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Enabling and hindering factors influencing adherence to asthma treatment among adolescents: A systematic literature review

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Abstract

Objectives: The aim of this systematic literature review is to study the enabling and hindering factors influencing adherence to asthma treatment among adolescents. Furthermore, it explores the role of caregivers and the healthcare provider in terms of supporting adolescents to manage and live with asthma. **Data sources:** The literature review was conducted using the MeSH terms asthma, adherence, health literacy, behavior, adolescents, tools, healthcare provider, caregiver, peer influence, self-management, quality of life, morbidity and mortality in PubMed, PsycInfo, MEDLINE and CINAHL. **Study selection:** The literature search resulted in 652 articles of which 304 were screened based on title and abstracts. Ninety-one of the screened articles were then selected for full-text assessment resulting in 42 articles for in-depth analysis. **Results:** The literature review identified nine enabling and hindering factors relevant for adherence to asthma treatment among adolescents: behavior, belief, self-management, health literacy, role of health provider, assessment of adherence, role of caregiver, role of peers and the national asthma guidelines. **Conclusion:** Working with this particular age group is complex and further research in understanding adolescent's behavior, motives, beliefs and perceptions towards adherence to asthma treatment is required to guide them towards better self-management and acceptance of their condition.

Keywords

Behavior, personality, beliefs, self-management, health literacy, caregiver, peers, health provider, assessment, guidelines

History

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Introduction

Asthma is one of the major non-communicable diseases worldwide. The prevalence of asthma has continuously increased over the last five decades, resulting in 235 million people suffering from it [1,2]. Although, effective asthma therapy regimes, which can alleviate or help to control symptoms are available, many patients do not adhere to treatment. In fact, only 50% to 60% of asthma medication is being taken as prescribed [3], which constitutes as a risk factor for morbidity and mortality [4]. Furthermore, non-adherence to asthma treatment reflects a decreased control of the disease which results in poor health outcomes, decreased quality of life [5] and increased healthcare costs [6,7]. Moreover, it leads to sleep disruption, missed school and work days, limited sports or recreational activities, and increased emergency visits [8]. On the contrary, well-controlled asthma leads to fewer symptoms and almost normal lung functionality regardless of the severity of the disease [8]. Despite these enhancing effects, adherence to asthma is still a misunderstood problem which results in poor asthma control [9].

Understanding the underlying concerns of patients will lead to better adherence to recommended treatment regimes, increased patient and physician satisfaction and increased involvement of patients in treatment [10]. Medical non-adherence is known to be triggered by the complex and long duration of asthma treatment and reinforced by a lack of self-management skills and health literacy knowledge; “the ability to read and comprehend medical information” [11]. Furthermore, research has shown that caregiver have a profound role in their child's asthma management. In fact, caregivers with sufficient level of asthma knowledge are more likely to support their children's adherence behavior [12]. The doctor-patient relationship has also been emphasized as a decisive factor in adolescents' adherence behavior. More precisely, the role of the healthcare provider is to support their asthma patients by building and maintaining a trustworthy relationship and by providing tailored information and advice [13].

To get an in-depth understanding of the reasons behind non-adherent behavior, patient's beliefs, concerns, needs and personality traits must be evaluated. This information can be used to identify individuals at risk for poor adherence and intervene in accordance. Although Lindsay and Heaney [14] found that children between the ages of 7 and 9 years are more likely to adhere to treatment than young adolescents between the ages of 10 and 16 years; it remains unclear why adolescents adhere poorly to treatments.

Notably, to relieve the burden posed by non-adherence to asthma treatment among adolescents, barriers that hinder

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Table 1. PICOS.

PICOS	Defined PICOS	Additional search terms
Population	Adolescents with asthma	Young people, youth, teenager, children
Indicator	Non-adherence to asthma treatment	Non-compliance
Comparison	Adherence to asthma treatment	Compliance
Outcome	Behavioral reasons for non-adherence	Determinants, personality, self-management, beliefs, concerns, barriers, health literacy, knowledge, education, support, parents, caregiver, peers, doctor, healthcare provider
Setting	Not limited	–

adherence behavior need to be ameliorated. This requires a comprehensive and in-depth understanding of the reasons behind non-adherent behavior. Hence, this literature review aims to identify the enabling and hindering factors of adherence to asthma treatment including the role of caregivers and health provider for young people's adherence to treatment. The outcome of this study can serve as a reference point for the development of effective interventions that aim to tackle the problem of medical non-adherence to asthma treatment among adolescents.

Methods

The systematic literature search was performed in February 2014 by using the databases PubMed, PsycInfo, MEDLINE and CINAHL. The search terms were related to the key concepts: asthma, adherence, health literacy, behavior, adolescents, tools, healthcare provider, caregiver, peer influence, self-management, quality of life, morbidity and mortality that were guided by the PICOS (Table 1), and were entered into the databases in different combinations. For each database the search was limited to abstract or title in order to narrow down the search results.

After removing duplications, articles with promising titles and abstracts were identified by both authors under consideration of the predefined eligibility criteria consisting of articles written in English or German, studying populations preferably adolescents only or if necessary young adults under asthma treatment and articles analyzing the reasons for non-adherence to asthma treatment. All articles that were eligible for the literature review were analyzed in terms of indicators relevant for the research aim and with regard to limitations and research gaps. Thereafter, the pre-selected articles were reviewed in full-length for relevance according to the established inclusion criteria. More precisely, detailed information was systematically extracted based on the predefined eligibility criteria. At this point, it was once again important to see if the included article explained the reasons for non-adherence such as barriers, enabling or hindering factors of asthma treatment and were not discussing adherence or non-adherence from a different perspective (e.g., ways to assess adherence). Once the articles for the literature review were found, the content of the articles was summarized and subordinated into different perspectives.

Results

The literature search resulted in 652 relevant articles, of which 348 articles were duplicates and the remaining 304 articles were screened for relevance based on their title and abstracts (Figure 1). This resulted in 91 articles for which the full-texts were assessed for eligibility yielding 42 articles to be included in the literature review (Table 2).

Enabling and hindering factors influencing adherence to asthma treatment among adolescents

The literature review illuminated nine cross-cutting perspectives and themes relevant for non-adherence to asthma treatment among adolescents that were subordinated into patients' perspectives, systemic perspectives, societal perspectives and policy perspectives, which are described in the following (Figure 2).

Patient perspective: Behavior

Adherence to medication is a voluntary behavior that can be affected by multiple factors such as medication beliefs, concerns, personality traits and co-morbidities [15]. Regarding co-morbidities, mood disorders such as psychosocial problems [5] or depression have been associated with non-adherence to asthma treatment [16]. The most common reasons identified in Axelsson's [6] study were 'no perceived need' where the target population stated that they feel well without medicine or that they are trying to manage their disease without medicine. The second-most common reason identified was 'insufficient routines' due to side effects or medication dislike [6]. In addition, various findings have shown that adherence behavior decreases due to long treatment durations, decreasing symptoms, and increasing quantity of medications, whereas, unlike some assumptions, adherence behavior does not increase with the severity of asthma [14,17,18].

With regard to adherence to asthma treatment, two types of behaviors were identified: intentional and unintentional. Intentional is where adolescents do not adhere to treatment as a result of a conscious decision due to e.g., concerns or lack of trust in medicine [4,6]. Health-related risk-taking behavior of adolescents such as smoking and drinking alcohol or general disregard of health consequences is also associated with medication non-adherence [4]. Those who do not trust in medicine avoid triggers or tolerate symptoms rather than adhering to treatment [6,19]. Unintentional is where treatment is not followed due to unawareness, faulty inhaler technique or forgetfulness [6]. Adolescents reported that their busy, hectic and sometimes chaotic lifestyle makes it difficult to stick to routines [20]. Both behavioral types require different types of intervention [6,9,14]. From both types, those who do not adhere to treatment intentionally are the most difficult to treat, hence, both types require tailored intervention strategies [6,9,14,19].

Patient perspective: Beliefs

Patients beliefs are important to identify because they have a "powerful impact on patient adherence" [21]. Those who see their disease as unpredictable do not see the need to adhere

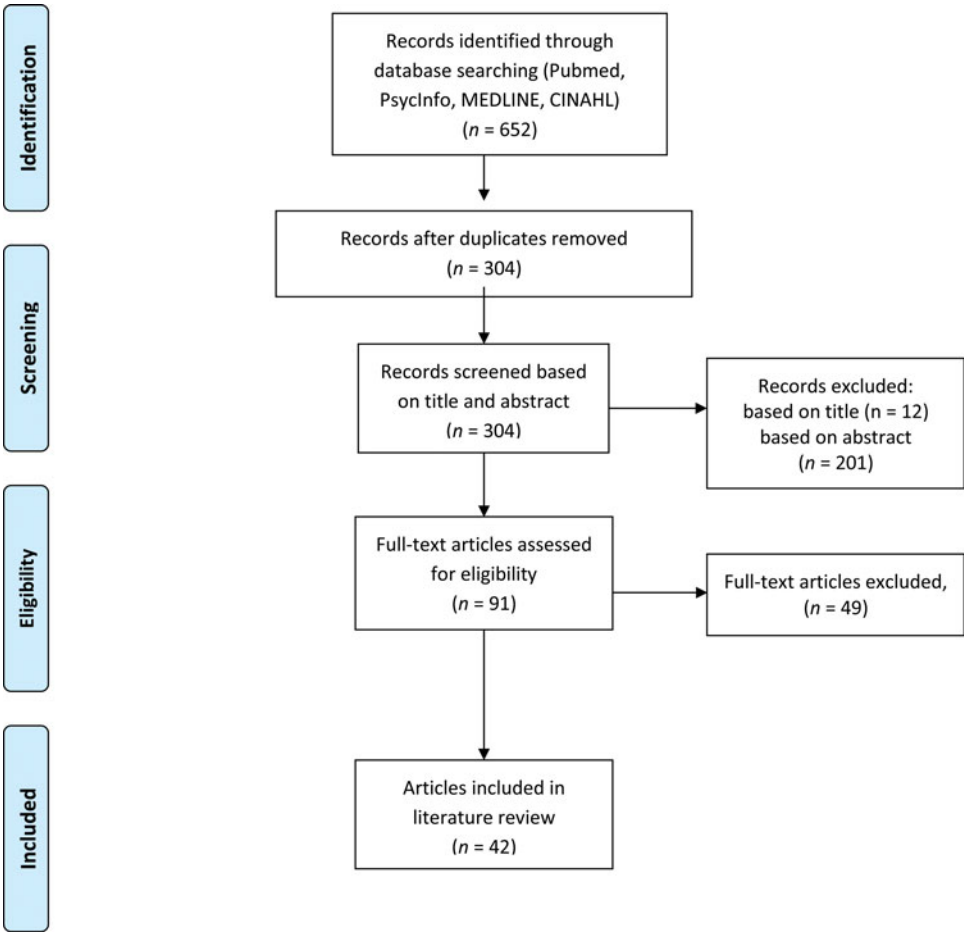


Figure 1. Flow chart (adapted from PRISMA 2009 Flow Diagram).

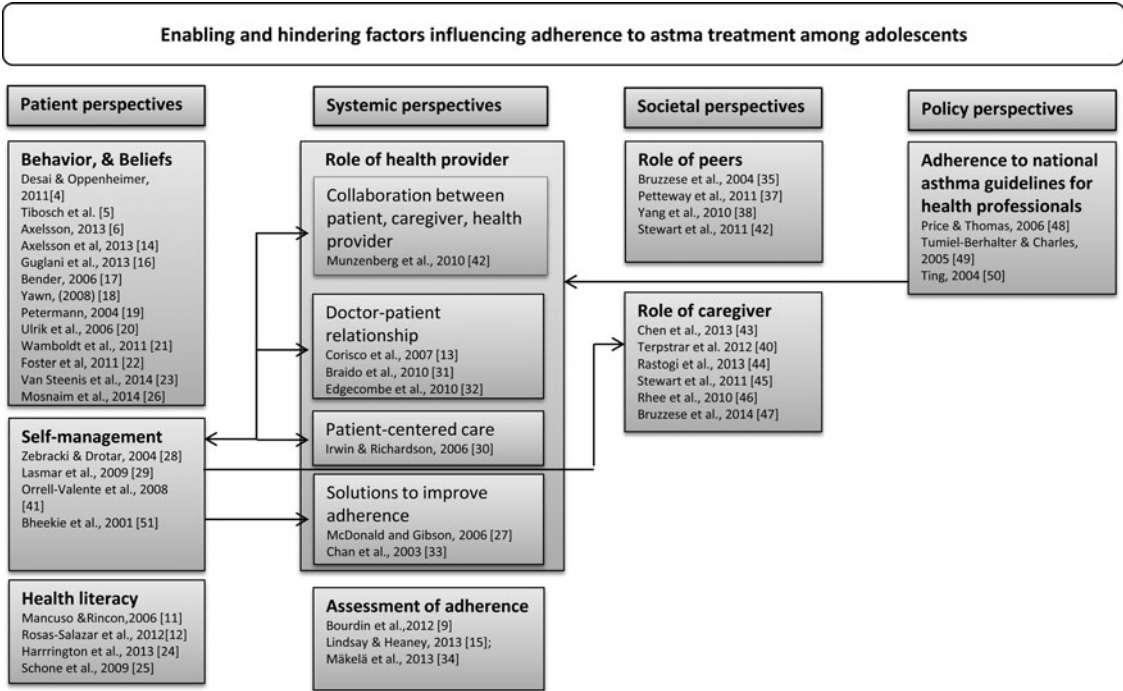


Figure 2. Overview of enabling and hindering factors.

Table 2. Overview of included studies.

Author, year	Location	Target Group	Disease	Aim	Methods	Definition Adherence	Outcome	Limitations and Overall Quality
Axelsson et al., 2013	Sweden	All ages $n = 516$	Asthma	Determine the mediating effects of beliefs about asthma medication between personality traits and adherence	Questionnaire	Not stated	Personality traits could be used to identify asthma patients who need support with their adherence behavior. Concerns partial mediator for influencing effects of agreeableness, conscientiousness, neuroticism	Self-reported adherence Sparse data on SES Good
Axelsson, 2013	Sweden	216 Young adults (22 years)	Asthma	Identify young adults stated reasons for not taking asthma medication	Questionnaire	Not stated	Important parameters for non-adherence to asthma treatment are negative affectivity and perceived asthma control	Selection bias Good
Bender, 2006	USA	Adolescents and young adults	Asthma	Reviews association between depression, risk behavior and nonadherence	Literature review	Not stated	New behavioral studies must be more well-designed in order to show a reliable associations and correlations	Not systematically Medium
Bourdin et al., 2012	France	All ages	Asthma	Discuss new definitions of therapeutic adherence in the scope of severe asthma, its assessment, the reasons for poor therapeutic adherence, and potential solutions investigate physician-related factors that can influence successful asthma management	Review	The ability to take medication accordingly. A partnership between patients and healthcare provider	Adherence is a vast domain of competency where a pluridisciplinary approach is required.	Medium
Braido et al., 2010	Italy	Healthcare provider	Asthma		questionnaire	Not stated	level of GPs and asthma specialist regarding the use of asthma control tool was not optimal. Respondents were also unable to correctly identify the level of asthma control. A large majority did not believe in the effectiveness of self-management plans	Good

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Table 2. (Continued)

Author, year	Location	Target Group	Disease	Aim	Methods	Definition Adherence	Outcome	Limitations and Overall Quality
Bruzzese et al., 2004	USA	Adolescents	Asthma	discuss developmental transition in cognition, knowledge, autonomy, identity development, and peer relations in term of their influence on adolescents' asthma management	discussion about developmental transition of adolescents and its influence on asthma management randomized control trial of a school based asthma education program Interviews	Not stated	Adolescents are at higher risk for asthma and its negative consequences compares to children. The presented intervention was shown to be feasible.	Feasibility study, has not assessed efficacy of study Poor
Bruzzese et al., 2014	USA	168 adolescents	Asthma	Test the self-determination theory to explain adherence to asthma medication regimens in African American adolescents	Interviews	Not stated	Helping families to better integrate asthma care in daily schedules may be an important intervention strategy to improve medication adherence among high risk African-American adolescents.	Self-reported data Baseline date from larger RCT Medium
Chen et al., 2013	Taiwan	65 children (6–14 years) and caregiver	Asthma	Evaluated effectiveness of a self-management interactive support (SMIS) program for caregivers of children with asthma	Randomized Control Trial	Not stated	Interactive support interventions reinforce learning incentives and encourage self-care and adherence to therapeutic regimens	Short follow-up period (1 year)
Chen et al., 2007	Canada	Children and adolescents 9–18 years ($n = 78$)	Asthma	Test associations of neighborhood, peer, and family factors with asthma outcomes in youth and to determine the pathways through which these social factors operate	Questionnaire	not stated	family factors may affect youth's asthma via physiological changes, whereas community factors may help shape the health behaviors of youth with asthma	Self-reported adherence → bias cross sectional study design good

(Continued on next page)

Table 2. (Continued)

Author, year	Location	Target Group	Disease	Aim	Methods	Definition Adherence	Outcome	Limitations and Overall Quality
Corsico et al., 2007	12 countries	971	asthma	Identify factors affecting changes in asthma treatment adherence in an international cohort	Follow-up study, structured clinical interviews, questionnaire logistic model used to study adjusted effect of determinants	Not stated	Doctors and nurses have a key role in educating and regularly reviewing the patients. The findings support efforts for better improvement of clinical communication	Self-reports of adherence not most accurate method Good
Desai and Oppenheimer, 2011	USA	Children and adolescents	Asthma	Shed light on the frequency and forms of nonadherence in children and adolescents, its consequences and methods to monitor medication usage	Review	The extent to which a person's behavior, taking medication, and/or executing lifestyle changes, corresponds with agreed recommendations from a healthcare provider	Adolescents and minorities appear to be at higher risk of non-adherence and increased mortality and thus require special attention and monitoring	Not a systematic literature review Medium
Edgecomb et al., 2010	UK	22 adolescents (11–18 years)	Asthma	Understand adolescents' health experiences with difficult asthma	Interviews	Not stated	Adolescents have a poor understanding of their medication and using it is often conflicted with other activities. They are very reliant on their parents.	Results may be biased through Hawthorne effect Medium
Foster et al., 2012	Australia	99 patients ages > 14	Asthma	Identify potentially modifiable beliefs and behaviors that predict electronically recorded adherence with controller therapy	Questionnaire	Not stated	Adolescents have experienced side-effects and opinions of friends/family about patient's medication use associated with poor adherence. Other influencing themes are e.g.: perceived necessity, safety concerns, effectiveness, motivation, ease of use	Good

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Table 2. (Continued)

Author, year	Location	Target Group	Disease	Aim	Methods	Definition Adherence	Outcome	Limitations and Overall Quality
Guglani et al., 2013	USA	422 urban adolescents	Asthma	Assess self-reported symptoms of depression as an effect modifier of the relationship between randomization group and controller medication adherence at 6-month follow-up	Randomized control trial	Not stated	Interventions aimed at improving medical adherence need to be tailored to for adolescents with depressive symptoms	Did not identify which component of intervention instrumental in motivating participant to be more adherent Results may not be applicable to other population Medium
Harrington et al., 2013	USA	277 parents of asthma patients 14 healthcare provider	Asthma	Assess how healthcare provider perceptions of parental health literacy influences treatment recommendations and instructions	Questionnaire	Not stated	Healthcare providers' perceptions about parents' health literacy can influence treatment recommendations and instructional practices	study may not be applicable to samples that differ demographically Medium
Irwin and Richardson, 2006	USA	general	Asthma	Highlight the importance and effectiveness of patient-focused care	Review	Not stated	Patient-focused care has shown to improve adherence to medication. Communication, continuity of care and concordance are highly relevant for effective and should be a key component in asthma management	good
Lasmar et al., 2009	Brazil	Children and adolescents with asthma	Asthma	Assess rates and factors related to Poor adherence to ICS over time in asthmatic children and adolescents	Randomized cohort study	Not stated	Adherence rates decreased over time even if the medication was provided for free. Factors related to Poorer adherence change over time. adherence has a dynamic pattern wherefore its determinants need to be re-evaluated continuously	Data collection through pharmacy records is not very accurate Medium

(Continued on next page)

Table 2. (Continued)

Author, year	Location	Target Group	Disease	Aim	Methods	Definition Adherence	Outcome	Limitations and Overall Quality
Lindsay and Heaney, 2013	UK	All ages	Asthma	Explore the facts and myths surrounding the factors driving nonadherence as well as how it can be identified and addressed	Review	The extent to which a person's behavior corresponds with agreed recommendations from a healthcare provider	Nonadherence is difficult to identify. Therefore, the assessment of non-adherence is of paramount importance in difficult asthma management.	Medium
Mäkelä et al., 2013	Scandinavia (Finland, Denmark, Sweden)	all ages adolescents specifically mentioned	Asthma and COPD	identify reasons behind non-adherence to therapies for asthma and COPD and examine evidence for correlations between the correct use of inhaler devices and improved adherence	Literature review	The extent to which patients were perceived to follow their physician's prescribing instructions/advice	Electronic assessment of medical adherence is the most accurate method.	Literature search not rigorous, search terms very limited Medium
Mancuso and Rincon, 2006	USA	175 adults with asthma Mean age 42 83% women	Asthma	Measure association between HL and asthma outcomes And assess how HL affects asthma through covariates	Questionnaire Emergency department utilization measured every 3–6 months for 2 years	Not stated	Less health literacy was associated with worse quality of life, worse physical function, and more emergency department utilization for asthma over 2 years	Selection bias Medium
Mosnaim et al., 2014	USA	Adolescents (11–16 years)	Asthma	Identify factors associated with non-adherence to daily ICS in minority adolescents	Questionnaire	Not stated	Older age and Poor ICS knowledge are both associated with poor adherence to ICS in minority adolescents.	No control group Other factors that affect adherence were not considered Poor
Munzenberger et al., 2010	USA	104 Caregiver and child (7–17 years of age) pairs	Asthma	Explores the relationship between children, caregiver, family, and asthma characteristics and responsibility for self-management activities.	Interview and chart review	Not stated	Responsibility for asthma management task is perceived differently by caregiver and children.	(Sample not generalizable) Study did not explore relationship between perceived level of responsibility and actual adherence Poor
Orrelle-Valente et al., 2008	USA	Children and adolescents (age 4–19)	Asthma	Examine [1] association between child age and extent of daily controller medication responsibility [2] role of caregiver in this [3] association between child's medication responsibility and overall adherence	Telephone survey with 351 parents	Not stated	Medication responsibility increases with age, child's age and parents race/ethnicity are significantly associated with medication adherence	Parents were asked about their children's behavior towards asthma medication responsibility and adherence. not accurate Medium

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Table 2. (Continued)

Author, year	Location	Target Group	Disease	Aim	Methods	Definition Adherence	Outcome	Limitations and Overall Quality
Petermann, 2004	Germany	All ages	Asthma	Overview of facts regarding the characteristics, costs and consequences of non-compliant behavior	Summary of main facts	Uses the word compliance: The extent to which patient's behavior corresponds with the recommendations of the healthcare provider. It is complex, dynamic and situation-dependent.	Non-compliance leads to high costs for the healthcare system. Improved doctor-patient relationship and education leads to better self-management of asthma and hence better health outcomes	Poor Based on the author's work mainly
Pettey et al., 2011	USA	835 elementary aged children (up to 15 years) and caregiver	Asthma	Described association between peer interactions and asthma related emotional experience, asthma control, and outcomes	Exploratory study (interviews)	Not stated	Providing children with communication strategies for disclosure of asthma status to peers that results in more supportive interactions may be needed	Sample predominately African American; findings not generalizable, emotional concepts and terms used were not tested for target group's level of understanding Medium No systematic review Poor
Price and Thomas, 2006	UK	Asthma guidelines	Asthma	Review the limitations of current asthma guidelines and describe important issues and remaining questions regarding asthma guidelines for use	Review	Adherence to physicians' recommendations	Country-specific or ideally local guidelines could provide more practical solutions for asthma care that influence patient choice and adherence to therapy. Those who underwent the intervention had fewer emergency department visits two years after the intervention	Selection bias Medium
Rastogi et al., 2013	USA	268 caregivers of ethnic minority children with asthma	Asthma	Assess whether educational interventions for parents decrease emergency department visits and hospitalization	Randomized Control Trial	Not stated	Family support is beneficial for improving asthma outcomes in adolescents. It ameliorated the barriers to treatment adherence	Good
Rhee et al., 2010	USA	126 adolescents (13–20 years)	Asthma	Examine the role of barriers to adherence in mediating the effect of family support in asthma outcomes	Questionnaire	Patient's range of behaviors such as taking medications [...] that align with medical and health advice to achieve optimum health outcomes.		

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Table 2. (Continued)

Author, year	Location	Target Group	Disease	Aim	Methods	Definition Adherence	Outcome	Limitations and Overall Quality
Rosas-Salazar et al., 2012	USA	Children and adults	Asthma	Raise awareness of the problem of Poor health literacy and asthma health outcomes, summarize current evidence linking health literacy and asthma, offer strategies to strengthen communication between patients and healthcare providers	Literature review	Not stated	Poor health literacy is a key barrier to asthma knowledge. Poor parental health literacy is associated with poor outcomes for their children	Methods were Not stated Medium
Shone et al., 2009	USA	Parents of children with asthma	Asthma	Examine association between parental health literacy and measures related to child asthma	Interviews	Not stated	Poor parent health literacy was independently associated with greater parent worry, parent perception of greater asthma burden and Poorer parent-reported quality of life	Selection bias (Poor HL, Poor income) Sample limited in asthma severity Medium
Stewart et al., 2011	Canada	44 mothers of children with asthma (4 – 16 years)	Asthma	Parents' intervention preferences were elicited. Based on this an online peer support group intervention was designed and piloted	Interviews (<i>N</i> = 44) Pilot intervention (<i>N</i> = 23)	Not stated	Parents prefer support interventions for children and parents in order to interpret available information and apply it in their situation.	Small sample size for pilot study Medium
Stewart et al., 2011	Canada	20 children (6–12 years) 35 caregivers	Asthma	Assess the support and education needs and preferred intervention	Semi-structured individual interviews	Not stated	Parents and children prefer a combination of in-person meetings and internet support	Good
Terpstra et al., 2012	USA	middle school youth	Asthma	Evaluation of a pilot asthma management intervention of middle school-ages youth and their adult network members (caregiver)	Randomized control trial	Not stated	Intervention increased caregivers' self-efficacy and adolescents sense of responsibility	Selection bias: only those took part who agreed to participate Differences at baseline between both groups Medium (Continued on next page)

Table 2. (Continued)

Author, year	Location	Target Group	Disease	Aim	Methods	Definition Adherence	Outcome	Limitations and Overall Quality
Tibosch et al., 2010	The Netherlands	339 Children and adolescents (6–16 years) and their caregiver	Asthma	Assess relationship between asthma related QoL and psychosocial problems	Questionnaire	Not stated	Prevalence of psychosocial problems in children and adolescents with asthma is considerable. They affect medication adherence. Assessment of asthma related QoL alone is insufficient.	Good
Ting, 2004	USA		Asthma	Use of simplified asthma tools to improve asthma care	Review	Not stated	NAEPP and GINA asthma guidelines are too complex for daily use, whereas the MSAGR is more user friendly. The findings highlight the importance of the practice environment on the implementation of national guidelines	Medium
Tumietl-Berhalter and Hershey, 2005	USA	Medical directors of 13 academic primary care sites	Asthma	Provide a descriptive account of the preparedness of academic primary care sites to follow national asthma guidelines	Cross-sectional (questionnaire)	Not stated	Lack of perceived symptoms main reason for non-adherence. reasons for suboptimal adherence seem to be accessible through education of patients and caregivers.	Limited generalizability Medium
Ulrik et al., 2006	Denmark	509 adults between 18 and 45	Asthma	Explore patient-related aspects of adherence among adult asthmatics	Online questionnaire	Non-adherence: deliberate deviation from recommended therapy. The authors differentiate between intentional and accidental non-adherence.	Selection bias: online questionnaire (selected group from a panel who replied) Poor	
Van Steenis et al., 2014	The Netherlands	93 (18–80)	Asthma	Investigate relationship between beliefs about asthma medication (ICS) and measure adherence (subjectively and objectively) and their agreement between these measures.	Questionnaire	Not stated	High necessity is associated with higher self-reported adherence	Selection bias (high educational level of participants, while among majority of Dutch asthma patients only 24.2% highly educated); only data from pharmacy used Medium

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Table 2. (Continued)

Author, year	Location	Target Group	Disease	Aim	Methods	Definition Adherence	Outcome	Limitations and Overall Quality
Wamboldt et al., 2011	USA	26 adolescents (12–20 years)	Asthma	Examine beliefs, feelings, and behaviors about inhaled asthma controller medication	Focus group interviews	Not stated	A variety of beliefs, feelings and behaviors influence decision about asthma medication use. misinformation, incorrect assumptions about their asthma and current life situations lead to poor adherence. The developmental change of social support during early adolescence need to be recognized	Selection bias (participants with high IQ and parents with high educational attainments) Good
Yang et al., 2010	UK	Young adolescents 9–14 years 86 parent-adolescent dyads	Asthma	Investigate the association between social support variables and healthy lifestyle for asthma management among early adolescents	Questionnaire	Not stated		Some omitted variables that hamper internal validity. other aspects of social support remain uninvestigated in this study such as adolescent's relationship with parents Other relevant variables missing (i.e., self-efficacy) Poor
Yawn, 2008	USA	All ages	Asthma	Reviews recent articles dealing with asthma variability, environmental factors, and co-morbidity that affect asthma control	Review	Not stated	Co-morbidities have a significant impact on asthma variability. Documenting asthma variability and adherence can lead to the development of treatments that can anticipate the level of symptoms	Poor Only one data base was used and only recent articles included.
Zebracki and Drotar, 2004	USA	77 adolescents 11–17 years and their caregivers	Asthma	Relation of outcome expectancy and perceived self-efficacy for asthma prevention and management in adolescents to asthma self-management, adherence to treatment and asthma morbidity	Questionnaire and interviews	Not stated	High outcome expectancy was associated with greater asthma morbidity but unrelated to self-management or treatment adherence. Self-efficacy was related to treatment adherence but unrelated to asthma morbidity or self-management	Self-reported adherence Correlational study, wherefore causal inferences are precluded Good/Medium

to prescribed medicine [6]. The personality traits low agreeableness, low conscientiousness and high neuroticism, meaning being reluctant, disorganized and moody, are associated with perceived concerns about asthma medication and adherence behavior [22]. However, Axelsson et al. [22] found out that medication beliefs can mediate the influencing effects of those three personality traits on adherence to treatment.

There are different types of beliefs such as concerns and necessities which influence adherence behavior. An example for concerns is fear due to side-effects or the fear to become dependent on medicine; whereas patients with high necessities believe that medication is needed for controlling their asthma; therefore, they have a higher tendency to self-reported adherence [23]. In contrast to the patients with concerns, people who believe in the effectiveness of their medicine are more likely to adhere to it. More precisely, patients with a skeptic attitude are less likely to adhere to treatment than patients with an accepting attitude who believe in the importance of medication [20, 22].

Patient perspective: Health literacy

Health literacy is defined as an “individual’s capacity to access, understand, communicate, evaluate, utilize, and make decisions based on health information” [24]. Health literacy is a key factor for good asthma management in children and adults. In contrast to this, poor health literacy poses a key barrier to obtain and apply adequate asthma knowledge [12]. Furthermore, limited health literacy is associated with a lower quality of life, poor physical functionality and increased emergency visits [11].

To improve asthma outcomes, patients need to learn how to understand and implement self-management approaches [25]. Improved asthma education is associated with effective symptom control, better self-management of the disease and better asthma control, whereas, poor understanding of treatment and its importance pose a risk to adherence [18]. Research has shown that asthma is less well controlled especially among adolescents of lower socioeconomic status and ethnic minorities [4, 26]. The main reason for this appears to be a low level of understanding health related information, low health literacy and language barrier [26]. For ethnic minorities, both older age and low asthma knowledge are associated with poor adherence [26]. The complexity of treatment regimens and the lack of comprehension of treatment benefits set a barrier to adherence and therefore create a lack of trust between patient and healthcare provider.

Patient and systemic perspective: Asthma self-management

Self-management is interlinked with adherence where “adherence refers to behavior prescribed by the doctor and self-management refers to the individual’s behavior” [27]. The concept of self-management is linked to the patient perspective as well as the systemic perspective. This is because even though it requires that the patients themselves accept their disease and its treatment and become autonomous in implementing the treatment plan, it is defined as a partnership between the patients, their healthcare provider and if needed, their caregiver.

Patients play a major role in managing their disease by receiving knowledge, confidence and feedback from skilled professionals which can be used to tailor treatment to individual needs [27].

Asthma self-management is a complex patient focused approach that requires ongoing reevaluation of symptoms due to the dynamic patterns of asthma [28,29]. The main four areas of this approach are: communication (between patient and health care provider), partnership (finding common ground on treatment), health promotion (how to stay healthy) and physical care (medication and treatment), all of which are in line with Public Health priorities [30]. A patient-focused approach is associated with improved physician performance, increased patient satisfaction, better asthma health outcomes and time and resources savings. This approach requires a detailed understanding of patients’ behaviors, beliefs, expectations and concerns. It emphasizes the need to understand the patient and their individual needs and not only the disease and enhances collaboration between patient and healthcare provider by sharing responsibility [30].

Systemic perspective: Role of health provider

The doctor-patient relationship and the patient’s level of education are decisive factors for non-adherence [31]. However, this relationship differs depending on whether an asthma specialist or a General Practitioner (GP) is consulted. In contrast to asthma specialists, GPs are more likely to have a paternalistic approach because they are inclined to limit the patients’ liberty and autonomy by not actively involving them in the treatment process [31]. Wamboldt et al. [20] found out that adolescents perceive it as beneficial when they have a good relationship to their doctor. In fact, those who did not have a good relationship were more likely to withhold information in order to avoid confrontation and to minimize the time spent with their doctors [20]. The key role of doctors is to educate and review their patients on a regular basis and to support them when needed. Moreover, they need to make an effort to establish and keep a good relationship with their patients [13]. This involves good communication, which cannot only avoid the provision of incorrect and incomplete knowledge about medication intake but also enhance adherence to medication [32].

Systemic perspective: Assessment of adherence

Assessing adherence is an ongoing and crucial process for asthma management. It is a major step in reducing exacerbations, occurrence of side-effects, hospitalization, emergency care visits, wrong treatment and avoidable healthcare costs [14]. There are several methods to measure non-adherence among asthma patients (e.g., direct, indirect, subjective or objective) all of which differ in accuracy, effort and cost [7,23]. One method is prescription records, which give a proportion of the number of inhalers used over a certain period of time. This proportion can then be compared to the recommended proportion in order to evaluate long-term use. This method, however, is unable to detect short-term behavioral changes towards adherence. A second method is inhaler weighing and dose counting, a process which can be confounded by “test

doses or dumping” by discharging medication for a “satisfactory level” [14]. In contrast to these methods, electronic measures are costly but also more objective and accurate for monitoring inhaled medication [21,33].

Societal perspective: Role of peers

The particular age group of young adolescents is going through a “developmental transition in cognition, knowledge, autonomy, identity development and peer relations,” which impacts their asthma self-management [34]. Apart from this, the social environment is an important determinant of health [35]. Social support influences human beliefs and attitudes towards their health [36]. During adolescence there are two main sources of support coming from parents and peers [37]. Peer influence has a large impact on the health behavior of young adults because they spend a vast amount of time interacting with peers [34,36]. More precisely, positive attitudes, values and behaviors of peers contribute to adolescent’s development whereas negative attitudes have an adverse effect on asthma management and predict negative asthma outcomes. Peers who are not accepting of the disease make the patients feel different and uncomfortable [34]. Studies have shown that young people diagnosed with asthma face a higher rate of rejection by peers than non-asthma patients. Social rejection in turn is associated with social stress which can result in the occurrence of asthmatic symptoms such as inflammatory responses. Therefore, peer support and peer acceptance is an important determinant for building up self-esteem, increasing positive coping and relieving social isolation [36,38]. In fact, social support has been proven to promote adherence to asthma medication [21]; whereas social barriers such as “not wanting to take medication in the presence of peers” serve as a hindering factor to medical adherence [4]

Societal perspective: Role of caregiver

The developmental stage of adolescents from becoming independent from their caregivers is a crucial stage. It includes the shift from parental control to adolescent control with regards to their disease. Along with age, the child’s responsibility towards his/her health increases simultaneously. In this stage it is very important that parents learn to give their children more autonomy in managing their asthma [39]. According to Orrell-Valente et al. [40] children at the age of 11 take on average 50% of the responsibility of their medication intake. This percentage increases to approximately 75% by the age of 15 and 100% by the age of 19. Due to these changes, a constant partnership between patient, caregiver and health provider is important for optimal health outcomes as each party has their own roles and responsibilities that change over time [41].

The most common problem of caregivers of children with asthma is their lack of understanding of the concept of asthma treatment and not acting in accordance to the symptoms. The literature review revealed that low parental health literacy is associated with increased emergency visits, missed school days and inappropriate medication use amongst children with asthma [24]. On the contrary, increasing caregivers’ asthma knowledge via educational programs has been proven to be effective in asthma management [42].

Parents, including parents of ethnic minorities [43] need guidance to interpret information, and translate it into knowledge in order to facilitate their judgment about the severity of their child’s disease in order to support the child to act in accordance to need [19, 44]. Another contributing factor to medical non-adherence is parental motivation and their belief in their child’s asthma medication [4]. Furthermore, family stability and family support in general was found to reduce adolescents’ negative attitude towards their asthma medication and their healthcare provider which has a positive effect on adherence [4,45] Among ethnic minorities, family support for integrating asthma care into adolescents’ daily routines also showed a positive effect towards medical adherence [46].

Policy Perspective: Adherence to National Asthma guidelines

The literature review also illuminated how national asthma guidelines are implemented. The Global Initiative for Asthma (GINA) is a “program to reduce asthma prevalence, morbidity, and mortality in collaboration with the World Health Organization and the National Heart, Lung, and Blood institute of the National Institutes for Health in the United States” [47]. It has developed evidence-based asthma guidelines that list common risk factors, emphasize the need to follow treatment on a regular basis, provide criteria for determining asthma severity and recommends treatment and asthma management according to asthma severity [47]. Adherence to national asthma guidelines leads to health improvements and better quality of life of asthma patients. More precisely, it leads to decreased asthma-related hospitalization and emergency care use [48]. Guidelines are important for disease diagnosis and management [49].

Putting those guidelines into practice requires the collaboration of the healthcare provider, the patient and the system [48]. In fact, the guidelines “recommend understanding patient’s knowledge, beliefs, and concerns, increasing patient involvement and providing information” for better asthma outcomes [32]. However, these guidelines are frequently not followed by physicians. The reasons for it are “lack of awareness, lack of familiarity, lack of agreement, lack of self-efficacy, lack of outcome expectancy, inertia of previous practice, [and] time limitations” [48]. Other barriers which hinder the incorporation of these guidelines into practice are lack of equipment and complexity of their applicability in real life. Physicians claim that the guidelines are disease-oriented rather than patient-oriented and that patient variations and heterogeneity of asthma is not always taken into account [48,49].

Discussion

The findings of this literature review reveal that multiple perspectives and factors affect adherence and one single factor cannot fully explain the reasons behind non-adherence to asthma treatment [9]. However, before going in-depth into the identified factors, it is noteworthy to mention that among recent literature, the term compliance has been replaced by the term adherence because the term compliance is being associated with patients being subordinated to medical advice. In contrast to this, adherence is thought to be more accurate in reflecting and acknowledging a patient’s right to decide whether they want to follow treatment or not [7,14]. It supports the concept of a partnership between patient and healthcare provider. This

standpoint is in line with the identified enabling and hindering factors in this review.

More precisely, it is suggested that a partnership on eye-level between patient and healthcare provider and a more patient-focused approach needs to be strengthened in order to establish a link between adherence to asthma treatment and self-management [27]. However, there are barriers to this approach which need to be considered. One of these barriers is that although patients are able to monitor their asthma, their assessment is mostly unreliable because they commonly underestimate the severity of their disease, leading to false management. Moreover, they are unable to detect changes and adjust treatment accordingly due to inadequate supervision, assistance and asthma education [50].

This barrier can be linked to the identified role of health literacy regarding adherence to asthma treatment. The review revealed, that the wrong beliefs of most patients regarding their ability to control their asthma in accordance to their symptoms and severity of disease, outlines a mismatch of individual perception and needed control of asthma, which implies the need for more education and support for young patients [8]. Health literacy has been identified as a crucial factor for adolescents' adherence behavior; however, the extent of its importance is unknown. In fact, McQuaid et al. [3] found out that even though children's knowledge about asthma increases with age, their medication adherence decreases. This implies that the interaction with other enabling and hindering factors needs to be analyzed in order to figure out the complex reasons behind non-adherence.

Other inferences regarding adherence to asthma treatment show that positive medication beliefs can serve as a mediator to overcome personality traits such as skepticism, intolerance and reluctance, which hinder adherence [22]. Furthermore, removing concerns and emphasizing the need for medication can help to foster adherence whereby one can suggest that it would be more effective to focus on strengthening necessities rather than diminishing concerns in order to improve adherence [23]. Social support from caregivers and peers has also been identified as an important factor that has the ability to enhance adherence to treatment [4].

This literature review also shows that it is crucial to target young adolescents in particular because the developmental and behavioral challenges during this transition period from child to adult have a major impact on effective self-management of asthma [28]. The risk taking and impulsive nature of adolescents, their susceptibility to peer influence, fear of embarrassment, rebellion or their wish for independence from their caregivers comes in the way of making reasoned health choices which can result in non-adherent behavior [20,33]. This emphasizes that caregivers as well as health providers need to consider the special needs of adolescents in order to tackle non-adherence to asthma treatment among this age group.

However, one must also consider that there are no simple tools available to measure adherence and most tools are either inaccurate, biased or costly making it more problematic to approach the problem. Measures such as the peak flow meter can easily be practiced at home; however, the peak flow meter is not as frequently used by patients as reported [51]. Furthermore, the reluctance of patients in this age group to admit non-adherent behavior is a complex contributory factor as well,

which makes it difficult to assess adherence [21]. Above it all, the dynamic patterns of asthma require ongoing assessment and re-evaluation of symptoms and adjustment of treatment in accordance [28,29].

To date, different types of interventions have been effective in improving adherence to asthma treatment. On the one hand, an easy and effective intervention on how healthcare provider can improve their patients' adherence behavior is to monitor adherence at each visit, simplify the asthma medication regimen by minimizing the number of medications and the frequency of their doses and most importantly, making sure the patient understands the given asthma information regarding their asthma severity and the importance of following their treatment as prescribed. Furthermore, understanding the patients' needs in order to tackle non-adherence and tailoring treatments to their lifestyles and acceptability by developing with the patient an individualized asthma action plan [4,27]. Moreover, it is beneficial to have the same healthcare provider over a long period of time [4]. On the other hand, a more difficult but also effective intervention strategy is the provision of asthma knowledge and the provision of asthma self-management classes delivered by young asthma patients themselves [52]. Regarding the barrier of forgetfulness, Axelson [6] recommends reminder messages or inhalers equipped with reminder functionality.

In spite of efforts to design the literature review as rigorous as possible following the PRISMA guidelines [53] it has some limitations. One limitation is that due to the use of the MEDLINE database (subset of PubMed) in addition to PubMed, the number of duplicates was quite high in the search results. The duplicates however, did not affect the results of this review. Another limitation was that the authors did not use standardized forms for data collection. Furthermore, for three eligible abstracts, the corresponding full articles were not accessible. Three additional articles had to be excluded due to language criteria and some others had to be excluded because of their focus on other age groups. Another limitation is that not all included articles target adolescents only. Some included articles target larger age groups in which adolescents are included. One last limitation of this study is that the included articles were not assessed for the risk of bias. Regarding the overview in Figure 2, a limitation is that some articles could have been clustered to several perspectives and factors but the authors chose to place them to the most fitting factor only.

Conclusion

The literature review revealed that there is no typical non-adherent behavior for adolescents. Nevertheless, nine enabling and hindering factors were identified that influence adherence to asthma treatment among adolescents. The factors include behavior, belief, self-management, health literacy, role of health provider, assessment of adherence, role of caregiver, role of peers and the national asthma guidelines. Whereas the importance of behavior, beliefs and self-management were well-described in the literature, it becomes apparent that the role of health literacy of adolescents as well as of caregivers and the importance of a well-balanced doctor-patient relationship regarding adherence to asthma treatment among adolescents need to be researched further. Therefore, this study implies that

further research needs to focus on a multidimensional approach that includes the patient, systemic, societal and political perspectives with its underlying factors in order to enhance the success of adherence to asthma treatment among adolescents.

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