

## **Barriers and facilitators to asthma self-management in adolescents: a systematic review of qualitative and quantitative studies**

Simone Holley<sup>1</sup>, PhD, Ruth Morris<sup>2</sup>, BSc, Rebecca Knibb<sup>3</sup>, PhD, Sue Latter<sup>4</sup>, PhD, Christina Liossi<sup>5</sup>, DPsych, Frances Mitchell<sup>6</sup>, BSc Graham Roberts<sup>1,6,7</sup>, DM

1. Clinical and Experimental Sciences and Human Development in Health Academic Units, University of Southampton Faculty of Medicine, Southampton, UK.

2. NIHR/Wellcome Trust Clinical Research Facility, University Hospital Southampton NHS Foundation Trust, Southampton, UK.

3. Aston University, Birmingham, UK.

4. Faculty of Health Sciences, University of Southampton, UK.

5. School of Psychology, University of Southampton, UK and Department of Paediatric Psychology, Great Ormond Street Hospital for Children NHS Trust, London, UK

6. The David Hide Asthma and Allergy Research Centre, St Mary's Hospital, Isle of Wight, UK.

7. NIHR Southampton Respiratory Biomedical Research Unit, University Hospital Southampton NHS Foundation Trust, Southampton, UK.

**Corresponding Author:** Professor Graham Roberts, Paediatric Allergy and Respiratory Medicine (Mailpoint 805), Southampton University Hospital NHS Foundation Trust, Tremona Road, Southampton SO16 6YD, UK. Telephone: 02381206160. Fax: 02380878847

Email: [g.c.roberts@soton.ac.uk](mailto:g.c.roberts@soton.ac.uk)

Key words: pediatrics, patient compliance, self care,

This study was supported by a research grant from Asthma UK (AUK-PG-2013-213).

**Short title: Asthma self-management in adolescents: a systematic review**

**ABSTRACT**

**Background:** Many adolescents have poor asthma control and impaired quality of life despite the availability of modern pharmacotherapy. Research suggests that poor adherence to treatment and limited engagement in self-management could be contributing factors.

**Objective:** To conduct a systematic review of the barriers and facilitators to self-management of asthma reported by adolescents using a narrative synthesis approach to integrate the findings.

**Design:** MEDLINE, EMBASE, CINAHL, and PsycINFO were searched for all types of study design. Full papers were retrieved for study abstracts that included data from participants aged 12 – 18 years referring to barriers or facilitators of asthma self-management behaviours.

**Results:** Sixteen studies (5 quantitative and 11 qualitative) underwent data extraction, quality appraisal, and thematic analysis. Six key themes were generated that encompassed barriers and/or facilitators to self-management of asthma in adolescents: *Knowledge, Lifestyle, Beliefs and Attitudes, Relationships, Intrapersonal Characteristics, and Communication.*

**Conclusions:** There is a pressing need to prepare adolescents for self-management, using age-appropriate strategies that draw on the evidence we have synthesised. Current clinical practice should focus on ensuring adolescents have the correct knowledge, beliefs, and positive attitude to self-manage their illness. This needs to be delivered in a supportive environment that facilitates two-way communication, fosters adolescents' self-efficacy to manage their disease, and considers the wider social influences that impinge on self-management.

## INTRODUCTION

Asthma is one of the commonest long-term conditions affecting adolescents.<sup>1</sup> Many have poor control and impaired quality of life despite the availability of modern pharmacotherapy.<sup>2,3</sup> Adolescence is a difficult developmental period during which hormonal, physical, and emotional changes create turmoil for the young person.<sup>4</sup> The process of developing independence and transitioning into adulthood may conflict with the actions and beliefs required for good self-management of asthma.<sup>5</sup>

Self-management of asthma in adolescents has been conceptualised as the behaviours to prevent, monitor, manage, and communicate asthma symptoms in order to control outcomes.<sup>6</sup> Research indicates that adolescents have limited engagement in self-managing their asthma and there is inefficient communication between adolescents and healthcare professionals (HCP) about their illness.<sup>7,8</sup> These are likely to be important factors in explaining poor adherence to treatment and poor asthma control in this age group.

Existing systematic reviews focus on educational interventions<sup>9-11</sup> or specifically medication adherence<sup>12,13</sup> as opposed to self-management. To the best of our knowledge none have focused on barriers and facilitators to self-management from the adolescents' perspective. However, a recent systematic review has summarised the barriers and facilitators to effective self-management of asthma across all ages.<sup>14</sup> This identified ten overarching themes such as partnership between patient and HCP, issues around medication, and education. Given that adolescence is already associated with challenges, such as gaining autonomy, the self-management of asthma in this period of life might be expected to have its own particular influences. Furthermore, clinical services in the UK focus on either adults or a child / adolescent population, and hence our review focuses specifically on this latter age group. We

conducted a systematic review of adolescent-reported barriers and facilitators to the behaviours conceptualised as necessary for adolescent' asthma self-management.<sup>6</sup>

## **METHODS**

In collaboration with an experienced medical librarian, a search strategy was developed based on keywords and MeSH terms and adapted to suit each database (MEDLINE, EMBASE, CINAHL, and PsycINFO). The original search was conducted for the period January 1996 – May 2014 (see Appendix 2) and updated in May 2016. The date range was restricted to ensure that data were relevant to current management of adolescents with asthma. The search was limited to articles published in English and excluded conference abstracts, PhD or Masters theses and non-systematic reviews. At this literature search stage, we chose a strategy that was wider than just the influences on self-management to minimise the risk of omitting important studies.

Full papers were retrieved for study abstracts that included data (quantitative or qualitative), reported by participants aged 12 – 18 years, identifying factors that had a direct impact on self-management of asthma,

Two authors (GR and SH) reviewed the full text for relevance and agreed the final papers for inclusion in the review. Data from each paper were extracted by two of three coders (SH, RM or GR). References to communication were not explicitly linked as a barrier or facilitator of asthma self-management in the selected papers, but given the importance of communication in the conceptual model of adolescent asthma self-management,<sup>6</sup> we chose to include these data. Information was extracted pertaining to: study aims, participants, sampling, recruitment, design, intervention, setting, data collection and analysis methods, and study findings. We excluded studies that just described an educational or technological intervention. We also

excluded financial barriers as healthcare in the UK is free up to the age of 19 when in full-time education.

A quality appraisal of included studies was conducted independently by three researchers (SH, GR, and RM). Qualitative studies were quality appraised using the method described by Harden et al,<sup>15</sup> one mixed methods study was appraised as qualitative as only the qualitative data was utilised in the results for this review. Quantitative studies were quality appraised using the Cochrane Risk of Bias Tool.<sup>16</sup> To be included in this review, subject matter was considered more important than quality of the study methodology, although we highlight methodological issues where they were found, therefore no studies were excluded on the basis of poor quality.

#### *Data analysis*

A meta-analysis of the quantitative studies was not appropriate due to the heterogeneity in outcomes. As our aim was to combine the evidence from quantitative and qualitative studies, we used a narrative synthesis approach<sup>17</sup>, which was informed by the guidance produced by Popay *et al.*<sup>17</sup> Thematic analysis was used to identify common themes and concepts within and across qualitative and quantitative studies.

The text was coded according to its meaning and content to identify emerging themes. Written interpretations of quantitative data was coded in the same way as qualitative data. Three authors (SH, GR, RM) then met to review and discuss the emerging themes and to identify commonalities. This was an iterative process with subsequent discussions to enable themes to be further refined. Once agreement had been reached, the papers were read again by one author (SH) to ensure no relevant data had been missed.

## **RESULTS**

## **Study selection**

The search process is outlined in the flow diagram (Figure 1). The titles and abstracts of 3,886 records were reviewed by two authors (SH, GR) resulting in 101 records being retained for full-text retrieval and review. A further three records were excluded as the full text was not available and 46 were excluded as both reviewers agreed the article was not relevant to the review. A further 36 records were excluded for methodological reasons such as inappropriate age range of participants, i.e. too young (<11 years) and / or too old (>18 years). We included three papers where the youngest participants were 11 years, and 3 papers where the oldest participants were 20 given that most of their participants were in our adolescent age range. The final review consisted of eleven qualitative and five quantitative studies, including 1,011 participants that were subjected to data extraction and quality appraisal. The aims, sample characteristics, methodology and findings of these studies are described in table 1. The quality appraisals of the qualitative and quantitative studies are described in tables 2 and 3 respectively. All the qualitative studies were rated as 'medium' or 'high' quality. The majority of the quantitative studies were assessed as 'unclear risk', due either to the lack of details and/or the use of unvalidated measures.

## **Thematic analysis**

Our thematic analysis generated six key themes that encompass barriers and/or facilitators to self-management behaviours – preventing, managing, monitoring, and communicating with others - of asthma in adolescents. A summary is presented in table 4.

## **Knowledge of asthma and treatments**

Adolescents who reported a greater knowledge of asthma reported far fewer barriers to self-management.<sup>18</sup> Compliance was reported to improve following a severe exacerbation.<sup>8</sup> Lack of knowledge about medication regimes<sup>8,19</sup> and inhaler techniques can lead to non-adherence.<sup>20</sup>

Some adolescents lacked knowledge about triggers such as how pets in the home can affect asthma.<sup>8</sup> Others were knowledgeable about triggers but did not feel able to control or avoid them as we discuss in the next section.<sup>21</sup>

### **Lifestyle influences**

Difficulty in remembering to take care of their asthma was a barrier to self-management.<sup>18</sup> Not taking medication as prescribed occurred due to forgetting;<sup>7,8,20,22-24</sup> difficulty organising time (e.g. being in a rush for school in the morning or disruption to usual routines);<sup>8,22,23</sup> not wanting to interrupt leisure activities;<sup>7,23</sup> or when the medication regime conflicted with other priorities.<sup>8</sup> Other barriers to self-management were: losing inhalers;<sup>22</sup> the inconvenience of carrying<sup>20</sup> and the time needed to use spacer devices;<sup>8</sup> smoking;<sup>8</sup> and difficulty avoiding triggers such as cigarette smoke,<sup>21</sup> or the weather.<sup>25</sup>

Facilitators to self-management included a daily routine for the medical regime<sup>7,19,20</sup> and cues for remembering to take medication,<sup>7,19</sup> such as leaving inhalers in readily seen places.<sup>22-24,26</sup> Adherence may be a habit as indicated by past self-reported adherence to medication predicted self-reported adherence one year later.<sup>27</sup>

### **Beliefs and attitudes to asthma and medication**

Not taking medication, or not using treatments as prescribed, occurred due to beliefs that medication is ineffective;<sup>7,8,20,22,24</sup> asthma is not a serious disease;<sup>19,21</sup> they would outgrow asthma (and were non-adherent to test this);<sup>19</sup> and, taking medication is a sign of weakness (in adolescent boys a belief portrayed to them by their fathers).<sup>19</sup> Attitudes that led to non-adherence included: they ‘knew their bodies better’ than their doctors and therefore felt ‘safe’ to deviate from medical guidance;<sup>20</sup> denial of having the disease;<sup>20</sup> adverse medication side effects such as the taste;<sup>7,22</sup> and fear of potential side effects such as weight gain<sup>8</sup> or addiction to medication.<sup>22</sup>

Positive attitudes towards asthma resulted in fewer barriers to self-management<sup>18</sup> and better adherence was associated with positive attitudes towards medication.<sup>27</sup>

### **Relationships with others**

Parents facilitated self-management by providing reminders or encouragement to take medication,<sup>8,20,23,24,26,28</sup> as did peers<sup>20</sup> who also advised them to break from activities, warned of triggers, and shared medication (among friends with asthma).<sup>26</sup> Coping with asthma was better if social support encouraged a calm approach and they accepted help from others.<sup>25</sup>

Some adults were barriers to asthma self-management, for example, teachers could be either insensitive or unsupportive<sup>21</sup> and school policies could prevent adolescents from carrying inhalers.<sup>26</sup> Peers could be a barrier to self-management as some adolescents were unwilling to give up time with their friends to take care of their illness.<sup>18</sup>

Negative attitudes towards HCPs were frequently reported barriers to self-management<sup>18</sup> and being seen in a paediatric clinic was “alienating”.<sup>8</sup> In contrast, better self-management was reported when a positive relationship with the HCP was promoted and when the HCP was



competent, understanding, and helpful and reminded them about key things.<sup>26,19</sup> Adolescents were more likely to comply with their treatment when they had support from nurses.<sup>23,29</sup>

### **Intrapersonal characteristics**

Apathy towards asthma and medication was shown by some adolescents who reported not being “bothered” to take medication.<sup>8,20</sup> Motivation, energy and willpower have been shown to significantly predict adherence to medication.<sup>29</sup>

Adolescents reported situations where others did not take their illness seriously and they identified that it was difficult for them to act assertively in such situations.<sup>7</sup> This included adults who smoked around them<sup>7</sup> and expectations from teachers that could exacerbate symptoms during physical activities.<sup>21</sup>

Fewer barriers to self-management were reported by adolescents who scored higher on a questionnaire designed to measure self-efficacy (perceived ability to perform a desired behaviour) in children with asthma.<sup>18</sup> Another intervention study reported an increase in adherence after 24 months, but no change in self-efficacy.<sup>30</sup> Adolescents who reported feeling in “control” of their asthma symptoms were more likely to carry their inhalers outside the home.<sup>31</sup>

Taking medication or experiencing asthma symptoms in front of others was reported as embarrassing in several studies<sup>8,19,20,31</sup> and was associated with not carrying medication.<sup>31</sup> Although in one study using inhalers in front of peers was not considered embarrassing<sup>32</sup>. Poor adherence was also associated with feeling ashamed about having asthma.<sup>27</sup> However, others reported “accepting” they had asthma and were more likely to tell others about their asthma.<sup>7</sup> In contrast, some adolescents tried to forget they had asthma,<sup>18</sup> or did not discuss

their asthma with others because they had a desire to appear “normal”<sup>26</sup> and this also lead them to “push” themselves (for example in sports) so as to appear no different to peers.<sup>21</sup>

Embarrassment also acted as a facilitator to self-management within the context of a medical consultation. Where medication use was electronically monitored, some adolescents wanted to demonstrate adherence and did not want to experience the embarrassment of HCP knowing they had not taken them.<sup>22</sup>

### **Communicating with others**

Communication factors were not directly implicated in self-management behaviours such as taking medication but they impact on how patients gain support especially when asthma is out of control. In keeping with this, descriptive experiences of ineffective communication about asthma were identified in four studies, all of which were designed to elicit adolescent views and experiences of asthma self-management. As adolescents begin to assume greater responsibility for asthma self-management, effective communication with others during this period is critically important.<sup>6</sup>

Deliberately not reporting medication deviations to healthcare professionals<sup>8</sup> occurred sometimes to avoid confrontation<sup>19</sup> or because of difficulty in being honest when parents were present if they do not want to disclose information such as smoking.<sup>8</sup> Adolescents reported apprehension about attending outpatient clinics alone,<sup>8</sup> feeling afraid to ask questions, or paying no attention to the information given by the HCP as they did not understand.<sup>7</sup> A reluctance to discuss asthma with others was also reported.<sup>21</sup>

## **DISCUSSION**

This systematic review and narrative synthesis has uniquely identified and integrated adolescent-reported barriers and facilitators to self-management of asthma, and summarised these into six key themes. Many of these related to adherence to asthma medications. The key take home messages from this review for healthcare professionals are given in table 5.

Adherence to medication is a key component of asthma self-management. When adolescents lack *knowledge* of asthma, their medications, and how to use them properly, they are less likely to be adherent to their treatment. *Lifestyle* factors such as time constraints were often linked to forgetting to take medication. Adolescents are not unique in this as adherence to prescribed treatment, including unintentional non-adherence,<sup>33</sup> in developed countries is estimated to be as low as 50%.<sup>34</sup> *Beliefs and attitudes* summarises how negative or erroneous beliefs and attitudes towards their illness, medication, and HCP can lead to non-adherence with treatment, whereas positive attitudes towards asthma and medications can have a facilitative influence on self-management. This is not surprising given that low rates of adherence in many other long term conditions (LTCs) (including asthma) have been associated with patients' beliefs about their personal need for medication and concerns about adverse side effects.<sup>33</sup> Our finding reinforces the UK's National Institute for Health and Clinical Excellence report that adherence is best understood in terms of the beliefs and preferences that influence the person's perceptions of the treatment and their motivation to start and continue with it.

The theme *Relationships* highlights the importance of parents who can facilitate self-management through support, reminders, and education. Teachers, HCPs and friends can also influence self-management and are potential facilitators that can be used as support structures, particularly the latter given recent research indicating that decision-making in adolescence may be particularly modulated by peers.<sup>35</sup>

*Intrapersonal Characteristics* emphasises the embarrassment reported by adolescents from having asthma or using treatments in front of others. Adolescents are particularly sensitive to social environmental cues and process social emotions differently to adults,<sup>36</sup> which may explain their desire to appear 'normal'. A lack of assertiveness can prevent adolescents from advocating their needs, indicating that increased confidence and self-advocacy skills to act in such situations would empower them to better self-manage.

The final theme, although not explicitly linked to self-management behaviours, was *communication*. Effective communication with others has been identified as a necessary component of adolescent asthma self-management,<sup>6</sup> and recognised more generally as an important element of self-management across a range of long term conditions.<sup>37</sup> HCPs' communication skills have been associated with patient adherence and HCPs' communication training can improve patient adherence.<sup>38</sup>

Our study has a number of limitations. Studies were not excluded on the basis of quality; due to the paucity of studies in this area it was felt important to retain all the data. Although all the qualitative studies met the criteria to be considered of 'medium' or 'high' quality there were some concerns regarding the small number of participants in some focus groups. As already noted, we were unable to accurately rate the quality of the quantitative studies due to the lack of details and concerns due to the use of unvalidated questionnaires. Most studies were not designed to explicitly identify factors that influenced self-management behaviours (such as taking medication). Future research could attempt to address this by better linking identified barriers and facilitators of asthma self-management to actual behaviour.

For many patients with asthma, self-management is often further complicated by comorbid allergic disease. Likewise, the difficulties of self-managing a long term condition during adolescence is not limited to asthma. Adolescents with other LTCs, such as diabetes and

juvenile idiopathic arthritis, also encounter similar barriers and facilitators to illness self-management such as knowledge, parental involvement and intrapersonal issues.<sup>39</sup> The knowledge, attitudes and life skills that underpin engagement with self-management of LTCs are acquired at different rates in different children as they mature<sup>5</sup> and this does not necessarily materialise at age 18, the age at which health services in the UK expect young adults to take responsibility for their disease management. Given that adults with LTCs, including asthma,<sup>14</sup> also encounter barriers to self-management, there is a pressing need to prepare adolescents for self-management, through age-appropriate strategies.

Our findings support existing literature that identifies across a range of long term conditions in all ages, the more successful interventions to improve self-management have been multicomponent, and demonstrate the need to include knowledge, psychological strategies, practical and social support in future interventions<sup>37</sup> if we want to ensure effective on-going engagement of adolescents with self-management. Critical components of such an approach will need to enhance knowledge of asthma and treatments which should also positively influence some of the negative or erroneous beliefs and attitudes that conflict with effective on-going self-management skills. Psychological strategies will also be essential to: modify beliefs that cannot be addressed through knowledge alone; address interpersonal issues such as increasing motivation to self-manage and embarrassment around peers; and to increase self-confidence to advocate for oneself. The issues arising from the tripartite relationship between the adolescent patient, parent, and HCP also need consideration and will require actions to influence the behaviour of HCPs and parents to facilitate better communication between all parties.

There is evidence to suggest that consultations between adolescents and HCPs' are not currently patient-focused<sup>8</sup> therefore clinical practice needs to be transformed to deliver care in

a supportive environment that facilitates two-way communication, fosters adolescents' self-efficacy to manage their disease, and considers their wider social influences.

## ACKNOWLEDGEMENTS

We would like to acknowledge the help of Paula Sands (Librarian, University of Southampton) in developing the search strategy for this systematic review. The study team would like to thank the trial steering group for their advice, in particular, Mike Thomas, Gary Connett, Hans Michael Haitchi, Woolf Walker, Arvind Nagra, Julian Legg and Tricia McGinnity. Lastly, we would like to thank the Asthma UK – Joanna Martin Project, for funding this study.

## COMPETING INTERESTS

The authors have no conflicts of interest or financial relationships relevant to this article to disclose.

## References

1. Kurukulaaratchy RJ, Matthews SM, Arshad SH. The natural history of fatal childhood asthma - A case from the Isle of Wight birth cohort. *Journal of Asthma* 2008;**45**(10):944-47.
2. Fleming L, Wilson N, Bush A. Difficult to control asthma in children. *Curr Opin Allergy Clin Immunol* 2007;**7**(2):190-5.
3. Rabe KF, Adachi M, Lai CK, et al. Worldwide severity and control of asthma in children and adults: the global asthma insights and reality surveys. *The Journal of allergy and clinical immunology* 2004;**114**(1):40-7.
4. Steinberg L. Cognitive and affective development in adolescence. *Trends in Cognitive Sciences* 2005;**9**(2):69-74.
5. Sawyer SM, Aroni RA. Self-management in adolescents with chronic illness. What does it mean and how can it be achieved. *Medical Journal of Australia* 2005;**183**(8):405.
6. Mammen J, Rhee H. Adolescent Asthma Self-Management: A Concept Analysis and Operational Definition. *Pediatric Allergy, Immunology, and Pulmonology* 2012;**25**(4):180-89.

7. van Es SM, le Coq EM, Brouwer AI, et al. Adherence-related behavior in adolescents with asthma: results from focus group interviews. *Journal of Asthma* 1998; **35**(8):637-46.
8. Edgecombe K, Latter S, Peters S, et al. Health experiences of adolescents with uncontrolled severe asthma. *Archives of Disease in Childhood* 2010; **95**(12):985-91.
9. Bravata DM, Gienger AL, Holty JE, et al. Quality improvement strategies for children with asthma: a systematic review. *Arch Pediatr Adolesc Med* 2009; **163**(6):572-81.
10. Wolf FM, Guevara JP, Grum CM, et al. Educational interventions for asthma in children. *Cochrane Database of Systematic Reviews* 2003(1):CD000326.
11. Haby M, Waters E, Robertson C, et al. Interventions for educating children who have attended the emergency room for asthma. *The Cochrane Library* 2001.
12. Kahana S, Drotar D, Frazier T. Meta-analysis of psychological interventions to promote adherence to treatment in pediatric chronic health conditions. *Journal of Pediatric Psychology* 2008; **33**(6):590-611.
13. Ahmad A, Sorensen K. Enabling and hindering factors influencing adherence to asthma treatment among adolescents: a systematic literature review. *J Asthma* 2016(just-accepted):00-00.
14. Kirby S, Miles C, Arden-Close E, et al. P51 Barriers And Facilitators To Effective Self-management Of Asthma – A Systematic Review And Thematic Synthesis. *Thorax* 2014; **69**(Suppl 2):A96.
15. Harden A, Brunton G, Fletcher A, et al. *Young people, pregnancy and social exclusion: A systematic synthesis of research evidence to identify effective, appropriate and promising approaches for prevention and support*: EPPI-Centre, Social Science Research Unit, Institute of Education, University of London, 2006.
16. Higgins JPT, Altman DG, Gøtzsche PC, et al. *The Cochrane Collaboration's tool for assessing risk of bias in randomised trials*, 2011.
17. Popay J, Roberts H, Sowden A, et al. Guidance on the conduct of narrative synthesis in systematic reviews. A product from the ESRC methods programme Lancaster: Institute of Health Research 2006.
18. Rhee H, Belyea MJ, Ciurzynski S, et al. Barriers to asthma self-management in adolescents: Relationships to psychosocial factors. *Pediatric Pulmonology* 2009; **44**(2):183-91.
19. Wamboldt FS, Bender BG, Rankin AE. Adolescent decision-making about use of inhaled asthma controller medication: results from focus groups with participants from a prior longitudinal study. *Journal of Asthma* 2011; **48**(7):741-50.
20. Buston KM, Wood SF. Non-compliance amongst adolescents with asthma: listening to what they tell us about self-management. *Family Practice* 2000; **17**(2):134-8.
21. Velsor-Friedrich B, Vlasses F, Moberley J, et al. Talking with teens about asthma management. *J Sch Nurs* 2004; **20**(3):140-8.
22. Naimi DR, Freedman TG, Ginsburg KR, et al. Adolescents and asthma: why bother with our meds? *Journal of Allergy & Clinical Immunology* 2009; **123**(6):1335-41.
23. Blaakman SW, Cohen A, Fagnano M, et al. Asthma medication adherence among urban teens: a qualitative analysis of barriers, facilitators and experiences with school-based care. *J Asthma* 2014; **51**(5):522-9.
24. Koster ES, Philbert D, de Vries TW, et al. "I just forget to take it": asthma self-management needs and preferences in adolescents. *J Asthma* 2015; **52**(8):831-7.
25. Knight D. Beliefs and self-care practices of adolescents with asthma. *Issues Compr Pediatr Nurs* 2005; **28**(2):71-81.
26. Jonsson M, Egmar AC, Hallner E, et al. Experiences of living with asthma - a focus group study with adolescents and parents of children with asthma. *Journal of Asthma* 2014; **51**(2):185-92.
27. van Es SM, Kaptein AA, Bezemer PD, et al. Predicting adherence to prophylactic medication in adolescents with asthma: an application of the ASE-model. *Patient Educ Couns* 2002; **47**(2):165-71.
28. Araujo A, Rocha RL, Alvim CG. Adolescence and asthma management: The perspective of adolescents receiving primary health care. *Revista Paulista de Pediatria* 2014; **32**(3):171-76.

29. Kyngäs HA. Nurses' support: essential factor for the good compliance of adolescents with asthma. *Nursing & Health Sciences* 2000;**2**(4):211-16.
30. van Es SM, Nagelkerke AF, Colland VT, et al. An intervention programme using the ASE-model aimed at enhancing adherence in adolescents with asthma. *Patient Educ Couns* 2001;**44**(3):193-203.
31. Cohen R, Franco K, Motlow F, et al. Perceptions and attitudes of adolescents with asthma. *Journal of Asthma* 2003;**40**(2):207-11.
32. Quaranta J, Wool M, Logvis K, et al. Interpersonal Influences on the Self-management Skills of the Rural Asthmatic Adolescent. *Online Journal of Rural Nursing and Health Care* 2014;**14**(2):97-122.
33. Horne R. Compliance, adherence, and concordance: implications for asthma treatment. *Chest* 2006;**130**(1 Suppl):65S-72S.
34. Sabaté E. *Adherence to long-term therapies: evidence for action*: World Health Organization, 2003.
35. Blakemore S-J, Robbins TW. Decision-making in the adolescent brain. *Nature neuroscience* 2012;**15**(9):1184-91.
36. Blakemore S-J. Development of the social brain in adolescence. *Journal of the Royal Society of Medicine* 2012;**105**(3):111-16.
37. Taylor S, Pinnock H, Epiphaniou E, et al. A rapid synthesis of the evidence on interventions supporting self-management for people with long-term conditions.(PRISMS Practical Systematic Review of Self-Management Support for long-term conditions). *Health Serv Deliv Res* 2014;**2**:53.
38. Zolnieriek KBH, DiMatteo MR. Physician communication and patient adherence to treatment: a meta-analysis. *Medical care* 2009;**47**(8):826.
39. Lindsay S, Kingsnorth S, Hamdani Y. Barriers and facilitators of chronic illness self-management among adolescents: a review and future directions. *Journal of Nursing and Healthcare of Chronic Illness* 2011;**3**(3):186-208.



Table 1. Study Characteristics

<b>Study ID (ref)</b>	<b>Aims</b>	<b>Participants</b>	<b>Data collection</b>	<b>Data analysis</b>	<b>Summary of findings</b>
Blaakman 2014	To understand the adolescent perspective around asthma management including prevention and adherence.	Aged 12-16 years (n=28) with persistent asthma and prescribed preventer medication. Participating in a pilot study examining daily observed medication therapy at school and motivational interviews. Rochester, US	Qualitative study with data collected through semi-structured interviews at final review.	Qualitative content analysis.	Themes categories, (1) “general asthma management” – positives: routines, independence, connecting daily medication use with fewer symptoms; negatives: hurrying, forgetfulness, competing demands; or (2) “program-specific” half reported positive rapport with their school nurse but a few felt nurse was dismissive, leaving the classroom, distance to the nurse’s office, necessity of hall passes and morning school routines, many connected using medications to fewer symptoms.
Buston et al. 2000	To understand better the reasons for non-compliance in	Aged 14- 20 years (n=49) diagnosed with asthma >1 year ago. Did not approach	In-depth interview conducted in the home.	Interviews were transcribed in full and analysed using a grounded theory	Majority admitted to non-compliance with self-care regimes. Reasons given were: forgetfulness; belief that medication is ineffective; denial of having asthma or belief that asthma not serious;

	adolescents with asthma.	those deemed inarticulate or with behavioural problems. Sampled from hospital asthma clinics in Glasgow, UK.		approach. Transcripts were indexed and a coding frame developed.	difficulty using inhaler; inconvenience; fear of side effects; embarrassment and laziness. Relative and friends were noted as important for medication reminders, despite annoyance with parents for 'nagging'.
Cohen et al. 2003	To examine the perceptions of inner-city adolescent asthmatics and their attitudes towards self-treatment.	US high school students (n = 200). Multi-staged stratified sampling. Pilot questionnaire administered to 2800 students, subset of 200 were identified with asthma, 80% completion rate.	32 item self-report questionnaire.	Descriptive statistics only.	41% did not know the name of their asthma medication, 38% reported taking asthma pump when going out. 29% reported feeling embarrassed having an asthma attack with friends, 32% embarrassed to take medication in front of friends. Embarrassment related to not carrying pump and not taking medication with friends.
Edgecombe et al. 2010	To understand the experiences of adolescents living	Aged 11-18 years (n = 22). Uncontrolled, severe asthma, no	Semi-structured interviews for qualitative data.	Transcripts were systematically analysed using thematic approach	Two overarching themes: 1) medication and adherence, and 2) interaction with healthcare professionals and adherence with their advice.

---

	with difficult asthma, particularly their interaction with healthcare professionals and use of medications.	other chronic medical condition. Purposively sampled from outpatient clinic in Southampton, UK.		in an iterative process. Emergent themes were identified and coded. Some transcripts were second coded. Deviant cases were addressed.	Adolescents had a poor understanding of their medication and using it often conflicted with other activities. Adolescents are very reliant on their parents and lack confidence in attending appointments alone. Healthcare professionals need to work to empower them to gradually take on the responsibility for their asthma.
Jonsson et al. 2013	To describe the experiences of living with asthma among adolescents with asthma and parents of young children with asthma.	Aged 13 – 18 years (n=9) with asthma. Doctor diagnosis of at least 2 years, on daily treatment with ICS, and outpatients visit at least once a year. Purposively sampled from outpatient clinics in Stockholm, Sweden.	Interview schedule with four focus groups. Two with parents and two with adolescents.	Transcribed data were analysed using systematic text condensation.	Three themes were identified: strategies, frustrations and expectations. Adolescents wanted to be like their peers and developed their own strategies for self-management of asthma, which included not always taking medication as prescribed. Participants wanted competence and understanding in asthma care from healthcare professionals.

---

Koster et al 2015	To assess adolescent asthmatics needs and preferences regarding medication counselling and	Aged 12-16 (n= 21) years with asthma from both primary and secondary care. On ICS. Either from pharmacy or clinic. Netherlands	Qualitative with 2 online focus group and one face to face one. Questions focused on adherence behaviour and needs and preferences in adherence support.	Qualitative thematic analysis	Forgetting was major reason for poor adherence. Others: lack of perceived need or benefit. Strategies to improve: reminders from parents, reminder on smartphone applications.
Knight 2005	To identify the beliefs and self-care practices of adolescents with asthma in a private high school.	Aged 13-18 years (n = 10). Moderate-severe asthma. Convenience sample from school in Hawaii, US.	Semi-structured interviews.	Transcriptions were analysed to identify themes, using a modified grounded-theory approach of constant comparative methods.	Knowledge acquisition, self-efficacy, and social support were associated with behaviours that control asthma with better outcomes. Greater knowledge acquisition and symptom recognition were associated with exposure to multiple educators, especially school-based programs. High self-efficacy was facilitated through positive experiences - teenagers recognized that they had fewer asthma events and severity once they were

---

					in better physical condition, on preventive medicines, and/or used trigger avoidance success. Social support for teens was very helpful and included parents, family, friends, coaches and teachers, and healthcare providers.
Kyngas 2000	To identify the factors that predict compliance with health regimens by adolescents with asthma	Aged 13-17 years (n = 266). Diagnosed more than 1 year. Random whole population sample in Finland.	58-item structured self-report questionnaire posted to participants. 88% response rate.	Logistic regression to determine the factors that predict compliance with health regimens.	The greatest predictor for compliance with health regimens was support from nurses, followed by motivation. Energy and willpower were also significant predictors.
Naimi et al. 2009	To assess beliefs about adherence and asthma management.	Aged 15-18 years (n=39). Moderate - severe asthma. Convenience sample from outpatient clinic lists or during an inpatient stay in	Mixed methods. Two open-ended 1:1 interviews a month apart, electronic monitoring of adherence (EMA).	A data reduction process with content analysis. Researchers independently looked for common themes by using grounded theory structure. Themes were	HBM themes from the interviews were: self-reported adherence, perceived severity of asthma, effects on daily activities, benefits / risks of ICS. Teens took medication inconsistently, had erroneous beliefs about them, dislike taste, "too busy" to take and "forget". Teenagers recommend "reminder" solutions to poor

---

---

		Philadelphia, US.		summarized and interpreted within the framework of the Health Belief Model. Themes were compared with the EMA data.	adherence. Twenty percent believed that taking controller medication was unnecessary, and another 18% expressed ambivalence about its benefits
Quaranta et al 2014	To understand how self-management behaviours of the adolescent with asthma are influenced by the perceived expectations for self-management behaviours from healthcare providers, school	Rural adolescents aged 13-17 years (n=7) with asthma. USA	Focus groups were conducted with with focus on which influenced management behaviours.	Thematic analysis	The majority of participants perceived provider and parental expectations for asthma management as only consisting of medication compliance. The students did not report any perceived expectations from the school nurse except independent inhaler use. There was no expectation to report use to the school nurse. The participants felt that their teachers were not aware of their asthma diagnosis; therefore, no expectations were noted. Expectations from peers had no influence on self-management behaviours.

---

---

nurses, teachers,  
family and friends.

Rhee et al. 2009	To assess common types of barriers to self-management. Examine associations between barrier perception and psychosocial factors including knowledge, attitudes, and self-efficacy.	Aged 13-20 years (n = 126). Persistent asthma for more than 1 year. No other chronic health condition. Recruited via community flyers, schools, and healthcare providers in New York, US.	Illness Management Survey (barriers); Asthma Knowledge Questionnaire; and Attitude towards Illness Questionnaire. Non validated measures: Asthma Self-Efficacy and Asthma Control questions.	Descriptive statistics to analyse common barriers. Factor analysis was performed on the Illness management survey. Hierarchical regression used to examine the extent to which barrier perception was predicted by asthma control, knowledge, attitude and self-efficacy.	Common barriers were: unwillingness to give up things (63%); difficulty remembering (53%); trying to 'forget' they have asthma (50%). 46% reported five or more barriers. Factor analysis revealed barriers in four domains: negativity toward providers and the medication regimen, cognitive difficulty, peer/family influence and denial. Self-efficacy was the most influential factor that showed a strong negative association with all four barrier subscales independent of asthma control and sociodemographic characteristics. Poor attitudes to asthma were also associated with barriers of cognitive difficulty and social influence. Males consistently reported higher barriers such as negativity, social influence and denial. Self-
---------------------	--	---	--	---	---

---

---

					efficacy predicted all four barrier types.
van Es et al. 2002 (22)	To investigate whether attitudes, social influence, self-efficacy, and intention can predict self-reported adherence after 1 year.	Aged 11-18 years (n = 86). Physician diagnosed asthma prescribed daily inhaled prophylactics for minimum 2 months. Recruited from pediatric outpatient clinics in Netherlands.	Questionnaires measuring attitudes, self-efficacy, social influences, and adherence (self-reported). Data collected as part of RCT intervention at baseline and after 12 months.	Linear regression used to examine the relationship between baseline determinants and adherence after 12 months.	The most important determinant of self-reported adherence at 12 months was previous self-reported adherence (i.e. adherence at baseline) followed by 'feeling ashamed about asthma', positive attitude to medication, and intention.
van Es et al. 1998 (7)	To explore the self-management behaviour of adolescents, particularly adherence behaviour.	Aged 12-16 years (n = 14), physician diagnosed asthma and on daily treatment of prophylactic medication. Recruited from outpatient clinics in Netherlands.	Three focus groups (of 2, 5, and 7 teenagers) discussed self-management behaviours; feelings about having asthma; opinions of the health care	Transcripts were coded by an observer and independent physician. Information was analysed by coding statements into five topics. Once complete the analysts compared their coding	All participants said they forgot to take daily medication, often because they were in a hurry. Reminders or cues were needed to take medication. Some were late starting medication when symptoms appeared and did not use medication in advance of expected symptoms. Reasons for not taking medication included: not wanting to stop activities; dislike of taste or side-

---



---

			provided by the paediatrician; recommendations for healthcare providers; and patient education materials.	and discussed any disagreements to form a consensus. Data were analyzed within groups, then responses of the different groups were combined.	effects; belief that medication is ineffective, or because they did not have symptoms. A minority reported smoking, embarrassment, or lack of confidence in speaking out. All were “fed up” with having asthma. Lack of honesty with doctor and lack of understanding about medications. Teenagers wanted more information in person and in a visual format.
van Es et al. 2001 (24)	To assess an intervention programme aimed at enhancing adherence to asthma medication	Aged 11-18 years (n = 112). Doctor diagnosed asthma on daily preventer medication. Recruited from outpatients in Netherlands.	Questionnaires. RCT of intervention program versus usual care. Self-reported adherence at baseline, after 1 year, and 2 years.	T-tests were used for between group comparisons of adherence, and possible determinants of adherence.	No statistically significant differences were seen between groups except at 24 months follow up when self reported adherence was higher.
Velsor-Freidreich et al. 2004	To explore experiences and behaviours related to the self-	Aged 14-18 years (n = 24). Recruited from four schools in city, urban and rural areas,	Four questions used to stimulate discussion in four focus groups.	Discussion tapes transcribed verbatim and colour-coded to identify each school. Transcripts	Four themes emerged: 1) wanting to be normal – not wanting to discuss asthma with peers. 2) unpredictability of the disease – difficulties in maintaining normal life. 3) credibility of the teen

---

(18)	management of teens with asthma.	identified by school nurse in US (exact location not provided).		were then disseminated to the research team and themes identified.	with asthma – teenagers understand the seriousness of their asthma but not always the adults around them. 4) Self-management issues - reliance on parents, difficulties avoiding triggers, inconsistencies between beliefs/knowledge and actual behaviour. Communicating needs to adults was seen as a benefit but asthma was not discussed with peers.
Wamboldt et al. 2011 (16)	To examine beliefs, feelings, and behaviours about ICS to develop more effective management strategies.	Aged 12 – 20 years (n = 26) recruited from previous study in Denver, US. Physician diagnosed asthma on ICS.	Six focus groups comprised of 3–5 participants.	Verbatim transcripts of these groups were analyzed using the long-table method of content analysis to identify key themes raised by participants.	A variety of beliefs, feelings, and behaviours influence decisions about how to use asthma medication. Some understood the importance of daily medication and were committed to the treatment plan prescribed by their provider. Poorer adherence resulted from misinformation, incorrect assumptions about their asthma, and current life situations.

---

ED emergency department; GP general practice, ICS inhaled corticosteroids,

Table 2. Quality appraisal checklist of qualitative studies (CASP)

First Author	Aims and objectives clearly reported	Adequate description of the context in which the research was carried out	Adequate description of the sample used and methods to identify and recruit sample	Adequate description of the methods used to collect the data	Adequate description of the methods used to analyse data	Attempts to establish the reliability of data collection tools	Attempts to establish the validity of data collection tools	Attempts to establish the reliability of the data analysis methods	Attempts to establish the validity of data analysis methods	Appropriate data collection methods for helping young people to express their views	Appropriate methods for ensuring data analysis grounded in the views of young people	The study actively involved young people in its design and conduct	Overall quality criteria
Blaakman	Yes	Yes	Yes	Yes	Yes	No	No	Yes	No	Unclear	Yes	No	Medium
Buston	Yes	Yes	Yes	Yes	Yes	Yes	NR	NR	NR	Yes	Yes	NR	Medium
Edgecombe	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	NR	High
Jonsson	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	NR	Yes	Yes	NR	Medium
Knight	Yes	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	NR	Medium
Koster	Yes	Yes	Yes	Yes	Yes	No	No	Yes	No	Unclear	Yes	No	Medium
Naimi	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	NR	Yes	Yes	NR	High
Van Es	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	NR	Yes	Yes	NR	Medium
Velsor-Friedrich	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	Yes	NR	Medium

---

Quaranta	Yes	Yes	Yes	Yes	Yes	No	No	Yes	No	Unclear	Yes	NR	Medium
Wamboldt	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	Yes	NR	Medium

---

NR = not reported. <7 = low; 7-9 = medium; 10-12 = high

Table 3 Quality appraisal of quantitative studies using the Cochrane risk of bias tool

	Adequate sequence generation	Allocation concealment	Blinding / patient related outcomes	Incomplete outcome data addressed	Free of selected reporting	Free of other bias	Other method notes	Overall quality assessment
Cohen	NA	NA	NA	Unclear	Unclear	Low	Unvalidated questionnaire	Unclear
Kyngas	NA	NA	NA	Unclear	Unclear	Low		Unclear
Rhee	NA	NA	NA	Unclear	Unclear	Low		Unclear
Van Es 2001	Unclear	Unclear	No	Unclear	Unclear	Low		Unclear
Van Es 2002	Unclear	Unclear	No	Unclear	Unclear	Low		Unclear

NA = not applicable

Table 4. Summary of themes with illustrative quotations (where provided)

	<b>Barriers</b>	<b>Facilitators</b>
Knowledge	<p><b>Poor knowledge of asthma, treatment regimes, and devices</b></p> <p><i>“I usually take my blue inhaler but then if it’s really bad I the preventer because... it’s quick acting” [8]</i></p>	<p><b>Severe exacerbation</b></p> <p><i>“I just make sure I do it otherwise I’m gonna be ill, that’s one of the reasons I came into hospital was because I carried on forgetting to take my inhalers” [8]</i></p>
Lifestyle	<p><b>Forgetting to take medication</b></p> <p><i>“At the weekend I’m fairly poor [at remembering] because I go out quite a lot at nights and come in late. I generally forget then, or if I’m up really late in the morning I quite often forget....” [20]</i></p> <p><b>Time constraints</b></p> <p><b>Not wanting to interrupt other activities</b></p> <p><i>“don’t really forget to take it but if I’m like doing something and I feel tight and it’s something that I don’t want to be pulled away from then I won’t take it” [8]</i></p> <p><b>Inconvenience of spacers</b></p> <p><i>“..need to look for the spacer most of the time and I’m like, oh I can’t be bothered to</i></p>	<p><b>Routines</b></p> <p><i>‘first I clean my teeth then I take my medicine’ [7]</i></p> <p><b>Cues and reminders for remembering medication</b></p> <p><i>“I take them by myself but my mum has to remind me otherwise I don’t do it” [8]</i></p>

---

*look for this, let's just take it without the spacer" [8]*

**Unable or unwilling to avoid triggers**

Beliefs and  
attitudes

**Side effects**

*"I don't like the taste or the way it feels in your mouth or anything...." [22]*

**Beliefs that medication is ineffective**

*"I don't [need to take F/S]... Because when I don't take it, I feel the same as when I do take it. To me, it doesn't make a difference. . ." [22]*

**Beliefs that asthma is not serious**

*"I've never really thought of asthma as being serious"[19]*

**Denial of asthma**

*"when I first got diagnosed.., I went through the stage of 'I haven't got asthma, that's it', and I ended up having a massive attack from not taking the medication"*  
[20]

Relationships

**Unsupportive teachers and school policies**

*"and the teachers... there's a whole lot of shame and there's a lot of frowning that goes on.."[21]*

**Negativity towards HCP**

**Positive attitudes towards asthma and  
medication**

**Accepting help from others**

**Reminders and support from peers**

*"they always like give me my inhalers and stuff" [8]*

**Competent and supportive HCP**

*"It's better to meet someone who knows what I need*

---

		<i>than to be forced to meet ten people and tell them the whole story over and over again" [26]</i>
Intrapersonal	<p><b>Apathy towards asthma and medication</b></p> <p><i>"I just can't be bothered really" [8]</i></p> <p><b>Experiencing symptoms or taking medication is embarrassing</b></p> <p><i>"I'd rather just do it when I'm alone so no one's like staring at me with amazement that I'm taking an inhaler" [19]</i></p> <p><b>Lack of assertiveness</b></p> <p><b>Feeling ashamed of having asthma</b></p> <p><i>"I am the only one in the class who has got asthma, and then I'm a bit ashamed of it." [7]</i></p> <p><b>Wanting to be 'normal'</b></p>	<p><b>High motivation</b></p> <p><b>High self-efficacy</b></p> <p><b>Feeling in control of asthma</b></p> <p><b>Taking responsibility</b></p> <p><b>Acceptance of asthma</b></p> <p><i>"Well, I suppose I've just grown up with it, the fact that I've got it. It's just a part of me" [7]</i></p>
Communication	<p><b>Withholding information from HCP</b></p> <p><i>"well sometimes I said everything was ok but then I had been feeling quite poorly a few days earlier"[7]</i></p> <p><b>Difficulty being honest with HCP when parents present</b></p> <p><i>"there's some stuff you don't feel comfortable talking about around your mum" [8]</i></p> <p><b>Afraid to ask HCP questions</b></p> <p><b>Not paying attention to HCP</b></p>	

---



*“If I like talk to the Dr or something I sometimes get really bored—he’s just going on about the same thing for about an hour—that’s really annoying” [8]*

**Not discussing asthma with others**

---

Table 5. Key messages for healthcare professionals

- Many adolescents have poor knowledge about asthma and treatments
- Non-adherence is frequently caused by forgetting to take medication
- Adolescents with established routines are better able to self-manage
- Some adolescents do not use treatments or use them incorrectly due to erroneous beliefs about their asthma and medication
- Asthma self-management is difficult for those with a lack of support at school
- Parents play a key role in reminding adolescents to take medication
- Many adolescents feel embarrassment about their asthma and using medication, particularly around their friends and peers
- Many adolescents report difficulties in communicating with their healthcare professional

Figure 1 Flow Diagram of Search Process

