Title: Barriers and facilitators to self-management of asthma in adolescents: an interview study to inform development of a novel intervention

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Abstract

Background and Objective

Despite literature that spans twenty years describing the barriers to asthma self-management in adolescents, successful, clinically-based interventions to address this important issue are lacking. Given the limitations of some of the previous studies, we conducted a study that aimed to gain a broader insight into barriers and facilitators to self-management of asthma by adolescents, not just adherence to treatment, and triangulated their views with those of their parents and healthcare professionals.

Methods

Focus groups and interviews were conducted separately for 28 adolescents with asthma aged 12-18 years, 14 healthcare professionals, and 12 parents. Focus groups and interviews were audio-recorded and transcripts from each participant group were analysed separately using inductive thematic analysis. We triangulated the three perspectives by comparing themes that had emerged from each analysis.

Results

Adolescents', parents', and healthcare professionals' views were summarised into ten related themes that included forgetting and routines, knowledge, embarrassment and confidence, communication with healthcare professionals, triggers, support at school, apathy, and taking responsibility. We found that adolescents, parents and healthcare professionals raised similar barriers and facilitators to self-management and our results provide further validation for previous studies.

Conclusion and Clinical Relevance

Our study highlights that healthcare professionals may need to consider a range of psychological and contextual issues influencing adolescents' ability to effectively self-manage their asthma, in particular, how they implement treatment routines and the understanding that adolescents have of their condition and treatments. Crucially, healthcare professionals need to consider how this information is communicated and ensure they facilitate open, inclusive, two-way consultations. From this more comprehensive understanding, we have developed interventional strategies that healthcare professionals can utilise to empower adolescents to improve their asthma self-management.

Introduction

The impact of asthma on daily life extends beyond the typical symptoms of wheeze, breathlessness, chest tightness and cough. Adolescents with asthma are more likely to have poorer physical and mental health and report lower quality of life compared to their peers without asthma.[1] Furthermore, despite the availability of effective pharmacological treatments, many continue to have poor asthma control, which is often attributed to poor adherence to treatment.[2]

Adherence to treatment is not the only behaviour needed to successfully self-manage asthma in order to gain optimal asthma control. Self-management includes carrying out behaviours that monitor and prevent symptoms, [3] such as avoiding triggers, and also requires effective communication about one's asthma with family, friends and healthcare professionals.

A number of studies have sought to gain an understanding of poor treatment adherence or broader concepts of self-management in adolescents with asthma. We conducted a systematic review and narrative synthesis of literature that included adolescent reported barriers and facilitators to asthma self-management. The key themes that emerged were: knowledge, lifestyle influences (such as routines), beliefs and attitudes, relationships with others, intrapersonal characteristics (such as motivation), and communicating with others (such as healthcare professionals).[4] There were, however, methodological limitations of some studies included in this review. There were concerns about the quality of some studies due to inadequate study design, methodology or reporting details; the inclusion of participants outside of the typical adolescent age range (less than 10 or over 18 years of age); and, heterogeneity in the study settings (e.g. hospital clinics and schools). In addition, many studies were focused on treatment adherence only and did not examine wider components of self-management, for example behaviours to prevent and manage symptoms, such as monitoring symptoms and avoiding triggers.[5] Hence the findings may better reflect the issues of treatment adherence than self-management.

The findings from our systematic review are consistent with a recent publication reviewing barriers and facilitators of effective self-management.[6] Similar issues were identified such as the need for partnerships between the healthcare professional and their patient and the importance of health beliefs. However, this review includes studies across all age groups and was not focused on adolescent issues. The literature included in our systematic review spans nearly 20 years, with similar barriers and facilitators being highlighted across this time period. This suggests that healthcare systems have yet to successfully address the issues of adolescent asthma self-management. The reasons for this are unclear but it is possible we have yet to fully understand the influence that the complex inter-relationship between the adolescent, parent, and healthcare professional has on self-management. For example, a recent qualitative study explored self-management of asthma in adolescents and included parent perspectives. Adolescents often neglected to report normal asthma symptoms to parents, which was linked to subsequent lack of symptom reporting to HCPs.[7] Much of the existing literature is focused on the *adolescent* yet we argue that any successful intervention to improve their self-management would benefit from understanding the current perspective of parents and HCPs. Firstly because they may have a different understanding of the factors that influence adolescents self-management, compared to adolescents themselves, and secondly to understand whether the support that parents and HCPs provide is aligned with the adolescent's needs and expectations. A successful intervention, therefore, is likely to target the behaviour of parents and HCPs, for example in developing effective partnerships.[8 9]

Furthermore, there are a limited number of studies describing successful interventions to improve asthma outcomes and self-management in adolescents in clinic settings. Studies have reported mixed

results in the ability of clinic-based interventions to improve adherence[10,11] and/or psychological indicators of self-management (such as motivation or self-efficacy).[12,13] Many other studies tend to be educational group-based interventions delivered in school settings in the US and may not be practical or appropriate for the health and education contexts in countries outside of the US. So, whilst studies have shown intervention effectiveness in trials,[12,14] we need a better understanding of how interventions aimed at improving self-management might work within the complexity of the clinical setting, including how to enable HCPs to embed interventions in routine practice. In order to develop a robust and effective intervention aimed at improving adolescent self-management of asthma, we argue that two fundamental issues need to be addressed. Firstly, methodologically robust qualitative studies are required that focus on understanding the broad concept of self-management in adolescents across a variety of settings. Secondly, studies are needed that include the views of healthcare professionals and parents concerning adolescent asthma self-management.

This study aimed to address these issues by utilising robust, contemporary qualitative research methods to gain a broader insight into self-reported barriers and facilitators to adolescent asthma self-management, not just adherence to treatment. In addition, we extend previous research further by obtaining and triangulating perspectives from adolescents, healthcare professionals and parents. Triangulating more than one data source can offer a more comprehensive approach to data collection in qualitative research[15] thereby providing a more holistic understanding of complex phenomenon.[16] We planned to utilise our findings to design an effective intervention that will be implemented in a clinic setting.

Aim

The primary aim of this study was to explore views about barriers and facilitators to self-management of asthma from the perspective of adolescents, their parents and their healthcare professionals (HCPs). The data were also used to develop an adolescent self-efficacy in managing asthma outcome measure and to inform development of an intervention to support adolescents to better self-manage their asthma.

METHODS

Setting and Participants

The study was conducted between October 2014 and March 2015 in primary and secondary care sites in Southampton and Isle of Wight (UK). The study was given a favourable opinion by the East of England National Research Ethics Committee – Cambridge Central (study reference 14/EE/0172).

Eligible participants were identified by searching patient lists of GP surgeries and hospital pediatric outpatients for adolescents aged 12-18 years with doctor-diagnosed asthma, prescribed regular prophylactic medication for asthma, and with no other significant long-term medical condition. The initial approach was by letter or in person from their usual doctor or nurse. Older participants (16-18 year olds) were given the option to take part in either a focus group or a 1:1 interview, younger

participants were asked to take part in a 1:1 interview only. Purposive sampling was used to ensure a range of ages, gender, and asthma severity.

Parents (or guardians) and HCPs of the adolescents who agreed to participate in the study were approached in person to take part in focus groups, although 1:1 interviews were conducted where participants were unable to take part in a focus group.

Twelve parent/guardians agreed to take part ranging in age from 34 to 55 years, 10 were female, 2 were male. The HCPs included three respiratory paediatricians, an adult respiratory physician, a general paediatrician, three secondary care asthma nurse specialists, two primary care nurses, community asthma nurse, a school nurse and a general practitioner (GP).

Written informed consent was sought from all participants as well as parental consent for adolescents. All participants were assured of confidentiality.

Focus groups and interviews

A semi-structured interview schedule was used which was informed by a review of the literature[4] and discussion with experts in the area; this included psychologists with expertise in asthma, allergy and self-efficacy for management of long-term conditions, and a pediatric asthma consultant. The questions were not prescriptive but served as a topic guide to encourage discussion of asthma self-management and were designed to explore the views and experiences of participants (see box 1). The interview schedule was piloted in the first interview, no changes were deemed necessary and data was therefore included in this analysis.

Focus groups took place at a hospital, individual interviews were conducted either at a hospital or in participants' homes. A psychologist (SH) with experience in conducting focus groups and interviews with adolescents conducted the interviews and facilitated focus groups using a semi-structured interview guide - a research nurse was present for the adolescent focus group. All the adolescent interviews and the focus group were conducted without any parent or guardian present.

An interim analysis of adolescent transcripts was conducted by SH and GR to assess whether data saturation had been achieved. Although it was clear at this point that no new themes were emerging, further interviews were conducted to ensure an even spread of ages and asthma severity.

Data analysis

Interviews and focus groups were audio-recorded and transcribed verbatim. Transcripts were analysed by two investigators (SH and DW) adopting the inductive thematic analysis approach recommended by Braun and Clarke.[17] Thematic analysis is recognised as a versatile approach to qualitative data analysis. This was done independently of the interim analysis for data saturation.

Adolescent transcripts were analysed first and the early phases involved independently reading (and re-reading) a selection of the adolescent transcripts to become familiar with the data and generating

initial codes. The two investigators met to discuss the initial codes and review the transcripts. Over a number of weeks all the transcripts were read and reviewed in this manner, with the two researchers refining and combining initial codes into themes. Mindmaps were used to visually represent the data and facilitate discussion. Initial coding was done manually, NVivo was used by one researcher (SH) in the later stages of thematic analysis to organise and store codes, themes, and transcripts. The same procedure was conducted with the parent and HCP transcripts, which were reviewed and discussed in tandem. The researchers attempted to perform the initial coding of these transcripts without considering the themes that emerged from the adolescent data.

The final stage – triangulation - involved comparing and reviewing the themes from the three participant groups to determine if they were complementary or contradictory.

FINDINGS

A total of 75 adolescents were approached. Six adolescents took part in one focus group and a further 22 adolescents were interviewed 1:1 by SH. Twenty-four adolescents declined to take part and follow up contact was unsuccessful in the remaining 23 who did not respond to telephone calls or messages. Demographic information about the adolescent participants is shown in Table 1.

Eighteen parents/guardians were approached, four declined (due to lack of time) and two did not attend the focus group as arranged. Twelve parents took part in the study, in two focus groups (4 participants in each) and four 1:1 interviews.

Seventeen HCPs were approached to take part. Three were unable to attend the agreed focus group or 1:1 interview due to unforeseen circumstances. Fourteen HCPs took part in two focus groups (n=3, n=8) and three 1:1 interviews. The HCPs included respiratory paediatricians, secondary care asthma nurse specialists, primary care nurse, school nurse and general practitioners (GP).

The focus groups lasted approximately 1.5 hours and interviews lasted 20-60 minutes.

Barriers and facilitators to asthma self-management

Both investigators (SH, DW) were in agreement that themes from the three data sources were almost identical and were therefore summarised together. Furthermore, each barrier theme could be related to a connecting facilitator theme. Table 2 summarises and presents the linked themes that emerged from the analysis, whilst Table 3 provides illustrative quotes from each participant group.

Barrier*: Forgetting medication;* Facilitator*: Routines and reminders*

Remembering to take medication was often difficult, either regularly or in situations that were out of the normal routine, with similar issues raised by adolescents, HCPs and parents. Typically this was

attributed to being in a rush in the morning before school, staying up late, or being out of the normal routine (e.g. on holiday). Some adolescents also reported not using their reliever because: they forgot to use it when they were experiencing symptoms; they had forgotten to carry it with them; they could not remember if they had taken their medication; or they had run out of medication.

In contrast, all participant groups said having a routine or using cues and reminders helped them remember to take their medication. Parents frequently provided reminders and, to a lesser extent, friends. Participants reported that it was helpful to keep medication in visible places, for example on a bedside table, and they were more likely to remember medication if they were unwell.

Barrier*: Burden of treatment;* Facilitator*: acceptance of medication*

All participant groups talked about the burden or inconvenience of using asthma treatments. In particular, spacers took time to use; were bulky and difficult to carry around; noisy; or, they were 'irritated' by having to use medication. Adolescents and parents also talked about self-management being difficult when medications were being frequently changed. In contrast, some adolescents talked about accepting the need for, or recognising the benefits of, medication. HCPs said that having a less burdensome device (for example a smaller spacer) could help with adherence.

Barrier*: Lack of knowledge about asthma and treatments;* Facilitator*: knowledge*

A lack of knowledge about medications and asthma was reported as a barrier to self-management by all participant groups. Not understanding how medications worked, being confused about treatments, and being given conflicting information from primary and secondary care HCPs was a barrier that adolescents, parents, and HCPs discussed. Adolescents discussed not fully understanding what asthma is, being given too little information, or too much in large books, and held unhelpful beliefs about their asthma and/or treatments such as inhalers being ineffective. HCPs and parents were concerned that adolescents often did not know how serious asthma was.

Some adolescents said they knew a lot about their asthma, and that this information had come from their HCP or parents who had given them the information in a way they understood. Some adolescents also recognised the improvement to their asthma symptoms from taking their treatment. HCPs felt that adolescents needed regular education and that visual information was useful. Parents said it was useful for adolescents to know their symptoms, and, as mentioned above, know about their triggers.

Barrier: *Feeling anxiety or panic*; Facilitator: *staying calm*

Adolescents and parents said that asthma symptoms were exacerbated by anxiety or stress, sometimes caused by the worry of not having their inhaler with them when they were having trouble breathing. Both adolescents and parents said that taking steps to stay calm and relaxed was helpful

and some adolescents recognised they should not panic in order to control their breathing. This theme was not identified in the HCP views.

Barrier: *Triggers / allergies*; Facilitator: *Having strategies to avoid triggers*

All participant groups identified asthma triggers that were difficult to avoid, these included temperature changes, winter, illness, dust, hay fever, exercise, pets, and exposure to deodorants at school. One adolescent admitted to smoking cigarettes despite recognising the negative impact on asthma. Some parents said their child was unable to recognise their triggers and HCPs were concerned about exposure to parents' cigarette smoke.

Some adolescents were taking steps to minimise the impact of triggers, such as keeping pets out of bedrooms, helping to keep the house and their bedroom clean, and not visiting friends or family where triggers were an issue. Some had also stopped exercising, or avoided exercise as it triggered asthma symptoms. Parents also said adolescents needed to recognise their triggers and know what to do.

Barrier: *Embarrassment and stigma*; Facilitator: *Confidence and support from friends*

Having asthma, or using asthma medications in front of others including friends, was embarassing for adolescents and this view was shared by all participants groups. Adolescents reported not using medication in front others because of this, and that having asthma made them feel 'different' – a view also held by parents and HCPs.

However, not all adolescents felt embarrassment, some were confident using treatment around others, either because they had been taking treatments for many years, or they had friends who knew how to support them when they were having exacerbations, although not all adolescents perceived any benefit in talking to their friends about their asthma. Parents and HCPs also highlighted the important influence that peers have at this age, both positively and negatively. HCPs felt asthma was portrayed negatively in the media, and parents were concerned about the lack of understanding about asthma from other adults they encountered.

Barrier: *Lack of motivation;* Facilitator: *Taking responsibility*

Some adolescents admitted either they were too lazy or could not be bothered to take their medication or they did not prioritise it. HCPs and parents discussed lack of motivation, risk-taking, and rebelling during adolescent years as a barrier to self-managament. All participant groups expressed the view that growing up and deciding to take responsibility for their medication was helpful to self-management.

Barrier: *Difficult communication with HCP*; Facilitator: Good comunication and support from HCP

Many adolescents and their parents discussed communication issues with their HCPs. HCPs were described as: rude and patronising; giving incorrect or conflicting information; not giving enough information (being prescibed inhalers without being shown how to use them); not properly listening to the patient; and speaking in an officious manner. Adolescents also felt: unable to ask questions because they did not want to appear 'stupid'; unable to be honest about forgetting or not taking treatment; confused about information; and they avoided answering questions from a HCP that they found difficult talking with. HCPs recognised that patients could give false or no information and could be uncommunicative during consultations.

However, not all adolescents experienced these problems, parents and adolescents reported HCPs who were nice and used language they understood; listened to them and gave them information that was comprehensible; and who were generally very supportive. HCPs also recognised that being caring and supportive was beneficial.

Barrier: *Clinic structure and environment*; Facilitators: *Objective feedback and consultations without parents*

Adolescents felt alienated in clinics full of very young children and said that making time for appointments was a barrier due to school or college and work. Some felt their HCP did not 'do anything' and that nothing changed with clinics being repetitive and they thought the HCP should be able to do more to treat them. Seeing different consultants, rather than the same one at each appointment was also an issue, and HCPs expressed difficulty in quickly establish relationships in this situation. Adolescents described parents dominating consultations, preventing them from describing their current condition, although some adolescents liked having their parents in clinic and felt they were necessary to remember information or answer questions for them. Some parents said they needed to be in clinic appointments due to the lack of communication from their child.

Adolescents liked being given objective measures of their asthma severity, like spirometry and peak flow and HCPs also recognised this was useful for patients. Some adolescents felt their HCP was always trying something new, which they found helpful. Adolescents, parents, and HCPs recognised a value in adolescents seeing the HCP on their own for some of the consultation.

Barrier: *Lack of understanding at school*; Facilitator: *Supportive school staff*

Adolescents and parents described issues at school that were barriers to self-management. Some school staff lacked understanding or knowledge about asthma putting them in situations that could exacerbate their asthma. However, some adolescents had good support at school, with

knowledgeable nurses and staff that were caring understanding of the needs of adolescents with asthma. HCPs did not raise school issues as a barrier to self-management.

DISCUSSION

This study is the first we are aware of that has triangulated views about self-management of asthma from adolescents, their parents and their healthcare professionals. Using robust qualitative methods to obtain the views of multiple stakeholders, we aimed to focus on the broad concept of self-management in adolescents across primary and secondary care settings - a critical step in the development of a successful intervention to improve self-management in these patients. Summarising these findings using thematic analysis we found that adolescents, parents and HCPs raised very similar barriers and facilitators to self-management.

Our findings support previous systematic reviews [6,18] and studies that show treatment adherence is often difficult for adolescents due to forgetting medication (either intentionally or unintentionally),[19,20] medication being a burden,[19] lack of knowledge about treatments,[21,22] embarrassment,[19,23] and apathy.[19,22] We also found support for previous studies that identify other self-management issues such as the importance of communication between adolescents and HCPs, [19] knowledge about asthma,[21] avoiding triggers,[19] support from family,[24] friends, peers,[19,22] and school, [25,26] and anxiety and panic.[27] Our study also adds to the existing literature issues of self-management highlighting themes that have not been previously reported. Participants highlighted how the clinic interaction with their HCP was important and expressed alienation in clinics orientated towards young children. Adolescents also reported that consultations were difficult when they frequently saw different HCPs (a familiar experience in the UK health service), and when parents dominated consultations.

Our study also extends previous research by incorporating the perspectives of the three key stakeholders. Many of the perspectives of the three participant groups were very similar, suggesting that parents and HCPs have a good insight into the difficulties encountered by adolescents when self-managing their asthma. However, there were some issues that adolescents and parents reported that HCPs did not describe. These were panic and anxiety as a barrier, staying calm as a facilitator, and difficulties with school that can be barriers to self-management. HCPs may benefit from developing a broader understanding that these issues may affect the ability of their adolescent patients to effectively self-manage their asthma. Our findings support a model of self-management that includes a range of behaviours that are influenced by intrapersonal and interpersonal factors.[3] The importance of communication between HCPs and adolescents is a critical component of this model.

These findings have been used to develop a novel intervention to address an unmet need that targets both adolescents with asthma and their healthcare professionals. We argue that HCPs may need to alter their approach to adolescents with asthma if they are to be successful in improving adolescents' engagement with their healthcare and subsequent self-management. Using the key themes shown in Table 2, we have identified a number of targets that HCPs could consider together with their adolescent patients and suggestions for behavioural interventions to address these target areas are

provided (see Table 4). We have developed a novel adolescent asthma outcome measure the Adolescent Asthma Self-Efficacy Questionnaire (AASEQ; Holley & Knibb et al, in submission), which can also be used to identify self-management areas that may benefit from support. The AASEQ has been demonstrated to be a reliable and valid measure..

The findings of the study are limited by a lack of information about those who declined to participate, and therefore the perspectives of those included may differ from those who declined participation. In particular, we are cognisant that the perspectives of adolescents who are less engaged with their healthcare, particularly those who fail to attend appointments, may have been under-represented. In addition, our sample was limited to a white, English-speaking population, as a consequence of the study location. Future research would benefit from capturing the views of a more diverse population and take further steps to seek out the views of participants who are less engaged with the health care system.

Compared to previous studies, ours is strengthened by a focus on multiple aspects of self-management, not only adherence; the focused age range of the adolescent participants; and the inclusion of views from parents, HCPs and patients in both primary and secondary care.

Implications for clinical practice

Our study highlights that HCPs need to consider the implementation of treatment routines; ensure adolescents understand their condition and treatments and need to convey this knowledge in a format that will appeal to adolescents. Crucially, HCPs need to give due consideration to how this information is communicated and ensure they facilitate open and inclusive two-way consultations. Adolescents need to be able to communicate their symptoms and behaviour to HCPs if they are to work in partnership with them. Our findings suggest that adolescents are more likely to discuss self-management with their HCP if they are polite, understanding, accepting of non-adherence, and not paternalistic. HCPs also need to consider the important influence of anxiety and staying calm, friends and peers, possible barriers to self-management at school, and seeing adolescents without their parent/guardian. Future research should also attempt to capture the views of those adolescents who are not engaging with the healthcare system in order to enable health services to target this vulnerable group.

We have described a series of connected facilitators and barriers to self-management by adolescents with asthma. The marked concordance of adolescent, parent and HCPs data validates this description and emphasises the potential importance of these features for successful self-management. Our findings support and strengthen previous studies but also highlight that development of a successful intervention may benefit from targeting behaviour change in HCPs. With previous interventions targeting self-management in a clinical setting being largely ineffective in adolescents, this represents an important gap in asthma management.[28,29]

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Table 1 Demographic information about adolescent participants

	N	%
Female	14	50
Age, years 12-13	9	32
14-15	7	25
16-18	12	43
White British	25	89
Self-reported asthma triggers		
Weather	19	68
Pollen	20	71
Dust	17	61
Colds	22	79
Cigarette smoke	9	32
Exercise	18	64
Attending secondary care out-patient clinic	19	68
Long acting bronchodilator prescription	22	75
Salbutamol use > 4 days per week	12	43
Eczema	15	54
Animal allergy	17	61
Food allergy	10	36
Self-report of forgetting to administer preventer medication		
Never	8	29
Occasionally	13	46
Once a week	2	7
Half of the time	2	7
Most of the time	3	11

Table 2 Summary of barrier and facilitator themes from adolescent, parent, and healthcare professionals

Barrier themes	**Facilitator themes**
Forgetting treatment	Reminders and routines
Burden of treatment *Inconvenience of spacers*	Acceptance of asthma and medication
Lack of knowledge *About asthma and treatments*	Knowledge *Having the right knowledge in the right format*
Feeling anxiety or panic*	Staying calm*
Triggers and allergies *Such as pets, people smoking*	Having strategies to avoid triggers
Feeling embarrassed *About having asthma or using treatments*	Confidence and support from friends
Apathy and lack of motivation	Taking responsibility for asthma management
Difficult communication with HCP	Good communication and support from HCP
Clinic structure and environment *Appointments are time consuming*	Objective feedback and consultations without parents *Measures such as spirometry*
Lack of understanding from school*	Supportive school staff *

* Was not a theme from the HCP data

Table 3 Themes with Illustrative quotes from adolescents, parents, and healthcare professionals

Theme	Representative quotation		
	Adolescent (m=male, f=female, age in brackets)	**Parent**	**HCP**
Barrier: Forgetting treatment	"So sometimes I think I've done it but that might have been the day before… so like I need to remember when I've done it" (M13)	"I have to double check him, because he's forgotten or he's running late or he can't be bothered or he feels fine "	"The patient as well I think might have a false recollection of how much they have taken not because they are trying to mislead you but they might just forget it"
Facilitator: Reminders routines	" [I have] always lived in a routine... which if I didn't have it I wouldn't have been able to manage my asthma as well as I have or at least as I have cause it helps me set out the morning" (M17)	"She's also got a very regimented regime, because of how much she has to take, I think it's just ingrained in her now"	"If you can develop it into a habit then it's free from hassle, you do it automatically."
Barrier: Burden of treatment	"It's really awkward having a spacer... carrying it everywhere... but some days you've got trousers on and you don't really wanna carry round a rucksack just for this or... and you don't really want to carry it around in your hand." (M13)	"She didn't want to use the spacer … the inhaler itself is quite small, isn't it, and you can pop it in your pocket, but they don't like to carry the spacer"	**"**"It's difficult to take regular treatment… If you need to do this for the rest of your life more or less take control of the medication it's difficult and it doesn't change in adulthood."
Facilitator: Acceptance of medication	"I love my inhaler… it gives me instant relief" (F17)	"Luckily when he saw Dr x last time they gave him an easibreathe, and he thinks this is really the bee's knees… he doesn't mind flicking that"	"Just changing their volumatic to a vortex they are like, oh wow, I didn't know there were smaller spacers out there and would make such a difference in our bags, or we put them on easibreath, and just slight changes like that can hopefully motivate them a bit more"
Barrier: Lack of knowledge	"I guess like I've only just realised when filling out the forms and stuff, that actually I don't 100% know what asthma is… like I get told to take medicines and do this and do that, but I don't actually get told what that will do….just get told to do it." (F16)	"It's not just a blue and a brown inhaler, there's a green one and purple one… so it is understand really what the medication is doing and because it gets changed, for the poor child to understand that when they are still getting to grips with the last regime, I think it can be quite confusing for them."	"You might have a patient that comes to you from the GP or another clinic and they don't understand their treatment, they haven't had it explained to them in the first place, and can sometimes be quite easy to slip through the net."

Facilitator: Knowledge	“It helped me… the knowledge...I think it's a lot of help when she explains something to me... it's made it a lot easier to manage cause I know what’s happening.” (M16)	“If she can recognise herself, where am I today, and how was I feeling yesterday, and that kind of thing, I find that helps… the starting point for her is knowing how am I, and what do I need to do to manage it.”	"I find when I’m teaching asthma, I have pictures of the airways and where the treatment, how it works, I have to have something visual to show them and I find that helps”
Barrier: Feeling anxiety or panic **Facilitator: Staying calm**	“Cause I feel like I’m gonna have to keep taking those massive breaths and that's what I think when I’m more worried it makes that asthma worse cause I’m breathing so hard” (M14) “I shouldn’t get worked up or worried too much… so it doesn’t make it worse” (M14)	“Keep him calm when he is a bit off cause he panics and that's even worse it sets their asthma off. “He knows now to calm himself down and sort of moderate his breathing”	
Barrier: Triggers and allergies **Facilitator: Having strategies to avoid triggers**	‘It’s like people in school it’s quite all bunched up so if somebody's wearing a certain deodorant or something that my asthma don't like, then that could set me off’ (M13) “We clean the house every day, change bed covers every week, hoover like once or twice a day, we keep it really clean, don't have any pets and if I go to a friend’s house, stay away from their pets**”** (F15)	“And recognising other triggers, so I think it is recognising how they might think normally I just take it before PE and I am fine, and then one day they find that they are not, not appreciating that actually it’s a really cold day, or there’s a lot of, it’s grass season or something, it’s understanding that, isn’t it.”	“The parents immediately try and defend themselves and say I don't smoke in front of them, and the teenager will look at them as much to say it’s not true, you're picking out and you have to read between the lines”
Barrier: Feeling embarrassed **Facilitator: Confidence and support from friends**	“One of them laughs ‘cause their like ‘we've only walked up that hill and you already need your inhaler’... their making it worse and making me not want to take it which is like making me iller.” (F16) “My friends know, so at least if I have some sort of asthma attack or something, at least my friends know	“So I think she finds it embarrassing that she’s got asthma, because she’s taking inhalers and things to school and people have gone, Oh my god, what’s that. So she’s found that really embarrassing, really difficult and the devices that go with her inhalers that she should have taken to school and used she doesn’t.” “She's got quite a close group of friends that she's known a long time	“They don't like it and they're embarrassed about, taking a big spacer into school” "Friends can have quite a powerful influence and they might actually stick up

	that's what's going on, they can say, 'he's having an asthma attack' and then they know what to do" (M18)	and I don't think she would feel uncomfortable saying I don't feel well I need to go... so that helps"	for each other and look out for each other if they have the knowledge."
Barrier: Apathy and lack of motivation	"The worst thing you can ask a teenager is to remember something again and again and again… and their gonna be like 'oh I'm not gonna do this' and just give up or something.. they just won't bother... it sounds odd giving someone who has no sense of responsibility something to be responsible about it." (M16)	"They don't think, they don't think things out properly, and everything will happen to everybody else, so it will never happen to me, don't worry about it, don't stress about it, is <son> word, 'why are you stressing about it - it's my body',	"It's a lifestyle choice to not to be bothered about it because adolescents don't want to be bothered, and they will take the medication when they have to when it's symptomatic."
Facilitator: Taking responsibility	"I'm more mature about it and I don't miss my medicines 'cause before I used to think it doesn't do anything but now I realise it helps a lot" (F16)	'I think she's learnt it's not worth getting sick and she doesn't enjoy that feeling… so I think I'm quite lucky in that she seems to be quite sensible and I think she realises how ill she can be'	"Trying to take them seriously as a growing adult now helps, so that they will probably take on their own responsibilities."
Barrier: Difficult communication with HCP	"Mum talks and I sit there and listen, but then I don't think the doctor fully knows how it's been for me, but mum always says I don't talk, but I would talk if I was given the chance to talk… I don't think they fully know cause when I come out I think I would have said this and I would have said that but I didn't have the chance to." (F16)	"What needs to be done in my mind to re-engage <son> is communicate properly so he needs good communication"	"If they smoke, nobody wants to admit if they smoke. But if they are without the parent they will tell me how often they have tried a cigarette, and then they start to tell me how often have they forgotten the last few weeks of taking medication, not how often have you taken it but how often have you forgotten it"
Facilitator: Good communication and support	"Say I'm suffering with a specific thing and I want to talk to him about certain… err… things I can just speak to him about... easy... and he will give me an answer that I would understand	"They're not patronising, they don't do gobbledygook… Talking to him… Communicating with him in a way he can relate… in terms of the language they use…"	"I think again it goes back to that caring, we do care enough to spend time with them to be able to look at different things that are available."

	as a teenager so it's not going to big words from doctor." (M14)		
Barrier: Clinic structure and environment **Facilitators: Objective feedback and consultations without parents**	"The children and how noisy they are… they're annoying… they are all running round and they've got the little play room with the little cars" (F16) "It's nice to talk to someone who knows more than I do and how I can make it better, so I do find it useful coming here cause they'll always have a new solution that I could try" (F16)	"Not wanting to miss school… that's proving difficult for appointments and things if you have to come a lot" "by the time I'd gone in the door they'd already started talking to x ... I quite appreciated that cause in another year or so I don't know if I'll be going to the appointments.... she had to listen to what was being said"	"You can feel you can tell their faces dropping because "oh no it's another new person" and so trying to build up that relationship quickly and get a handle on their asthma and the contents of their life is quite difficult to do and then to come up with a management plan" "It is helpful to try and make sure you see teenagers by yourself without their parents, at least for a proportion of the time that they come to see you…But I think that I usually a more constructive consultation with the individual."
Barrier: Lack of understanding from school **Facilitator: Supportive school staff**	"I've said I can't do PE today cause my asthma's been really bad over the weekend, they'll [the teacher] be like 'well why can't you do it, everyone else has got to do it, you've got to do it as well', or they'll say you need to get your PE kit on and stand outside and watch everyone else, which really is not gonna benefit at all, 'cause if you're stood in the cold, the air's going to your chest anyway." (F15) "It helps when the teachers know and they do trust you that you are late to clasee because I had to stop to take my inhaler" (M14)	"Some people in schools seem to kind of view it as if it's maybe the child making an excuse… And I think sometimes teachers, staff in school maybe don't understand that it can be very serious and they think that maybe that child's just trying to skip off of games." **"**The new school is much better, they call me when his peak flow has dropped"	

Table 4 Recommendations for clinic interventions to address adolescent barriers and facilitators to asthma self-management

Barriers	Facilitators	SEQ area	SEQ Question	Clinic Intervention
Forgetting treatment Lack of knowledge about asthma and treatments Burden of treatment Inconvenience of spacers	Reminders and routines Having the right knowledge in the right format Acceptance of asthma and medication	Medication	I know how to correctly use my asthma inhaler/spacer/medication I know when to use my asthma medication I know which of my inhalers I need to take I know what my preventer inhaler is for I know what my reliever inhaler is for	Discuss how patient can establish personal reminders, routines and habits to take medication.[30] Goal setting regarding use of preventer(s), e.g. only miss once a week and record using a diary. Ask patient what they feel would be the consequences of not taking medication as prescribed; challenge as required OR discuss what the patient might be able to do if they complied with medication regime. Self-monitor, e.g. using a diary Revise knowledge about: preventer(s) vs reliever, e.g. action, speed of action; when to use reliever – symptomatic and pre-exercise use; when to use preventer including need to be used continuously.[31] Check inhaler is appropriate, e.g. will deliver medication, fits with their lifestyle. Check that patient can use inhaler; if necessary retrain.[10] Online support: videos of correct inhaler use, compare with a 'selfie' video.
Feeling of anxiety or panic Triggers and allergies, such as pets, people smoking	Staying calm Having strategies to avoid triggers	Symptom management	I can be prepared to deal with an asthma attack I know how to stay calm when I am having trouble breathing I know when I am out of breath because of my asthma rather than because of exercise I know when I am out of breath because of my asthma rather than because I feel a bit panicky I know how to control my asthma when I am having trouble breathing I know when to use my inhaler to manage a serious breathing problem I know what to do to avoid triggers for my asthma I know when I might need to go to hospital because of a serious breathing problem	Action plan in an appropriate format, e.g. on a mobile phone. Discuss how to manage various scenarios with different presenting symptoms. Role play various scenarios where need to manage different symptoms. Discuss various scenarios contrasting asthma with being "out of breath" and dysfunctional breathing / panic. Identify best approach for individual teenagers. This would include learning breathing techniques. Ensure teenager has knowledge about personal triggers including how they can avoid them[32] – e.g. use checklist to identify personal triggers for asthma and identify triggers in asthma management plan. Find out what patient thinks triggers their asthma – challenge erroneous beliefs if necessary. Discuss strategies to minimise exposure, for example changes to physical environment (e.g. allergen reduction measures)[33] or social environment (e.g. changing who they socialise with or where they socialise).[34] Aim for teenager to be able to avoid or reduce exposure to triggers. Scenarios – e.g. role-play[35] a situation which may lead to exposure to a trigger, opportunity to demonstrate self-advocacy. Goal setting task – decide on the goal and aim to keep to it. Management

				plan for minimising impact of exposure to unavoidable triggers, e.g. increase medication pre-exposure.
Apathy and lack of motivation	Taking responsibility for asthma management	Asthma beliefs	I am in control of my asthma I can do physical activity such as sports I can have a normal life I can do the things that I want to do I can control my asthma day-to-day	Aim for teenager to be able to do the things they would like. Scenarios - discuss scenarios where they are going to do an activity that might be expected to cause problems with their asthma. What can they do to minimise the impact on their asthma. Goal setting task – decide on the goal and aim to keep to it.
Feeling embarrassed about having asthma or using treatments Difficult communication with HCP Lack of understanding from school	Confidence and support from friends Good communication and support from HCP	Friends, family school	I can take my inhalers in front of my friends I can take my inhalers around other people at school I can talk honestly to my friends about my asthma I can talk honestly to my parents about my asthma I can talk honestly to my doctor or nurse about my asthma I can talk honestly to my teachers about my asthma I can ask my parents for help if I am having trouble breathing or having an asthma attack I can ask my teachers for help if I am having trouble breathing or having an asthma attack I can ask my friends for help if I am having trouble breathing or having an asthma attack	Aim for teenager to receive support from friends and peers. Discuss benefits of friends knowing about asthma and being available to assist self-management. Provide information (e.g. signpost to internet resources) that patient can explore with friends. Approach to dealing with peers; if necessary, be able to ignore negative reactions, e.g. role play. Aim for teenager to receive support from, and communicate successfully with parents.[30] Discussing how to re-negotiate relationship with parent: constructive use of reminders and / or advice from parents; encourage to take up responsibility from parents.[36] Encourage parents to let go and give teenager increasing amounts of responsibility. Aim to empower adolescent to take responsibility for their asthma and be confident when communicating with HCP. Transition teenager to see HCP alone for some of the consultation Health care professionals facilitating communication between them and patient.[37] Practical tools to support communication, e.g. list of questions to ask HCP. Aim for teenager to receive support from school. Learn how to communicate with teachers and advocate for themselves. Role play scenarios that allow them to demonstrate or exploring how to advocate for themselves.[35] Where necessary, healthcare professional liaises directly with school

HCP: Healthcare professional

SEQ: Self-efficacy questionnaire for asthma. See Holley et al (submitted) for details of the questionnaire

Box 1 Interview schedule

- What does good asthma control mean for you?
  - When do you feel your asthma is under control?
  - Can you tell me about a time when your asthma was under control?
- Do you do anything to keep your asthma under control?
  - Do you think there are things you do that make a difference to your asthma?
  - Is anything easy about controlling your asthma?
- Does anything stop you managing your asthma?
- Do you think the things you do make a difference to your asthma?
- Can you tell me about a time when your asthma was not under control?
  - How did you manage to get your asthma under control?
  - What did you do? Who helped?
- What things would you like to be able to do to manage your asthma that you are not able to do at present?
- What do other people do to help you manage your asthma?
  - This might be family, friends, doctors, nurses, or school
- Tell me about the doctors and nurses you see for your asthma?
  - What do you think their role is in helping you to manage your asthma?
- What happens in a typical consultation?
  - What do you like or find useful?
  - Is there anything you don't like or find unhelpful?
  - What would you find helpful?
- What role do you think your asthma doctor and / or nurse has for helping with your asthma management

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