perceptions of risk regarding asthma outcomes and beliefs about asthma control. Families also reported weight management engagement to be influenced by perceptions of the food environment, perceptions of the exercise environment (e.g. weather, anticipated social outcomes) and the availability of weight management support. Participants sought tailored support which gave consideration to the asthma-obesity interaction. It was suggested that this would help reduce perceptions of weight stigma in consultations, thereby supporting behavioral changes.

**Conclusions:** Individualized weight management plans that consider families concerns about asthma-related risk are needed to manage weight in children and young people living with asthma.

#### ARTICLE HISTORY

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#### **KEYWORDS**

Respiratory; pediatrics; obesity; management; qualitative research

#### Introduction

Asthma symptoms can increase in prevalence and severity when children and young people (CYP) living with asthma also have obesity (1). These CYP also have a lower responsiveness to asthma medication, increased prevalence of hospitalization and a lower quality of life compared with peers living with asthma who have a healthy weight (1–2). The few pediatric weight-loss interventions that have been designed specifically for asthma show promising results in weight reduction and improving asthma outcomes (3–4). Currently, the Global Initiative for Asthma Guidelines recommends weight management for asthma control (5). However, there are no guidelines on how to manage weight in CYP living with asthma or how to

overcome weight management challenges specifically related to asthma (5).

Given the complex and multi-faceted nature of the asthma-obesity relationship (1), understanding how to optimize weight management support for CYP living with asthma is a challenge. Factors including physical activity, diet, medication and anxiety have been associated with the etiology and/or management of both asthma symptoms and obesity (1). Literature also considers the bi-directional impact of asthma and health behaviors. For example, perceptions of exercise as dangerous for children with asthma (6), and weight status as a determinant of asthma medication adherence in children (7). Limited research has explored families' experiences of weight management for CYP who have asthma or how asthma and weight interact in CYP to shape their attitudes and experiences.

In addition, research suggests several barriers to accessing weight management support for CYP living with asthma. Pediatric healthcare professionals (HCPs) have previously raised concerns about discussing weight in asthma consultations, about weight stigma and insufficient weight management knowledge, as well as limited community-based weight management services available for referral (8–9). Nevertheless, families have reported a desire for HCPs to incorporate health-specific challenges in weight management conversations (10). Additionally, adolescents living with asthma have expressed a greater acceptance of weight conversations when discussed alongside asthma management (11).

As literature highlights the role of parenting practices upon child weight (12) and parents supporting asthma management in CYP (13), we need to improve understanding of how families living with pediatric asthma perceive and participate in weight management behaviors. Such understanding will support the development of tailored, family-centered interventions which are acceptable and engaging for this population (14). The aim of this research was to explore parents and CYP's views and experiences of managing weight while living with asthma, and to explore families' views on methods for supporting healthy weight alongside asthma management.

#### Methods

#### Recruitment

Children and Young People (aged 8–18 years) living with clinician diagnosed, or self-reported asthma, and their parents, were recruited via a Children's Hospital asthma clinic, a University online staff portal, and an online asthma research survey. After receiving study information, interested families contacted the research team to obtain further information, provide demographic information and arrange an interview. Demographic data was used to identify and select both healthy and overweight child participants to ensure variation in participant characteristics and meet the research aim. The study received ethical approval from Aston University Research Ethics Committee (#195–2017-RC) in addition to NHS Research Ethics Committee approval (#17/WM/0293).

#### **Data collection**

Qualitative methodology can be utilized to explore lived experience in the context in which it is perceived, such as weight management in pediatric asthma. Therefore, parents and CYP participated in

individual interviews either face-to-face (e.g. at a local hospital, at home) or over the telephone, in accordance with their preference. Young Person 4 was the only participant who requested to have her parent present during the interview. Interview questions were informed by research literature and study objectives and followed a semi-structured approach. The interview guide contained open-ended questions that supported participants discussing their own views and experiences and subsequent questions were individually tailored. Interviews explored weight in the context of asthma, weight management challenges associated with asthma and strategies for supporting healthy weight in those with asthma. Informed consent/young person assent and demographic data were obtained prior to data collection. Interviews lasted between 40 and 90 min and were conducted by the first author (RC). Parent 2 required an interpreter who was her nonparticipating eldest child. Participants received a £10 voucher to thank them for their time.

#### Data analysis

Interviews were audio-recorded, transcribed verbatim and anonymized. To facilitate the comparison of views and experiences between parents and CYP, and between those families of a CYP with a healthy weight and overweight, a thematic Framework Method was selected (15). The Framework Method is used in health research to facilitate in-depth analyses while exploring commonalities and differences between participants (16). Following the procedure outlined by Gale et al (16), two researchers independently engaged in a process of data familiarization, systematic coding of the text and grouping codes into themes to form a thematic framework. Several iterations of this process occurred until all transcripts were coded using the framework and data were charted into a matrix. Data management and retrieval were assisted by the use of NVivo software V11 (QSR international).

#### Results

A total of 18 participants from 9 families (9 parents and their 9 children), took part in interviews. See Table 1.

Data analysis generated three core themes: (1) fear of exacerbation, (2) concerns about weight gain, and (3) a need for appropriate support.

#### Theme 1: Fear of exacerbation

Parents expressed a strong sense of fear regarding the unpredictability of asthma and their ability to manage

Table 1. Characteristics of participants.

Participant number	Age	Gender	Ethnicity	Child weight category	Child age of asthma diagnosis (years)	Asthma Severity*
Parent 1	38	Female	Pakistani			<u> </u>
Young Person 1	16	Female	Pakistani	Overweight	5	Step 4
Parent 2	53	Female	Bangladeshi			
Young Person 2	14	Female	Bangladeshi	Overweight	2	Step 5
Parent 3	42	Female	White British	3		•
Young Person 3	11	Male	White British	Overweight	4	Step 4
Parent 4	35	Female	White British	,		•
Young Person 4	8	Female	White British	Healthy weight	<1	Step 3
Parent 5	37	Female	White British	, 3		•
Young Person 5	12	Male	White British	Healthy weight	5	Step 2
Parent 6	44	Male	Pakistani	, 3		•
Young Person 6	16	Female	Pakistani	Healthy weight	6	Step 1
Parent 7	36	Female	White British	, 3		•
Young Person 7	12	Male	White British	Healthy weight	<1	Step 2
Parent 8	53	Female	White British	, 3		•
Young Person 8	15	Male	White British	Healthy weight (previously overweight)	2	Step 1
Parent 9	46	Female	White British	- '		
Young Person 9	11	Male	White British	Overweight	5	Step 1

<sup>\*</sup>Asthma severity: as per British Thoracic Society/Scottish Intercollegiate Guidelines Network (BTS/SIGN) guidelines (17).

their child's asthma symptoms: "anything could trigger it and you never knew why it was happening" (Parent 2). At times this worry developed into hyper-vigilant symptom monitoring as well as "overly protective" (Parent 7) parenting strategies to reduce the risk of asthma exacerbation, including restriction of physical activity.

CYP's ability to engage in physical activity whilst living with asthma was also perceived as limited: "with her asthma, obviously, she can't do too much" (Parent 1). Consequently, CYP felt reluctant to engage in vigorous exercise, as they doubted their capability and anticipated dyspnea: "I feel like I'm just going to be standing there using my inhaler" (Young Person 9). Difficulty in overcoming these asthma exercise barriers meant that some families did not believe CYP could exercise or manage their weight while living

Instead, families who feared exercise-induced asthma symptoms perceived restricting physical activity as an opportunity to reduce the immediate threat of asthma exacerbation. The degrees of restriction varied between families but increased with asthma severity. Thus, while some participants restricted exercise duration or opportunities due to perceptions of capability, some parents actively encouraged CYP to participate in more sedentary behaviors. Consequently, creating barriers to weight management:

Mum is quite careful with her now. She tells her not to do much and just sit and watch TV or go on her phone and Mum gets everything for her. She'll bring her food to her. She'll do everything. (Parent 2)

Families' perceived need to reduce or restrict exercise also extended to environments in which parents felt they had little control, such as schools. Experiences of insufficient school-based asthma care (e.g. P.E. teachers not believing reports of asthma symptoms) thus heightened parental anxiety, leading to safety behaviors including advising exercise avoidance: "there was [a] time we told her not to do any P.E." (Parent 2). Environmental factors, such as cold air in winter and pollen in summer, were also perceived as obstacles to CYP achieving asthma control while outside. To reduce families' fear of environmental triggers, one parent provided a scarf to go around her daughters' neck, while others ceased outdoor activities in months perceived as risky:

He's indoors. He's warm. His inhalers are there. I can see that he's okay. That can be nice. (Parent 7)

Uncertainty as to which types of exercise were "asthma-friendly" (Young Person 6) therefore acted as a barrier to physical activity. Greater practical exercise knowledge and support were thought to help bridge the gap between exercise concerns and exercise engagement. Some participants suggested a bespoke and "safe" (Young Person 9) exercise plan to be key to increasing families' confidence and exercise participation. Others felt that participating in exercise with HCPs present was necessary to enhance their self-efficacy and reduce asthma-specific concerns:

She got my confidence back actually too. Like, it's okay, if I do get out of breath because I know that now that I'm not going to go into an asthma attack. (Young Person 1)

While participants demonstrated an understanding of balancing food groups for weight maintenance, food choices were influenced by perceived asthma and

allergy outcomes. Trial and error was the most common approach to identifying foods that influenced asthma symptoms. Subsequently, diet modification was used as a technique to control asthma. While many families "restricted" (Young Person 6) foods perceived to be associated with asthma exacerbation, others were more radical:

My mom because she was like, if you become a vegan it will help you more with growing up as in like your body, your asthma and yeah stuff like that. (Young Person 5).

Some parents acknowledged that they lived in an obesogenic environment and doubted whether a food-related asthma threat would deter the consumption of specific foods by CYP. Parents perceived the home environment to offer an opportunity to covertly influence CYP's dietary intake through reduced availability of unhealthy foods. However, CYP were motivated to make smaller alterations to their diet to avoid future exacerbations. It was clear then, that for some families, engagement in diet-related weight management depended on whether they associated adverse asthma outcomes with particular foods:

I know if I eat all that heavy unhealthy stuff, my asthma is going to flare up. If I have a fizzy drink, that another thing that makes my asthma flare up [...] I know to stay away from it and it's fine for me because it's going to be me who gets affected. (Young Person 1)

For families who perceived food-related asthma outcomes to be "serious" (Parent 6), there was confusion as to why the relationship between asthma and diet was not discussed during medical consultations: "I don't even know if they know my [diet-related] anaphylaxis has caused asthma attacks" (Young Person 6). Furthermore, families believed that they would be more likely to "buy certain foods or adopt certain habits" (Parent 5) that could aid weight management if HCPs provided dietary information that was linked to asthma control:

They could've said 'These foods might trigger your asthma' and that would've been more helpful so then I know to avoid them or have a certain awareness of how much I'm taking. (Young Person 6)

#### Theme 2: Concerns about weight gain

Despite examples of asthma control being prioritized over weight management in the context of exercise, non-adherence was discussed as a strategy used by CYP to avoid anticipated weight gain: "She's like 'I'm

fat' [...] then I'll notice she'll miss the steroids" (Parent 1). This was mirrored in parents' sense of remorse for delaying health appointments for fear of being prescribed steroids which could lead to weight gain:

I still obviously wouldn't have not gone to the doctor. I just would have left it a bit longer just to make sure that, you know, he didn't get better. (Parent 8)

For some parents then, there was a sense of hopelessness in achieving a healthy weight whilst CYP were using steroids: "It's like a vicious cycle, he can't lose the weight" (Parent 9). One parent explicitly discussed how her daughters' ambivalence regarding her ability to manage weight whilst using asthma medication created inconsistent eating behaviors. Thus, for some families, excess weight was also perceived to be indirectly linked to asthma medication, particularly when increased eating was used to regulate the child's emotional response to their illness and treatment:

She will have nothing at all apart from water. Have her tablets, 'no I've already had my tablets. I've already had calories' [...] some days she is like, 'OK, I'm just going to eat and eat and eat and eat'. You know, you have two faces. [...] Maybe they [asthma medication] don't make her put weight on maybe. Because she's angry and she's eating all sorts of junk and making herself fat. (Parent 1)

It was highlighted how HCPs could use their position to promote health behaviors thereby incentivizing adherence as an aid to exercise engagement and CYP's weight management.

The association between child weight and CYP's emotional well-being was further emphasized, as some parents expressed concern about their child's self-esteem regarding their weight and worried that CYP would "put themselves down" (Parent 1) by comparing themselves with peers of a healthy weight. This negative self-concept was supported by one young person who claimed he would "feel better" (Young Person 9) about himself if he lost weight. Parents described different approaches to protecting CYP's emotional well-being. While some parents wished to avoid discussing the stigmatized topic of weight with their child, other parents highlighted the importance of encouraging young people to "accept and be confident" (Parent 6) in their bodies, placing a greater emphasis on their physical health than appearance.

Furthermore, CYP feared undesirable social outcomes due to the perceived salience of breathlessness and excess weight and, consequently, felt reluctant to engage in physical activity around peers. There was a sense of embarrassment and blame when peers attributed CYP's difficulty in exercise and weight to



being "unfit" and "lazy" (Young Person 9). One young person indicated that feelings of shame during exercise could be reduced if peers understood that excess weight can be related to living with asthma:

They would laugh at me, say I'm trying to make up excuses, they say I'm too fat or something like that [...] Maybe that people would understand that I'm not too fat and then maybe people would understand yeah, he's not fat, he just has asthma. (Young Person 9)

Confidence in exercise was also thought to increase in cases where family members and peers understood that asthma could create physical activity barriers and breathlessness. In comparison, one young person with a healthy weight normalized breathlessness and reported that social comparisons to peers who experienced weight-focused bullying motivated his weight management.

#### Theme 3: a need for appropriate support

Participants expressed how medicalized control of asthma was prioritized in healthcare appointments. Families of CYP who had experienced severe asthma symptoms were more accepting of weight management support not being provided: "their weight is the last thing you're worried about. It's a matter of keeping that person alive." (Parent 2). In comparison, families who had better asthma control expressed a sense of irritation that appointments were not being fully utilized:

I had a look at the health plan... on the back, there were different sections about exercise. They were just left. We hadn't even completed them." (Parent 7).

For these families, holistic asthma reviews were considered an opportunity to improve asthma control and prevent excess weight. While it was only families living with asthma and overweight who had discussed the asthma-obesity relationship with HCPs, these families often reported feeling invalidated for seeking support due to a dismissive approach that provided little practical support:

I just decided that they weren't really interested so I would try and deal with it myself. I felt I could. I just wanted extra support. (Parent 8).

Some families were reluctant to talk about weight with HCPs, describing it as an "uncomfortable" topic (Young Person 7). The stigmatized nature of obesity created feelings of "embarrassment" (Young Person 9) for CYP and parents due to a sense of personal responsibility and anticipated blame: "I'm kind of feeling ashamed that he's like that [...] I felt like it's all

my fault." (Parent 9). Developing families' understanding of the asthma-obesity relationship, easing into conversations slowly and avoiding terminology such as "fat" (Parent 2) was considered helpful for increasing receptiveness to weight management conversations:

If it's just one of those things that you have to deal with when you've got asthma or you might have to deal with, you know, then maybe it might be easier to approach the weight problem. (Parent 8).

Families believed that sharing peers' accounts of positive exercise outcomes when living with asthma would help other families to understand that exercise would "do them good as opposed to do them harm" (Parent 8), motivating them to engage the physical activity. Nevertheless, it was also recognized that families' exercise concerns may be deep-rooted meaning HCPs would need to "constantly remind" (Young Person 5) families of the benefits of exercise for asthma control to reinforce behavior change.

It was considered important to make access to ongoing weight management services as convenient as possible. Suggestions for the delivery of weight management support included embedding services in the local community, online resources and mobile applications. Asthma management using medication, strategies to support anxiety management, and asthma-specific diet and exercise information were considered essential components. An asthma-specific weight management group was further viewed as an opportunity to receive emotional support; a vital component of care missing from asthma consultations.

A lack of weight management support in the community and limited signposting by HCPs were further barriers identified to weight management. Experiences of HCPs recommending weight management but not referring or signposting to support services meant that some parents did not "know where to turn to" (Parent 9) for help. Families left medical appointments feeling "naïve" (Parent 9) for expecting weight management support to exist rather than feeling validated for seeking the support that was needed. Practicalities of accessing existing weight management facilities were also discussed, with safety, time and money frequently cited as barriers: "just a journey for somebody, that'll be a meal on the table for them" (Parent 1). Concerns about the practicalities of accessing weight management support were enhanced by the perception that resources may be wasted if CYP do not want to go:

What's the point if I've got to travel and he doesn't want to go there anyway? Even if it's like three lessons, somebody has to pay for that so it's kind of a waste of money in a way, do you [know] what I mean? (Parent 9)

#### **Discussion**

The views and experiences discussed by families in this research shed insight into the multifaceted challenges of weight management faced by CYP living with asthma. Findings suggest that, in general, families' engagement in healthy weight management behaviors are contingent with their beliefs about asthma control. Thus, the management of asthma and weight appear to be inter-dependent, making it challenging to consider one without the other. As such, families' perceptions of how weight impacts asthma risk or control are likely to be fundamental to understanding their readiness to engage in weight management behaviors.

Findings illustrate how families with CYP living with asthma consider the asthma outcomes of weight management behaviors and modify their engagement based on their asthma outcome beliefs. These findings are consistent with previous literature highlighting families' adjustment of diet and leisure activity as a method to maintain asthma control (6). It is also possible that families with low exercise self-efficacy beliefs or asthma-related anxiety may have increased anticipation of asthma exacerbation and decreased exercise engagement. Asthma-related anxiety has previously been associated with families avoiding situations interpreted as a threat to asthma control (18-21). Such avoidance and preventative steps may influence weight management if they include reducing or limiting exercise opportunities (5). It may be necessary then, for HCPs to consider families' exercise self-efficacy beliefs when supporting CYP's weight management, working to identify situations that provoke anxiety and providing strategies to manage these anxieties and overcome such barriers, to facilitate behavior change. Increasing self-efficacy in families' with asthma has previously raised exercise intensity, leading to a reduction in weight (22-23). Support from other disciplines may also be beneficial in some cases, for example, referral to psychology can provide a more specialized service outside of the asthma consultation.

Similar to previous literature (24), participants in this study reported increased appetite and weight gain as a consequence of asthma treatments. This was associated with negative emotions leading to inconsistent eating behaviors, non-adherence and decreased help-seeking behaviors. Inconsistent eating behaviors in pediatric asthma may develop as a strategy to manage weight gain resulting from asthma medication. Alternatively, anger and frustration caused by weight gain may also lead to emotional eating. Previous research has reported that adolescents with asthma are more likely to diet, skip meals and eat when sad compared to their peers' (25). Non-adherence and decreased help-seeking behaviors were also discussed by participants in this study as a method to avoid asthma treatment-related weight gain. It is possible that such techniques increase the risk of suboptimal asthma control, increased exercise limitations and excess weight (26). Non-adherence and decreased help-seeking may be more likely if families believe other asthma control methods, such as exercise reduction, are appropriate (27). Further research into why some families may prioritize asthma control in the context of exercise, and weight management in the context of adhering to asthma medication, would help to develop a more comprehensive understanding of how to provide individualized support.

In this study families also reported environmental challenges that created barriers to weight management, such as the obesogenic food environment, the risk assessment of exercise environments and lack of weight management services (8,9,28). Specific to living with asthma, seasonal asthma triggers and anticipated social outcomes of breathlessness were identified as influences on exercise engagement (29-30) As CYP with asthma and overweight are more likely to have seasonal asthma symptoms, it is also possible that a perpetuating cycle of seasonal asthma symptoms, outdoor physical activity avoidance and weight gain can develop (29). It may be beneficial for HCPs to recommend that families explore indoor activity opportunities during months perceived to carry an increased risk to asthma control (5). Furthermore, HCPs may need to consider CYP's social-concept when considering their exercise engagement. Hughes and colleagues (31) theorized that young people with asthma would reduce physical exertion if exercise-induced asthma symptoms was perceived as unappealing to peers. Techniques to overcome this barrier may offer an opportunity to increase exercise engagement at this age (23).

These findings also highlight the need for services to not only support the symptomatic experiences of asthma but for HCPs to convey understanding of the 'lived' experience of asthma and overweight during consultations. Further to showing empathy toward patients subjective experience, participants believed that HCPs educating them on the relationship between exercise and diet with asthma would reduce perceived weight stigma, increase confidence in asthma management and motivate behavior change (11). A HCP providing this



in a group with other families could be one way to enhance families' confidence in managing weight and provide the emotional support perceived to be missing from asthma consultations. Previous literature has found that parent support networks have been a useful instrument for providing emotional support, information and the sense of a community (32). Future research would need to investigate the feasibility and effectiveness of an asthma weight management support group as well as engagement at different ages.

#### Strengths and limitations

This study employed a purposive sampling strategy to recruit participants from a mix of backgrounds and a sample of participants with healthy weight and overweight/obesity. Thus, it provided a variety of experiences and beliefs of what may or may not work to help manage weight and allowed for comparisons to be made. Furthermore, this research recruited a wide age range of participants to gain an understanding of the issues across childhood and adolescence. Narrowing the participants' age groups in future research would help to understand in more depth, the barriers that are specific to different ages (e.g. 8-12; 13-16).

#### **Conclusions**

In conclusion, these findings highlight the complexity of the relationships between weight and asthma management in CYP. Overall families felt unsupported and ill-equipped to manage CYP's weight and were uncertain of how to maintain asthma control while engaging in health-promoting behaviors. Families would benefit from working in collaboration with HCPs to understand their concerns and to create individualized weight management plans that families feel comfortable and confident to follow.

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