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*ASTHMA CARE FOR
CHILDREN AND ADOLESCENTS*

Marina Jonsson



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Asthma care for children and adolescents
THESIS FOR DOCTORAL DEGREE (Ph.D.)

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Att finna en människa

Om jag vill lyckas med att föra en människa
mot ett bestämt mål, måste jag först finna
henne där hon är och börja just där

(Søren Kierkegaard)

ABSTRACT

Background: Asthma is one of the most common chronic diseases among young children and adolescents. With high quality health care, most children and adolescents with asthma can live an active and normal life. Yet, many children and adolescents have uncontrolled asthma, with symptoms and exacerbations which may affect their daily life. Adolescence is a sensitive period and asthma may be difficult to treat due to poor adherence to treatment. Little is known about health care professionals' adherence to asthma guidelines and the patient experience of living with a chronic disease like asthma.

Aim: The overall aim of this thesis was to evaluate health care professionals' adherence to national guidelines in asthma care and to explore consequences of living with a chronic disease like asthma.

Methods: Both quantitative and qualitative methods were used. In study I, medical records in Primary health care centres on children with asthma (0-16 years) (n = 424) were scrutinized based on quality indicators stated in national guidelines. In study II health related quality of life (HRQoL) was measured with the generic instrument EQ-5D and the study population consisted of 2,946 adolescents with and without asthma. They were recruited from the population based birth cohort BAMSE. Shared and individual experiences of daily living with asthma were explored through four focus group interviews (study III) among parents of children with asthma and adolescents with asthma and ten individual interviews (study IV) among adolescents with asthma.

Results: Study I showed that non-pharmacological treatment, such demonstration on inhalation technique, was less common (14%) than pharmacological treatment (58%). Documentation on tobacco smoke exposure showed low levels (14%). Spirometry tests were conducted in 14 % and at higher frequencies if there was access to an asthma nurse ($P=0.003$). Having asthma was shown to impair HRQoL (study II). Adolescents with asthma reported more pain and discomfort ($P< 0.001$) and a lower median EQ VAS than adolescents without asthma (85 vs 90, $P=0.002$), a finding which was still independent when adjusted for confounders. Adolescents with asthma reported impact on physical activities (study II and IV). Those adolescents with partly controlled or uncontrolled asthma reported lower median EQ VAS scores than those with controlled asthma (85 vs 90, $P=0.04$ and 70 vs 90, $P=0.003$). In study III, parents of children with asthma expressed frustration and a lack of knowledge of how to take care of their children. Adolescents with asthma developed their own strategies to manage their asthma (study III). Furthermore they reported struggles with ambivalence (study IV) between understanding and denial, confirmed but not defined by asthma, healthy but with asthma symptoms. Both parents and adolescents wanted to be met with understanding and competence.

Conclusion: There is a gap between the care provided for pediatric asthma at PHCs and the recommendations in national guidelines. Asthma during adolescence impairs HRQoL, with development of own strategies of self-management and several struggles of ambivalence between self-management and social interactions. Being a parent to a child with asthma entailed frustration and lack of knowledge. There is a need to be met with understanding and competence by health care professionals. These results support that asthma care need to be improved both in a nursing perspective and in a medical perspective.

LIST OF SCIENTIFIC PAPERS

This thesis is based on the following four papers, which will be referred to in the text using roman numerals.

- I. Jonsson M, Egmar A-C, Kiessling A, Ingemansson M, Hedlin G, Krakau I, Kull I. Adherence to national guidelines for children with asthma at primary health centres in Sweden: potential for improvement. *Prim Care Respir J* 2012; 21(3): 276-282
- II. Jonsson M, Bergström A, Egmar A-C, Hedlin G, Lind T, Kull I. Asthma during adolescence impairs health-related quality of life. *J Allergy Clin Immunol Pract.* 2015 Sep 2.
- III. Jonsson M, Egmar A-C, Hallner E, Kull I. Experiences of living with asthma – a focus group study with adolescents and parents of children with asthma. *J Asthma.* 2014 Mar;51(2):185-92
- IV. Jonsson M, Schuster M, Protudjer J P, Bergström A, Egmar A-C, Kull I. Perceptions of daily life amongst adolescents with asthma: the struggle with ambivalence (Submitted).

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LIST OF ABBREVIATIONS

ACT	Asthma control test
ACQ	Asthma control questionnaire
BAMSE	Barn Allergi Miljö Stocholm Epidemiologi
COPD	Chronic obstructive pulmonary disease
EIB	Exercise induced bronchoconstriction
ETS	Environmental tobacco exposure
FEV ₁	Forced expiratory volume in one second
GP	General practitioner
GINA	Global Initiative for Asthma
HRQoL	Health-related quality of life
ICS	Inhaled corticosteroids
IgE	Immunoglobulin E
SABA	Short-acting β -agonist
STC	Systematic text condensation
PAQLQ	Pediatric asthma quality of life questionnaire
PEF	Peak expiratory flow
PHC	Primary health care centres
VAS	Visual analog scale

PREFACE

I have worked as a pediatric nurse with children and adolescents with asthma since 1990 and have learned a lot from them and their families. I have always been interested in the meeting with the patients. Each meeting is unique because you constantly encounter people with experiences from different cultures and social situations. I have been curious about what these patients had to tell me: what had happened since we met last and how I could help. I have also seen that patients living with asthma are affected physically, psychologically and socially by their disease.

In my master's thesis I have studied the interplay between nurses and patients from a nursing perspective. The results inspired me to go on and study asthma from a patient perspective: how children and adolescents experience their illness, how they feel and also how health care professionals take care of children with an asthma diagnosis.

I have learned a lot while working with this dissertation, both in terms of knowledge and as personal growth. Additionally, I hope this thesis will provide increased knowledge and understanding of what it is like to live with asthma. Hopefully, the results will lead to children and young people being given care according to their symptoms, possibilities and needs.

1 INTRODUCTION

Asthma is one of the most common chronic diseases among young children and adolescents (1). In Sweden, 8–10 % of children and young people have asthma (2). Most children and adolescents with asthma are treated in primary care or child outpatient clinics.

The goal of asthma treatment is that every individual, in so far as possible, should live without symptoms and exacerbations (3). To achieve this goal, children and adolescents with asthma need support to manage their disease (3, 4). With high quality health care, most children and adolescents with asthma can live an active and normal life (5). However, many have asthma that is uncontrolled in regards to both symptoms and exacerbations (6, 7). Having uncontrolled asthma can have severe implications for daily life such as missed school days and working days for parents, as well as impaired Health-Related Quality of Life (HRQoL) (3, 4, 6, 8).

Adolescence is a sensitive period in life and having a chronic disease such as asthma could mean additional stress and challenges, beyond those of the normal development, which could affect both health and wellbeing (9-11). Moreover, it is known that asthma can be particularly difficult to manage in adolescents due to poor symptom control and low adherence to treatment (10, 12).

Pharmacological treatment is an important part of asthma care and many children and adolescents are prescribed asthma medication to use on regular basis (3). However, asthma management goes far beyond pharmacological treatment (13-15). Both children and adolescents with asthma must deal with environmental, psychological, physiological and social factors which may affect their daily lives and may be a part of patient education on self-management (16).

International guidelines on asthma management point out that asthma control is considered the goal of management (3). Therefore, patients' burden of asthma cannot be assessed only as disease severity; this also requires measurements of personal perception such as impact on everyday life, emotional functioning and HRQoL.

2 BACKGROUND

2.1 ASTHMA

Asthma is the most common non-communicable chronic disease among children and adolescents (1) and is a heterogeneous disease characterized by chronic airway inflammation. It is defined by a history of respiratory symptoms such as wheeze, shortness of breath, cough and chest tightness that vary over time and in intensity together with variable expiratory airflow limitation (3). The fact that symptoms are associated with variable airway obstruction is now highlighted in the Global Initiative for Asthma (GINA) guidelines (3) and shows that the new definition of asthma has taken the heterogeneity into account opening up for a more individual treatment strategy (17). Asthma disease can start at any age, but the first symptoms often occur during childhood (18). Asthma during childhood and adolescence often coexists with allergy and other allergy related diseases (19, 20).

2.2 ASTHMA MANAGEMENT

Treatment of asthma is aimed at achieving good control of symptoms, no exacerbations and maintaining normal activity levels (3). Maintaining normal activity levels is particularly important in children because engaging in play is vital to their normal social and physical development. Lung function should be normal, with no or minimal side effects of medication. Asthma management also includes patient education and support of self-management.

2.2.1 Asthma control

Asthma control means the extent to which the manifestations of asthma are controlled, with or without treatment (21). The definition from GINA (3) is widely used in both clinical settings and researchers contexts. Based on a patient's characteristics, GINA classifies asthma as controlled, partly controlled and uncontrolled.

GINA guidelines (3) include two domains for assessment: to achieve symptom control and to minimize the future risk of adverse outcomes. Assessing symptom control involves reducing day-time and night-time symptoms, reducing limitations in daytime activities and the need for reliever treatment. Factors that are associated with an increased risk of adverse events in the future include the risk of exacerbations, i.e., uncontrolled asthma, reduced lung function ($Fev1 < 80\%$ partly controlled, $< 60\%$ uncontrolled of predicted) (22), major psychological or socioeconomic problems, exposure to smoke, allergen exposure if sensitized, comorbidities, inadequate use of inhaled corticosteroids (ICS), poor adherence or incorrect inhalation technique.

Many studies describe discordance between patients' and health care professionals' assessments of the level of asthma control (21). One reason could be that patients and health care professionals interpret the word 'control' differently (21). Nurses have a central role in identifying patients at risk and the opportunity to provide enhanced care and education to achieve asthma control (23). There are various tools for monitoring and assessing asthma

control in the clinic (24). One is use of validated questionnaires, such as Asthma Control Test (ACT) or Asthma Control Questionnaire (ACQ) (25-29).

2.2.2 Pharmacological treatment

The foundation of asthma treatment is pharmacological treatment. With proper medication and a correct inhalation technique, most people with asthma can reach the goal of asthma treatment (30). Treatment intensity is determined by the degree of asthma control, where the medication should be used in different stages depending on the degree of symptoms. The medication ranges from only a short-acting β 2-agonist as needed up to regular treatment with a leukotriene antagonist or/and inhaled corticosteroids and a long-acting β 2-agonist (31). If control is not achieved with the conventional therapy, other medications could be supplemented such as oral corticosteroids, anti-IgE therapy or Theophylline (31).

2.2.3 Non-pharmacological treatment

The second part of asthma care is non-pharmacological treatment. It involves education and support of self-management based on the individual's needs: information about the disease, cessation of smoking and environmental tobacco smoke exposure (ETS), promotion of physical activities, avoidance of trigger factors, demonstration on inhalation technique and discussions about emotional and psychological aspects of the disease (32). To provide asthma care, collaboration within a team with the patient is essential, e.g., inter-professional collaboration (involving a physician and a nurse and a psychologist, dietician or physiotherapist when needed) (33).

Both national and international guidelines highlight patient education and support of self-management of asthma (3). The purpose of patient education is to strengthen and support the patient, so that he or she can control their disease and manage their daily life. Effective asthma management requires a partnership with the patient and/or parents, with a high level of agreement regarding the goals of treatment. It is also important to take a patient's own goals into account, as these may differ from conventional medical goals (3, 34).

Studies have shown that educational programs for self-management of asthma in children and adolescents could improve lung function, feelings of self-control and asthma control (35). Education programs can also reduce absenteeism from school, number of days with restricted activity, number of visits to an emergency department, and possibly number of disturbed nights (36-38). It has also been shown that self-management programs improve asthma knowledge among school-age children with asthma (39). It is recommended that all people with asthma and/or their parents be offered self-management education which should include a written personalized asthma action plan and be supported by regular visits (35, 40, 41).

Education should be tailored to the individual and his/her culture and beliefs (34). Person-centered care states that a patient is a person and should not be reduced to a disease, but rather that their subjectivity, their strengths, their future plans and their rights should be taken into account (42). In person-centered care, the health care professional focuses on knowing

the person behind the patient in order to engage the person as an active partner (43). Co-creation of care between patients, family and health professionals is the core component of person-centered care, a concept that is becoming widely used (44, 45).

2.3 ADHERENCE TO GUIDELINES

International evidence-based guidelines concerning children and adults with asthma (GINA guidelines) were formulated more than a decade ago and are updated continuously (3). The goal for asthma treatment is that every individual, in so far as possible, should live without symptoms and exacerbations (3, 33). To achieve this goal, children and adolescents with asthma need support in managing their disease (3, 4, 33). Both national and international studies have shown that patients with asthma are not optimally treated (4, 6, 46-48). In primary care, adherence to guidelines has been reported to be poor in adults with asthma (46, 49-51). However, the recommended care and the care actually provided do not always coincide (52, 53). Although 60-80 % of children over six years with asthma had a chronic allergic inflammation in the airways, half of them were treated with only β 2-agonists in monotherapy (54). This does not adhere to the guidelines, which recommend combining β 2-agonists with inhaled steroids or leukotriene antagonists in most cases (17). Evidence-based recommendations need to be presented in a way that is both accessible and relevant to clinicians and integrated into strategies that are feasible for health professionals to use in clinical practice (55). The GINA report (3) therefore now focus not only on the existing strong evidence base about *which* treatment should be recommended, but also on clinical tools (evidence-based where possible) for *how* this can be done in clinical practice (3).

In Sweden, updated national guidelines for asthma and COPD (chronic obstructive pulmonary disease) have recently been published (33). This updated version highlights central areas in asthma care such as; diagnostics, inter-professional collaboration, pharmacological treatment, smoking cessation, education and self-management, follow-ups for monitoring and symptom control.

2.4 HEALTH-RELATED QUALITY OF LIFE (HRQOL)

The most widely adopted definition of health is the WHO definition (1948): “*a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity.*” Subjective wellbeing refers to self-reported or experienced wellbeing and characterizes a person’s evaluation of his/her life, encompassing cognitive and affective components, such as life satisfaction, positive feelings and low negative feelings (56). HRQoL is a concept that covers an individual’s well-being in relation to the physical, emotional and social aspects of health (57).

For collecting information about a patient’s own perceived health, a validated questionnaire relating to HRQoL can be used. HRQoL can be measured through two approaches, using a generic or a disease-specific instrument (58).

A generic instrument makes it possible to compare results across different patient groups or against populations (59) and also to find non-organ-specific effects of asthma. This is important, especially since asthma is a systemic disease. With generic instruments there tends to be a risk of ceiling effect, i.e., that individuals report full health and some health problems are not detected by the instrument (57). EQ-5D is a generic instrument, applicable to a wide range of health conditions and treatment and can be used in both healthy and chronically ill subjects (59). Further, EQ-5D emphasizes both simplicity and many aspects of health; it takes about two minutes to complete, but aims to capture physical, mental and social functioning (58, 60, 61).

A disease-specific instrument addresses specific patient populations. Juniper Pediatric Asthma Quality of Life Questionnaire (PAQLQ) is one example of a validated disease-specific instrument applicable to children (7-17 years) with asthma (62).

From BAMSE, we have previously shown that asthma is associated with impaired HRQoL in early school age, using information reported by parents through the EQ-5D instrument (63). However, it has also been reported that children's and parents' reports of symptoms of allergic diseases sometimes differ (64) and since HRQoL is subjectively perceived, the best source of information is the individual itself.

2.5 LIVING WITH ASTHMA IN CHILDHOOD AND ADOLESCENCE

Asthma affects both physical and emotional aspects in a child's life and is also a common reason for child emergency visits and absence from school (65). The physiological aspects of being a child with asthma involve fear of exacerbations, anxiety and tiredness following asthma symptoms (66). Further, adolescents' and parents' perceptions of asthma and asthma management reflect a wide variety of beliefs, affecting disease-related behavior and emotional perceptions (67).

Having a child with asthma has impact on daily life for the whole family. Parents, especially mothers have reported experienced difficulties in helping their children with asthma to adapt to their illness and the issues they face in society, for example school life (68). Many parents are worried about side effects of the medicines that their child uses (69, 70). There can also be differences between fathers' and mothers' experiences of having a child with asthma, where fathers sometimes are more hopeful in regards to the child's future, while mothers feel guilt and blame themselves for failing to pay attention to their child (71).

Parents and health care professionals may have different perceptions and beliefs of what is important in treating asthma and achieving wellbeing (70, 72-75). Parents may feel that professionals proceed with health care without taking their opinions into consideration (75, 76).

Adolescents with asthma can have particular needs that differ from those of children or adults with asthma (77). Adolescence is regarded as a critical time in asthma management (78), as morbidity and mortality, as well as non-adherence, appear to be high among adolescents

(79). During adolescence, the young person gradually develops independence from his or her parents, and the peer group becomes increasingly important (14). Having a chronic disease like asthma during this sensitive period in life may add stress and challenges beyond those associated with normal development, and may affect both health and well-being (9-11). Most young people with asthma have a healthy self-image and engage in the same risky activities as their peers, such as smoking (14). Family support around the adolescents is important and family routines and effective problem-solving within families can promote better adherence to asthma treatment (80).

2.6 DEVELOPMENT CHANGES IN ADOLESCENCE

Adolescence is a time in which young people undergo a transformation from childhood to adulthood. This is accompanied by dramatic growth and changes in biologic, emotional, cognitive and social domains and also significant changes in cognitive development as well as relationships with family and peers (11). Closely related to peer relations is the adolescent's search for an identity (81). To achieve an identity, adolescents must assess their strengths and weaknesses and determine how to deal with them (9).

Adolescent thinking is different from that of children (9). Unlike children, who can only evaluate one aspect of a situation at a time, adolescents can consider multiple elements simultaneously and systematically. They can integrate diverse components of a situation in order to make decisions. Another skill is that adolescents have the ability to think abstractly and logically (82). Adolescents are also able to think about the future, whereas children only think in the present (11).

2.7 PHYSICAL ACTIVITY AND ASTHMA

Physical activity is essential for long-term and short-term physical and mental health outcomes and may improve academic performance and cognitive abilities (83). Good physical activity habits established in youth are likely to be carried through into adulthood while lower physical activity in adolescence will often continue, especially in males (84, 85). A major trigger for asthma symptoms is exercise, which can lead to exercise-induced bronchoconstriction (EIB) (86). This can lead to children and adolescents restricting their physical activity because of asthma (87-89). EIB may be improved by training, particularly when EIB symptoms are more prevalent or severe (86). Further, physical exercise is safe and can be recommended in almost all children with asthma (86).

2.8 QUANTITATIVE AND QUALITATIVE STUDIES

Both quantitative and qualitative methods are useful in medical research. Which method we used depends on our research questions. Below, differences between the two approaches are presented (Table 1) (90, 91).

Table 1. Differences between quantitative and qualitative methods

Criteria	Quantitative research	Qualitative Research
Research question	Whether? How much?	Why? How? What?
Purpose	Seeks explanations and predictions to develop generalizations	Seeks a better understanding or explanations of complex situations
Participants	Random or consecutive sampling Large numbers of subjects to satisfy the sample size calculations	Purposeful and frequently consecutive sampling Limited number of participants with different responses to capture variation of experiences
Methods and tools	Inclusion/exclusion criteria Ex: Randomized clinical trials, pre- and post-evaluations, observational studies and quasi-experimental trials Strict protocols and standardized questionnaires with established reliability and validity	Inclusion/exclusion criteria Ex: Individual or focus group interviews Semi-structured open-ended questions with permissive stems
Data analyses	Statistical analyses , objectivity	Searching for themes and categories, subjectivity
Findings	Numbers, statistic, aggregated data	Words, narratives, quotes

In both qualitative and quantitative methods, the goal is knowledge development in science which is accessed through systematic critical reflection (92). Three points summarize the basic conditions for both qualitative and quantitative research, *reflexity*, *relevance* and *validity*. *Reflexity* is about the researcher’s assumptions and interpretation frames. *Relevance* is based on what the knowledge can be used for. *Validity* refers to measuring what we intend to measure and the context in which our results are valid (91, 92). In quantitative studies it is also important to consider *reliability*: an instrument has to be reliable, i.e., a measurement should yield reproducible and consistent results (58).

2.9 QUANTITATIVE STUDIES

Quantitative methods are the systematic empirical investigation of observable phenomena via statistical, mathematical or computational techniques (91). The objective of quantitative research is to develop and employ mathematical models, theories and/or hypotheses relating to phenomena. Data may be collected through questionnaires, experiments or registers. Reducing bias is important, including construction of questions, research design, control groups and robust statistical techniques with their own requirements on data collection (93).

2.10 QUALITATIVE STUDIES

Qualitative methods aim to improve our understanding of different medical issues (94). They can be used to explore people’s experiences, interactions or attitudes. The most common way to collect data is through interviews, either individual interviews or focus group interviews

(90). There are various methods for analyzing qualitative data, depending on purpose and research questions. The most common methods are presented in Table 2 (92, 95-97).

Table 2. Common qualitative methods

Phenomenology	<p>To describe the "lived experience" of a phenomenon.</p> <p>What is the meaning, structure and essence of the lived experiences?</p> <p>The researcher tries to gain access to an individual's life world, i.e., their world of experiences, which is where consciousness exists.</p>
Grounded Theory	<p>The development of inductive "bottom-up" theory that is grounded directly in the empirical data.</p> <p>Each new individual observation is compared with existing data to identify similarities and differences.</p> <p>This approach will provide knowledge about a culture or group by speaking with informants or members of the culture or group.</p>
Content Analyses	<p>A systematic and objective way of describing and interpreting a phenomenon.</p> <p>A method for summarizing any form of content by counting various aspects of the content, both manifest and latent.</p>
Systematic Text Condensation (STC)	<p>A descriptive and explorative method for thematic cross-case analysis.</p> <p>The goal of STC is to present vital examples from people's everyday life experiences.</p>

2.10.1 Focus group interviews

Participants in a focus group have something in common, for example experiences of living with a chronic disease or demographic factors (e.g., age, sex, and ethnicity). This homogeneity promotes a sense of commonality that results in the sharing of insights (92, 98). Focus groups usually consist of five to eight informants who speak with each other for one to two hours under the direction of a moderator and an observer, who take notes and observe the interaction in the group (92). The moderator should ensure that all participants have had a chance to speak and follows the group dynamic process (99). Interaction between the participants is an integral part of the data collection process and aims to get a broader perspective of what it is like to live with a chronic disease such as asthma, through the participants expressing their views while listening to others (100).

2.10.2 Individual interviews with a phenomenological approach

Individual interviews can be useful when you want a deeper understanding of a phenomenon such as the experience of living with a chronic disease. Knowledge should be obtained from the informant's experiences and his/her own version of his/her story (92). The interview should have a descriptive orientation, as we strive to get the richest descriptions possible, where the participants' own words create images (92). In the interview situation, the interviewer should be as open as possible and sensitive to the respondent's story as well as focused on the purpose, so the phenomenon can be illuminated (95, 101).

Phenomenology is a philosophy of consciousness, as we cannot experience without consciousness (95). With a phenomenological approach, interviews should enable the experiences that are anchored in the participant's life world, i.e., the life experiences, as it looks for the person who lives in it (daily life, memories and expectations about the future) (95). To a certain extent, capturing the "life-world perspective" is part of all qualitative research approaches more or less, and STC is, according to Malterud, inspired by the phenomenological approach (92). The phenomenological approach looks at objects from the perspective of how they are experienced and searches for the essence of a phenomenon (102). Phenomenology attempts to avoid interpretations of experiences and therefore it is important to bracket preconceptions (although this is impossible to achieve fully).

3 GENERAL AND SPECIFIC AIMS

3.1 OVERALL AIM

The overall aim of this thesis was to evaluate health care professional adherence to national guidelines in asthma care and to explore consequences of living with a chronic disease like asthma.

The specific aims of this thesis were:

- To evaluate health care professionals' adherence to national guidelines for primary care management of children with asthma (study I)
- To examine Health-Related Quality of Life (HRQoL) among adolescents in relation to asthma and to investigate if the level of asthma control affects HRQoL (study II)
- To describe experiences of living with asthma among parents of young children with asthma (study III)
- To describe experiences of living with asthma among adolescents (studies III and IV)

4 METHOD AND PARTICIPANTS

4.1 STUDY DESIGN

This thesis used both quantitative and qualitative methods (Table 3). All studies were conducted in the Stockholm region.

Table 3. Overview of participants, data collection and data analyses in the thesis

Study design	Study focus	Participants and settings	Data collection	Data analyses
Study I Quantitative	Examine adherence to national guidelines	Health care professionals in Primary health care centres	Scrutinizing medical records on children with asthma, cough/obstructive bronchitis	Comparison of proportion and adjusting for clustering within PHC
Study II Quantitative	Examine health-related quality of life in relation to asthma	Adolescents with and without asthma Conducted within a population-based birth cohort	Questionnaire EQ-5D instrument	One-sample <i>t</i> -test with a finite population correction Chi ² test Mann-Whitney test Quantile regression
Study III Qualitative	Shared experiences of living with asthma	Parents of children with asthma and adolescents with asthma Conducted in a Child Outpatient Clinic	Focus group interviews	Systematic Text Condensation
Study IV Qualitative	Individual perceptions of daily life with asthma	Adolescents with asthma Conducted within a population-based birth cohort	Individual interviews	Systematic Text Condensation

4.2 THE QUANTITATIVE STUDIES (STUDIES I AND II)

4.3 EXAMINE ADHERENCE TO NATIONAL GUIDELINES (STUDY I)

4.3.1 Participants and settings

Study I was a cross-sectional survey including 18 Primary health care centres (PHC) in Stockholm (Figure 1). In total, 18 PHC were included, four in 2006 and 14 in 2007. This

gave a total of 647 medical records of children 0-16 years old with asthma or cough/obstructive bronchitis. Children with the diagnosis of cough or obstructive bronchitis who didn't fulfill the evidence criteria for asthma (n = 223) were excluded and the final study population included 424 children with asthma.

The asthma definition was fulfilled if the children had:

1. A diagnosis of asthma in the medical record (ISD-10 code J45) or
2. A diagnosis of obstructive bronchitis in the medical record (ISD-10 code J22) or cough (ISD-10 code R09) but fulfilling the evidence-based criteria for a diagnosis of asthma (103): a) Three or more obstructive symptom periods before age 2 or b) one obstructive period after age 2 or c) one obstructive disorder period regardless of age, if the child had eczema, food allergy, other allergy or if the child did not fully recover when the infection ended.

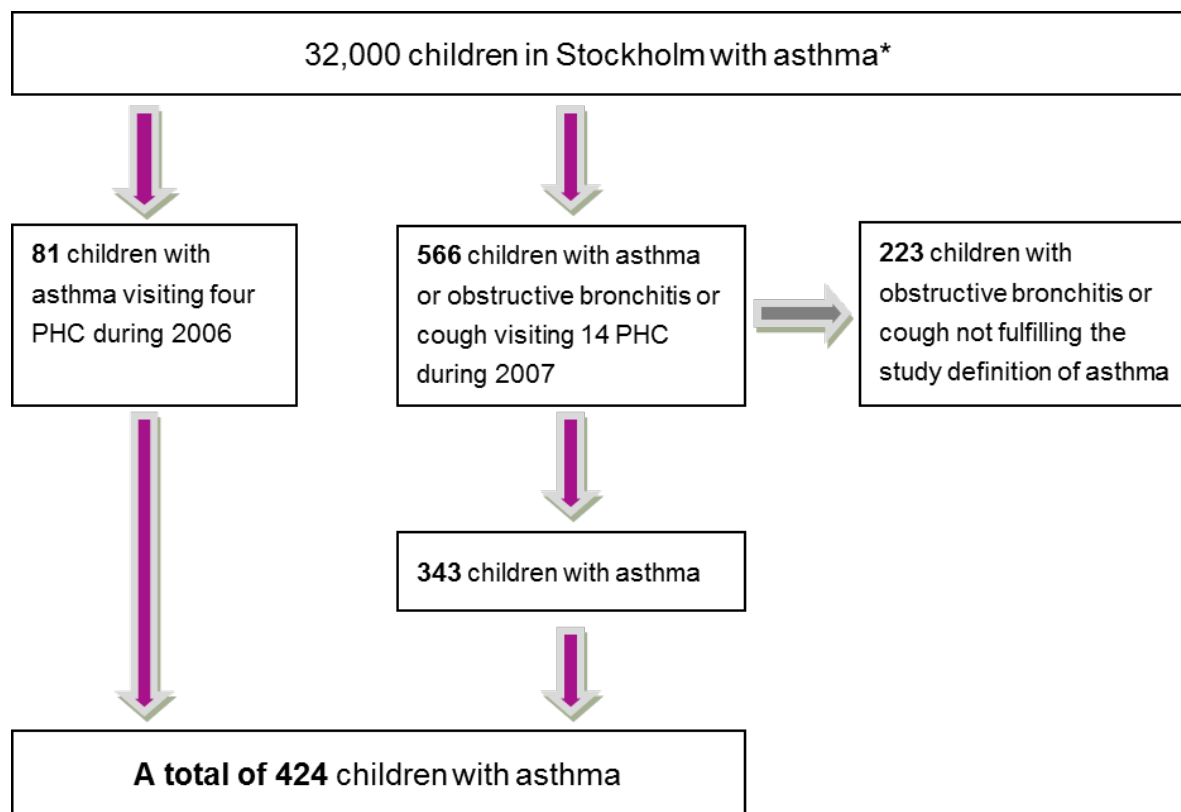


Figure 1. Trial profile: patient selection, inclusion and final study population.

*Children's health and environment in Stockholm County Centre for Public Health ISBN: 91-631-9023-0, (2006).

4.3.2 Data collection

Children with asthma and/or cough or obstructive bronchitis were randomly selected from diagnostic lists and divided into four groups based on age (0-4 years, 5-8 years, 9-12 years and 13-16 years old). The medical records for the included children were scrutinized by two nurses, both in full and with a focus on the last 12 months regarding quality indicators:

Full records: Information on patient history (including tobacco exposure), clinical examination, and non-pharmacological treatment. Allergic co-morbidity, performed PEF and spirometry “ever” were measured from the medical records just in 2007.

Records of the last 12 months: Information about clinical examination, tobacco exposure, pharmacological and non-pharmacological treatment and if the child had a planned follow-up.

4.3.3 Statistical analyses

All statistical analyses were performed with Stata Statistical Software (release 11.0, College Station, TX, USA). Quality was assessed on the basis of indicators of structure, process, and result, in the prioritized areas proposed in the national guidelines (2004) for care of childhood asthma (103). The proportions of prioritized actions based on the quality indicators were presented for the total study population and for three subgroups:

1. Access to a specialised asthma nurse
2. Initial prescription of inhaled corticosteroids in primary care
3. Regular treatment with inhaled steroids

Information concerning regular treatment with inhaled corticosteroids was only extracted from the medical records from 2007. Statistical values, such as proportions and measures of dispersion, were computed using standard parametric procedures.

The variables in the subgroups were examined from a cluster sample of 18 PHC units. The proportions were calculated and tested in accordance with differences in means for the two independent samples adjusted for clustering using the Huber-White sandwich estimator (104, 105). This statistical method adjusts for the estimate of the variance that depends on observations being more similar within a PHC (due to decisions, culture and priorities) than they would be in a random sample of individuals.

4.4 HEALTH-RELATED QUALITY OF LIFE IN RELATION TO ASTHMA (STUDY II)

Self-reported HRQoL was obtained using the generic instrument EQ-5D-3L (60, 106).

The EQ-5D captures the respondent’s current health status and consists of:

1. A descriptive system investigating five dimensions of mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. There are three levels (3L) of severity per dimension: no problems, some problems, and extreme problems.

2. A standard visual analogue scale (EQ VAS) where the respondent's self-rated health on a 20 cm vertical, visual analogue scale with endpoints labelled 'the best health you can imagine' and 'the worst health you can imagine'. The scale consists of an 11 cm line where each tenth was labelled 0, 10, 20, ..., 100, where 100 represented the best health and 0 the worst health.

EQ-5D was measured in relation to different phenotypes of asthma (Figure 2):

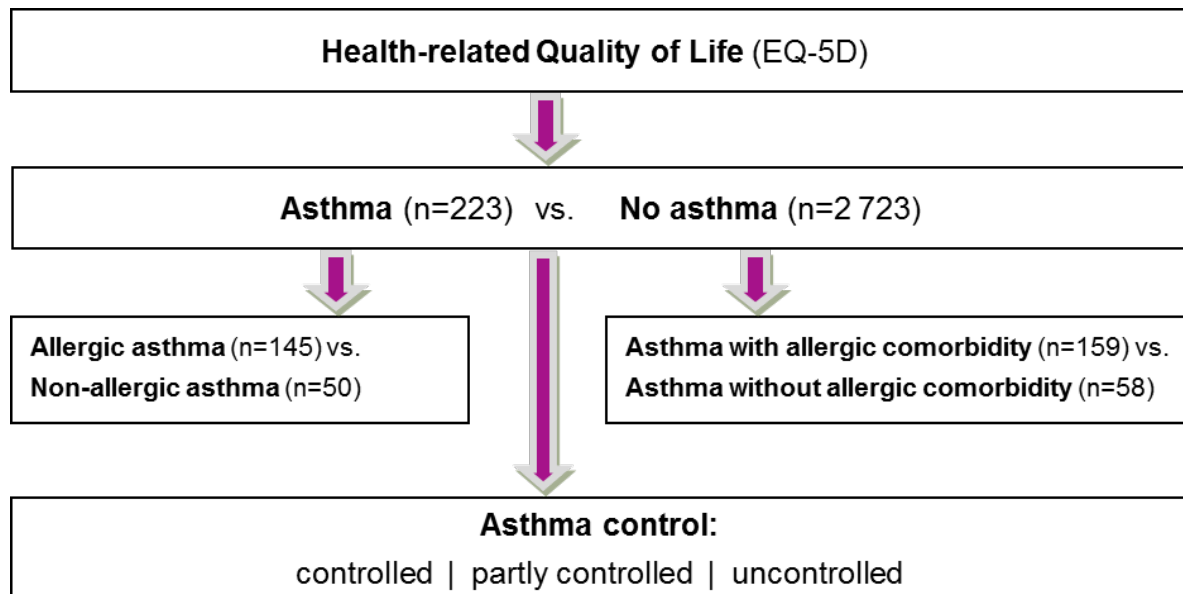


Figure 2. Presented how EQ 5D have been measured in relation to different phenotypes of asthma.

4.4.1 Participants and settings

The study was conducted within the population-based prospective birth cohort BAMSE. BAMSE is a Swedish acronym standing for Barn (Children), Allergi (Allergy), Miljö (Environment), Stockholm, Epidemiologi (Epidemiology), which originally consisted of 4,089 children born between 1994 and 1996 in predefined areas of Stockholm (107). Follow-up questionnaires focusing on symptoms related to asthma and other allergic diseases as well as key exposures and lifestyle factors have been filled out at regular intervals. The present study was conducted at the 16-year follow-up (mean age 16.5 years, range 15.7-18.). The study population consisted of 2,946 adolescents with data on background factors, asthma symptoms, other allergy-related diseases and HRQoL, who has also participated in the clinical examination.

4.4.2 Data collection

Self-reported data on asthma and allergy-related symptoms, lifestyle factors and self-reported HRQoL were obtained through questionnaires. In addition, data from blood sampling in the clinical examination was obtained.

4.4.3 Definition of health outcomes and asthma control at 16 years

Asthma: At least four episodes of wheeze in the last 12 months or at least one episode of wheeze in combination with occasional or regular use of inhaled steroids.

Allergy-related outcomes:

Eczema was defined as dry skin in combination with itchy rash for at least two weeks and typical localization on the arms, leg flexures, wrists/ankles, or neck in the last 12 months..

Rhinitis was defined as symptoms of sneezing, a runny or blocked nose, or itchy, red or watery eyes after exposure to furred pets or pollen in the last 12 months.

Asthma with allergic comorbidity: Asthma plus one or two of the allergy-related diseases (see above, rhinitis or/and eczema).

Allergic asthma: Fulfilling criteria for asthma in combination with a positive test for inhalant allergens (Phadiatop®) and/or food allergens (fx5®) (Thermo Fisher Scientific, Uppsala Sweden). Subjects were considered allergen-sensitized if IgE > 0.35 kU/L for Phadiatop® (birch and grass pollen; house-dust mite; mold; and cat, dog, and horse dander) and/or fx5® (egg, milk, fish, soy, wheat, peanut).

Asthma control: Self-reported markers associated with impaired asthma control in the last 12 months included limitations during exercise and/or avoiding activities due to asthma symptoms, night-time awakening due to asthma symptoms once a week or more, use of reliever more than twice a week (self-reported), and emergency room visits due to asthma (parent-reported). All markers were responded to with 'yes or no' and asthma control was classified according to the number of markers answered with yes: controlled (0 markers), partly controlled (1-2 markers), or uncontrolled (3-4 markers).

Health profile in EQ 5D: Health profiles (61) are presented as a five-digit code, which each digit representing the severity level of each dimension. For example the health profile 11123 represent no problems in the dimension of mobility, self-care or usual activities but some problems in pain or discomfort and extreme problems in anxiety or depression. The health profile compared those with and without asthma. A total of 243 different health profiles can be derived from the five dimensions.

4.4.4 Statistical analyses

All statistical analyses were performed with Stata Statistical Software (release 11.0, College Station, TX, USA).

Confidence intervals complemented with a finite population correction:

Used to compare the study population in this study with the original cohort regarding background characteristics with a 95% confidence intervals (95% CI). If the CI did not overlap, the proportion in the cohort was considered statistically significant.

Chi² test: Used to measure differences between groups with regard to the percentage of reported problems in the EQ-5D descriptive system. A P-value ≤ 0.05 was considered significant. Some problems and extreme problems in the EQ-5D dimensions were collapsed before conducting the analysis.

Wilcoxon–Mann–Whitney’s test: Used to measure differences between groups with regard to median EQ VAS scores.

The interquartile range (IQR): Identifies the range of values within which resides the middle 50 % of the scores. The lower bound of the interquartile range is the first quartile (Q1) – 25 % of the scores have a value lower than Q1 and 75 % of the scores have a value larger than Q1. The upper bound of the interquartile range is the third quartile (Q3) – 75 % of the scores have a value lower than Q3 and 25 % of the scores have a value larger than Q3.

Quantile multiple regression model: Used to examine how EQ VAS was affected by self-reported asthma, sex, smoking, and eczema, where the effect of each factor was adjusted for the other factors. We estimated the effect at the 25th, 50th, and 75th percentiles. P-values were based on the bootstrap method using 2,000 iterations (108). The 50th percentile of EQ VAS means those adolescents in the median and the 75th percentile of EQ VAS is those with a higher EQ VAS. Those with the lowest EQ VAS were in the 25th percentile.

The proportion of internally missing data was negligible; all adolescents had filled in the EQ VAS and only 0.3 % of the data was missing for the EQ-5D dimensions.

4.5 THE QUALITATIVE STUDIES (STUDIES III AND IV)

4.6 FOCUS GROUP INTERVIEWS (STUDY III)

In this study, we collected data through focus group interviews to afford rich insight into the participants’ realities of living with asthma.

4.6.1 Participants and settings

Four focus group interviews, two with parents of children with asthma (2-12 years) and two with adolescents with asthma (13-18 years old), were performed. The homogeneity in the groups served to raise a sense of commonality among participants through the shared experiences of living with an asthma disease or having a child with an asthma disease (100, 109).

The participants were recruited from two child outpatient clinics in Stockholm after approval from the manager in each clinic. One nurse at a clinic north at Stockholm and one at a clinic south of Stockholm identified and listed patients with asthma. The authors were provided with those lists, which included a total of 25 adolescents with asthma and 25 parents to contact. In total, the focus groups of parents included 11 participants and the groups of adolescents included nine participants.

Inclusion criteria for asthma: Doctor's diagnosis of asthma since at least 2 years, defined in medical records as ICD-10 code (diagnosis code J45 asthma, J45 0 allergy induced asthma, J45 1 not allergy induced asthma or J45 9 unspecified asthma) and prescribed with daily treatment with inhaled corticosteroids.

4.6.2 Data collection

Data was collected through semi-structured focus group interviews. The interview guide consisted of four main questions related to experiences of living with asthma. These questions encompassed meeting with health care professionals, self-management, living with asthma and support. The focus group meetings with parents were performed by a psychologist with extensive experiences of focus group interviews, with the author (me) as an observer. The focus groups with adolescents were performed by the author (me) as moderator, with one of the co-authors of the study as an observer. All focus group interviews were conducted at the child outpatient clinic where the participants had their appointments. The interviews took approximately 60-90 minutes, were tape recorded and transcribed verbatim.

4.6.3 Analysis

Data was analyzed using systematic text condensation (STC) as devised by Malterud (110). STC is a qualitative descriptive method presenting the experiences of the participants as expressed by themselves (110, 111). This is an elaboration of the phenomenological method using Giorgi's principles and descriptive approach (112).

The goal for STC is to present vital examples from people's everyday life experiences. The analysis process followed four steps (Figure 3): The STC process involves an analytic reduction with a shifting between decontextualization and a recontextualization (a varying between parts and whole) throughout the analysis process in steps 1-4, as recommended in qualitative studies (113).

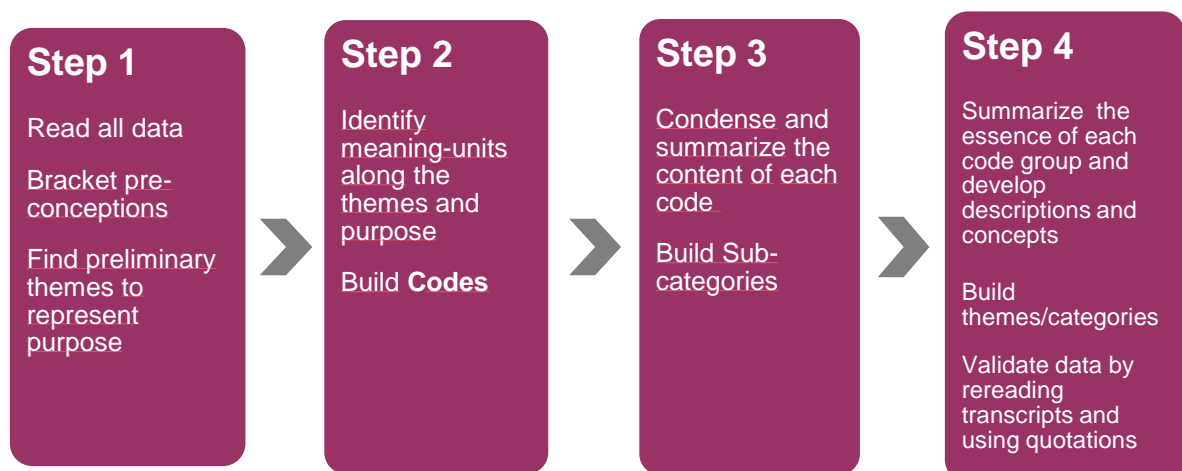


Figure 3. The analysis process of Systematic Text Condensation (STC).

4.7 INDIVIDUAL INTERVIEWS (STUDY IV)

The aim of the individual interviews was to come closer and deeper into the adolescents' everyday life. We were also inspired by the phenomenological approach to reach the deeper concepts (95) and gain understanding of what it means to live with a chronic disease (114).

4.7.1 Participants and settings

Five girls and five boys, 16-18 years old (mean age 16.9 years) with asthma were recruited from the Swedish population-based prospective birth cohort BAMSE (107).

Asthma was defined as at least two of the following three criteria: a) Symptoms of wheeze in the 12 months prior to the date of the parental questionnaire at 16 years or b) a doctor's diagnosis of asthma (ever) or c) taking asthma medicine occasionally or regularly in the previous 12 months (115).

Request for participation was done in two steps. First, a research nurse compiled a list of all adolescents with asthma in the 16-year follow-up and contacted one out of each 20 asking if the first author (me) could contact them and inform them about the study. This was done so the adolescents would not feel compelled to participate. If they agreed, the families received written information about the study and were asked for written consent.

4.7.2 Data collection

Data was collected through individual interviews with a semi-structured interview guide focused on thoughts, feelings and actions. To capture everyday life as a deeper concept we included questions with four common themes: body, relationships, time and space, which can be seen as the basis for how each human perceives his/her life (116). The questions were sometimes supplemented with follow-up questions (probes). The interviews, each of which was approximately one hour long, were tape recorded and transcribed verbatim.

4.7.3 Analyses

This data was analyzed using STC by following the four steps presented in study III (92, 111) (Figure 3). This version of STC was updated and modified to a certain extent (92). Now, the final headings are named categories instead of themes and these categories in step 4 (Figure 3) represent the headings in the chapter Results.

4.8 ETHICAL APPROVAL

All studies were approved by the regional ethics review board at Karolinska Institutet, Stockholm, Sweden. Register numbers for the permits were:

Study I: 2007/1497-31/34 & 2010/887-3

Study II: 2010/1474-31/3

Study III: 2008/1565-31/3

Study IV: 2010/1474-31/3 & 2013/76-32

5 RESULTS

5.1 HEALTH CARE PROFESSIONALS' ADHERENCE TO NATIONAL ASTHMA GUIDELINES (STUDY I)

All 18 PHCs had a spirometer and a nebulizer for treatment of acute asthma, as well as a pulse oximeter. An asthma nurse and a general practitioner (GP) with responsibility for asthma care were present at 12 of the 18 included centers.

Patient history: When scrutinizing the full records, allergic comorbidity (67% n= 229) and a family history of allergic disease (55% n=230) were documented more frequently than other aspects in the patient histories. Data on exposure to tobacco smoke was documented in 14% (n=58) and exposure to furry pets at home in 30% (n=127). The indoor environment was documented in 5% (n=20).

Pharmacological treatment: During the last 12-month period, 58% (n=246) of the children had been treated with inhaled steroids and 55% (n=178) on a regular basis. The GPs at the PHCs involved had initiated and prescribed inhaled corticosteroids to 29% of the children (n=117) and 41% (n=49) of these were prescribed regular treatment with inhaled corticosteroids.

Clinical examination: In total, 33% (n =111) had ever performed a peak expiratory flow (PEF) test and a third had undergone such a test in the last 12 months. Of the children aged 6 years and older, 22% (n=49) had ever performed a spirometry test (ever) and 14% (n=37) had performed a test in the last 12 months.

Non-pharmacological treatment: In total, 14% of the children had ever received patient education and demonstration of the inhalation technique, regardless of if they had access to an asthma nurse at their PHCs (Table 4).

The quality indicators were also studied in three subgroups (i.e. access to an asthma nurse, initial prescription of inhaled corticosteroids in primary care and undergoing regular treatment with inhaled steroids) (Table 4). A significantly higher proportion of children at PHCs with access to an asthma nurse had performed a spirometry test than those without access to an asthma nurse at their PHCs (12% vs 2% P=0.003). Further, a higher proportion of children treated with inhaled corticosteroids had received patient education (22% vs 6% P=0.006).

Table 4. Non-pharmacological prioritized actions in total and in three subgroups

Prioritized aspects	All children	Access to asthma nurse			Prescription of inhaled corticosteroids at the PHC			Regular treatment with inhaled corticosteroids		
	Yes n=424(%)	Yes n=291	No n=133	p-value	Yes n=117	No n=229	p-value	Yes n=178	No n=143	p-value
Exposure to tobacco smoke	58 (14)	44 (15)	14 (11)	0.445	15 (13)	41 (14)	0.714	24 (13)	15 (11)	0.529
Spirometry-test* children > 6 years of age	37 (14)	35 (12)	2 (2)	0.003	21(18)	16 (5)	0.032	15 (8)	11 (8)	0.845
Patient education**	59 (14)	41 (14)	18 (14)	0.921	23 (20)	33 (12)	0.110	39 (22)	9 (6)	0.006
Demonstration of inhalation techniques	58 (14)	41 (14)	17 (13)	0.753	23 (20)	33 (12)	0.107	33 (19)	1 (11)	0.145
Planned follow-up	206 (51)	15 (53)	54 (46)	0.423	75 (64)	129 (45)	0.012	97 (54)	71 (50)	0.366

* During the past 12 months ** Patient education includes education concerning the asthma disease, triggering factors and what to do when an exacerbation occurs.
PHC = Primary health care centres.

When summarizing the non-pharmacological prioritized actions (Figure 4) (spirometry test, inhalation technique, patient education, and documented data on exposure to tobacco smoke), we saw that 67% (n=286) of the children had not undergone any of these actions, one action was performed in 21 % (n = 87), two in 8 % (n=32) and three to four in 4% (n=19) of the children.

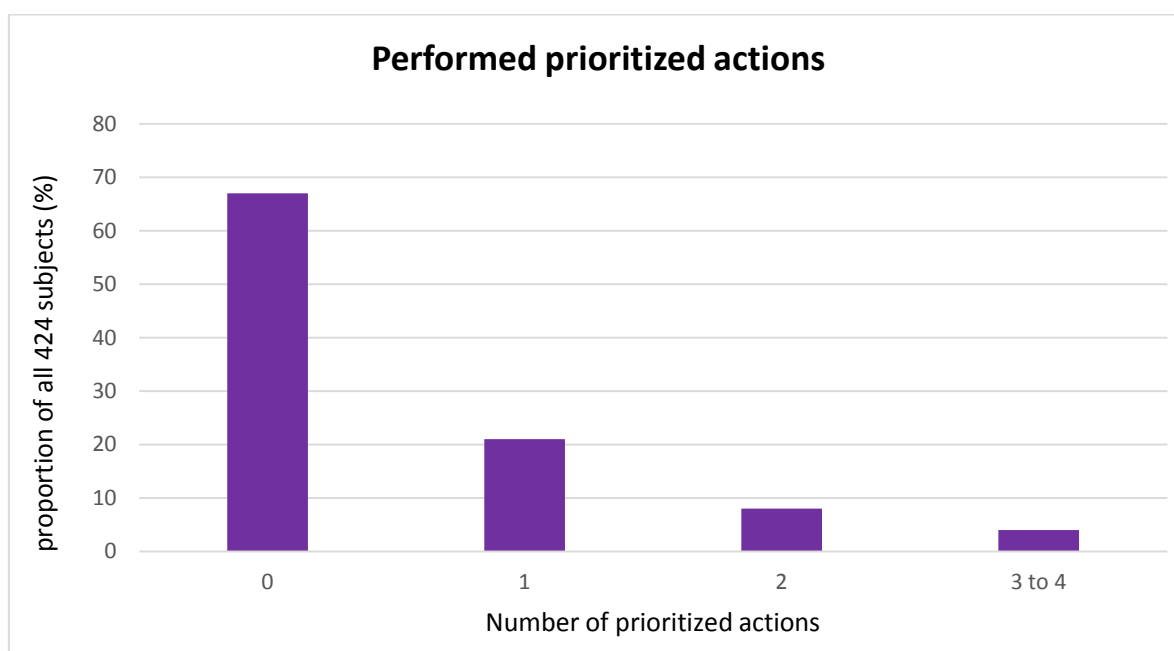


Figure 4. Performed non-pharmacological prioritized action in summary.

5.2 HEALTH-RELATED QUALITY OF LIFE IN RELATION TO ASTHMA (STUDY II)

Background factors in relation to EQ VAS in the study population (n = 2,946)

Adolescents in the study population reported a median EQ VAS of 90, ranging from 3-100. Girls reported a lower median EQ VAS score than boys (87 vs 90, respectively, $P < 0.001$). Self-reported smoking was associated with lower EQ VAS (83,5 vs 90, $P < 0.001$) than among adolescents who did not smoke.

EQ-5D in relation to asthma

Asthma was reported by 7.6% of the study population. Adolescents with asthma reported lower EQ VAS scores compared with adolescents without asthma (median 85 vs 90, $P = 0.002$), see Table 5. In addition, females with asthma reported lower median EQ VAS scores than males with asthma (85 vs 90). By applying a quantile multiple regression model assessing the association between HRQoL and asthma and adjusting for potential confounders (smoking, sex and current eczema), we found that asthma lowered the EQ VAS score in the 50th percentile ($P=0.053$) and in the 75th percentile ($P=0.006$). However, no significant association to sex was present.

Adolescents with asthma reported more problems in the EQ-5D dimension pain or discomfort compared with adolescents without asthma ($P < 0.001$) (Table 5).

Table 5: Distribution of EQ-5D among adolescents with (n = 223) and without asthma (n = 2,723)

Dimensions	Asthma (n = 223)		No Asthma (n = 2723)		P-value*
	n	(%)	n	(%)	
Mobility					
No problems	219	(98.2)	2693	(99.0)	0.26
Some problems	4	(1.8)	27	(1.0)	
Extreme problems	0	(0)	0	(0)	
Self-care					
No problems	220	(98.6)	2699	(99.2)	0.36
Some problems	0	(0)	13	(0.5)	
Extreme problems	3	(1.4)	8	(0.3)	
Usual activities					
No problems	212	(95.0)	2623	(96.5)	0.27
Some problems	9	(4.0)	87	(3.2)	
Extreme problems	2	(1.0)	8	(0.3)	
Pain or discomfort					
No problems	150	(67.6)	2229	(82.0)	<0.001
Some problems	71	(32.0)	480	(17.7)	
Extreme problems	1	(0.4)	8	(0.3)	
Anxiety or depression					
No problems	160	(72.1)	2111	(77.7)	0.053
Some problems	57	(25.7)	570	(21.0)	
Extreme problems	5	(2.2)	35	(1.3)	
EQ VAS Mean (SD)	83.02	(14.1)	85.6	(13.3)	0.002**
EQ VAS Median (IQR)	85	(80–90)	90	(80–95)	

* Some problems and extreme problems in the EQ-5D dimensions were collapsed before conducting the analysis. Differences between groups with regard to percentage of reported problems in the EQ-5D descriptive system were tested with chi² test statistics.

** Differences between groups with regard to median EQ VAS scores were tested with a two-sample Wilcoxon-Mann-Whitney's test and a P-value of ≤ 0.05 was considered significant.

Health profile in EQ 5D comparing asthma with no asthma

In the health profile in the EQ-5D dimensions among adolescents with and without asthma there was a higher proportion of those without asthma who reported full health 67% compared to those with asthma where the proportion was 53%, i.e., no problems in none of the five dimensions. 12% of those with asthma reported some problem both in the dimension pain or discomfort and in the dimension anxiety or depression compared to those without asthma where 6% reported problems in both those dimensions.

EQ VAS in relation to phenotypes of asthma

Adolescents with non-allergic asthma (n=50) had significantly lower median EQ VAS scores than adolescents with allergic asthma (n=145) (82.5 vs 85, respectively, P=0.03). In contrast, there were no differences in median EQ VAS among adolescents with asthma who also had eczema and/or rhinitis (n=159) compared with adolescents who only had asthma (n= 58) (85 vs 85, respectively, P =0.69).

EQ VAS in relation to level of asthma control

Among the adolescents with asthma, markers associated with impaired asthma control were common (Figure 5). Episodes of wheezing during exercise (82%) were reported most frequently, followed by avoidance of activities due to asthma symptoms (33%). In total, 11% of the adolescents with asthma had controlled asthma, 83% had partly controlled asthma and 6% had uncontrolled asthma. Both adolescents with partly controlled and those with uncontrolled asthma reported significantly lower median EQ VAS scores compared with those with controlled asthma (85 vs 90, $P = 0.04$ and 70 vs 90, $P=0.003$). Of further interest was the observation that adolescents with controlled asthma had the same median EQ VAS (90) as adolescents without asthma.

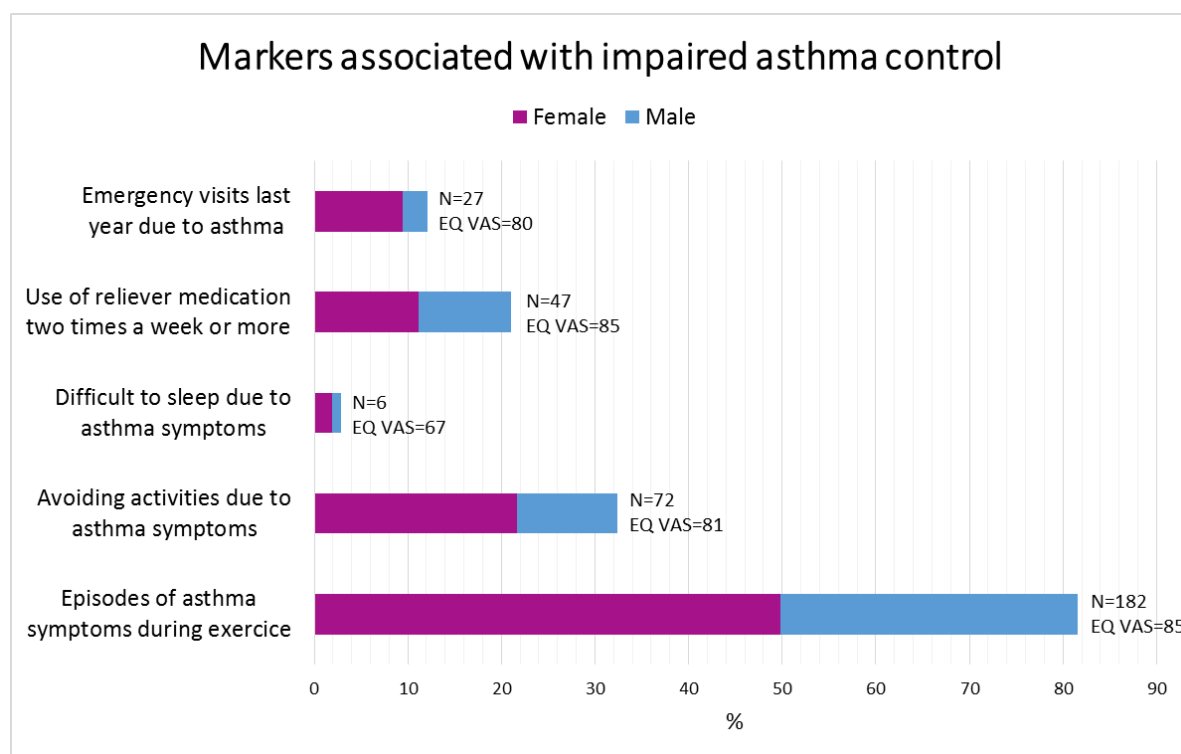


Figure 5. Markers associated with impaired asthma control and median EQ VAS among adolescents with asthma ($n = 223$).

EQ VAS in relation to smoking

In total, 11% of adolescents with asthma smoked sometimes or daily, a proportion similar to that among all adolescents in the study population (11%). In the group of adolescents with asthma, smoking was more common among girls than boys (14% vs 7%). In a quantile multiple regression model where we adjusted for confounders, an association between HRQoL and self-reported smoking was seen, with a significant reduction in median EQ VAS at 25th, 50th and 75th percentile with 5, 6 and 5 units ($P = 0.03$, 0.002 and < 0.001 respectively). The finding that EQ VAS was reduced at all three percentiles implying that smoking had a negative effect on wellbeing over a broad range of EQ VAS values.

Additionally, those adolescents who were smokers in the partly/uncontrolled group had a lower median EQ VAS than those who were smokers in the controlled group (92.5 vs 79.5, P=0.03).

5.3 LIVING WITH ASTHMA (STUDIES III AND IV)

5.3.1 Feelings of frustration (studies III and IV)

Feelings of frustration were expressed by both parents of children with asthma (study III) and by adolescents (study IV). Parents expressed feelings of inadequacy and anxiety over how to take care of their children when their symptoms got worse and over difficulties in understanding why and when the worsening of asthma appeared. They also felt lonely and stated that they must be able to manage and treat their children by themselves. The parents described frustration over a lack of knowledge regarding how to help their children inhale in a correct way.

Parents expressed frustration at not being believed by staff in pre-school and school, where their children's asthma symptoms were not taken seriously and teachers sometimes forgot to give asthma medication to the children. The same could also be seen when parents expressed feelings of not being listened to by teachers when they wanted changes enabling their children to cope with everyday life despite asthma (study III).

When the adolescents talked about frustration they also talked about to not being believed in school even though teachers knew that the adolescents had asthma, could have exacerbations and were not capable of performing all types of physical activities (study IV).

Among adolescents (study IV), we saw that they could be frustrated when they were defined by their asthma, e.g., when teachers were overly considerate of their asthma disease. It felt frustrating for the adolescents not to be able to run or exercises like their peers. They found it unfair that the asthma disease affected only them and were frustrated at having to interrupt vigorous exercise when their friends did not.

Feelings of frustration

Parents	Adolescents
<ul style="list-style-type: none">• Feelings of anxiety and inadequacy• Lack of knowledge• Not being believed• Feeling Lonely	<ul style="list-style-type: none">• Unfair to have asthma• Not being believed by teachers• Being defined by the asthma• Interrupt vigorous exercises

Figure 6. Summary of “feelings of frustration”.

5.3.2 Development of treatment strategies (studies III and IV)

Parents used different treatment strategies when taking care of their children (study III). As soon as asthma symptoms become apparent, parents immediately inhale their children, so they would not become more impaired and need to go to an emergency ward. Another treatment strategy among parents was to use PEF, as a tool to determine when it was time to increase the asthma medication.

According to a finding in the focus group interviews (study III), all adolescents were prescribed with daily treatment with ICS, yet found their own strategies to manage their asthma. They used asthma medication in different ways; sometimes before exercise, or as prescribed, but sometimes they just waited until the symptoms passed. The adolescents wanted to have regular check-ups to see if they were getting better or worse compared with in previous tests, i.e., "if it was worth it to continue taking the medication".

In study IV, the adolescents stated that they had learned to live with their disease, understanding why and when the symptoms affected them. They had accepted their symptoms, which meant that they had maturity and insight into how their bodies worked and how to manage symptoms. Adolescents took responsibility and saw the consequences of their actions. For example, they developed strategies to prevent symptoms, such as creating a schedule to remember to use their medication.

Development of treatment strategies

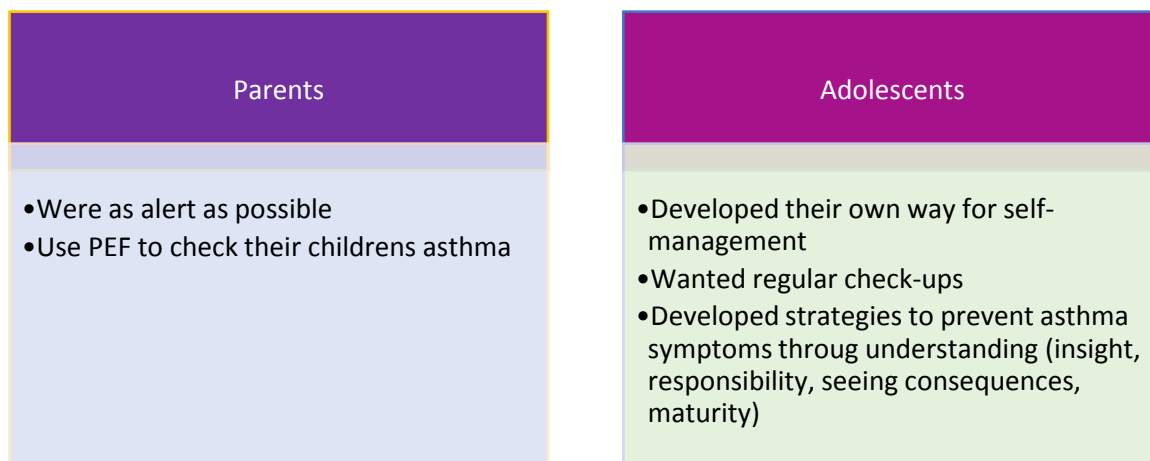


Figure 7. Summary of “development of treatment strategies” among parents and adolescents.

5.3.3 Adaptation strategies (studies III and IV)

Parents (study III) expressed that they needed to adapt everyday life to their child's asthma, so the child could participate in the same activities as children without asthma, such as sports, playing with friends and attending parties. This could sometimes result in infections for the child and thereby concern on the parents' part. Adaptation also required the parents to strive to communicate well, so health care professionals could truly understand the needs of their children.

In both the focus group study (III) and in the individual interview study (IV), the adolescents stated that they wanted to be like everyone else. They didn't want to be perceived as "different" because of their asthma. The adolescents have a strong desire to adapt to social interactions, be like their peers and perform like others. This could also mean denial of or ignoring asthma symptoms and attributing asthma symptoms during exercise to poor physical fitness, when actually it was asthma that affected them (study IV).

Adaptations strategies

Parents	Adolescents
<ul style="list-style-type: none">• Adapting to the child every day• Communicating well	<ul style="list-style-type: none">• Ignoring or denying symptoms• Being like others• Not attributing symptoms to asthma

Figure 8: Summary of "adaptations strategies"

5.3.4 Being met with understanding and competence (studies III and IV)

The parents wanted to be met with competence and understanding from both health care professionals and teachers in pre-school and school (study III). The parents stated that they wanted a health care professional who was competent in the field of asthma and knew how to care for patients with asthma and understand their needs. They also wanted teachers in pre-schools and schools to have knowledge and understanding of how to help and care for a child with asthma. Many of the parents described lack of competence in the asthma field, i.e., it had taken too long to achieve an asthma diagnosis for their child. Additionally, they expressed that they needed repeated education on asthma management. Almost all parents wanted to have the possibility to come and visit the child outpatient clinic when their children had acute asthma symptoms and did not want to be referred to the emergency ward and then have to wait several of months for an appointment with a pediatric specialist.

Both parents and adolescents (study III) expressed that they received asthma support from the pediatrician, but talked more about the asthma nurse at the child outpatient clinic. They expressed that the asthma nurse had competence, knowledge and understood the specific

needs they had. Having an asthma nurse who could visit the pre-school or school to inform teachers about asthma was an important factor for enhancing trustworthiness among teachers.

The adolescents also wanted to be understood by health care professionals in the context of their own experiences of living with asthma (study IV). When the adolescent received explanations about asthma from a doctor or nurse, displaying images was helpful for better understanding of the disease.

The adolescents described that they wanted to be seen with understanding, i.e., be confirmed by family, friends, coaches and teachers (study IV). Family support was important for confirmation, as it helped adolescents to feel calm and safe in their daily life. In addition, being seen and understood by teachers and coaches were essential steps in confirmation for adolescents with asthma, i.e., when teachers and coaches had the capacity to “see” them and understand that they were not always capable of performing physical activities, they felt confirmed. The opposite was also described when adolescents were not seen and confirmed by teachers or coaches. This could be in situations when a teacher did not believe them, such as when the adolescents have problems in making efforts in some sports. From the adolescents’ perspective it is of importance to be confirmed and seen as everyone else (like their friends) and as ‘normal’.

To be met with competence and understanding

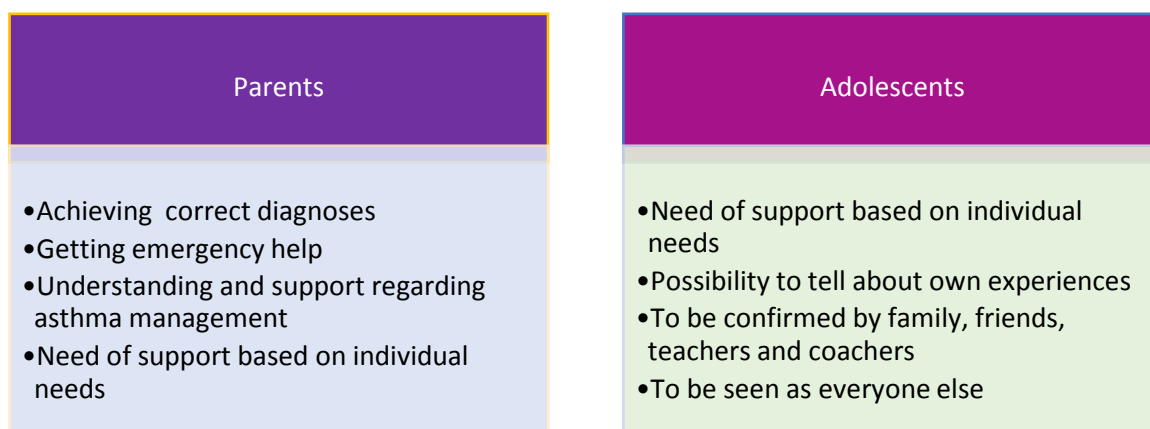


Figure 9: Summary of “to be met with competence and understanding”

5.3.5 Struggles with ambivalence (study IV)

Having asthma in adolescence seems to lead to several struggles with ambivalence affecting daily life.

Ambivalence was seen in the adolescents’ understanding of their disease: they had matured, gained insight and acceptance of their illness, but on the other hand they ignored and denied their asthma symptoms. They wanted to adapt in social situations and be like their peers.

Ambivalence was also seen in the adolescents' expectations of being confirmed, but not defined by their asthma. This means that the adolescents wanted to be confirmed, believed and listen to regarding the fact that they had an asthma disease, but not to the point that their asthma took center stage, so that they were defined by their disease.

Feeling healthy and normal, but on the other hand also describing many asthma symptoms, especially during exercise, was another ambivalence. The adolescents expressed that they often felt healthy and that the disease did not play a dominant role in their lives. However, most adolescents also described that they did not believe that their asthma would disappear permanently.

Struggling with ambivalence

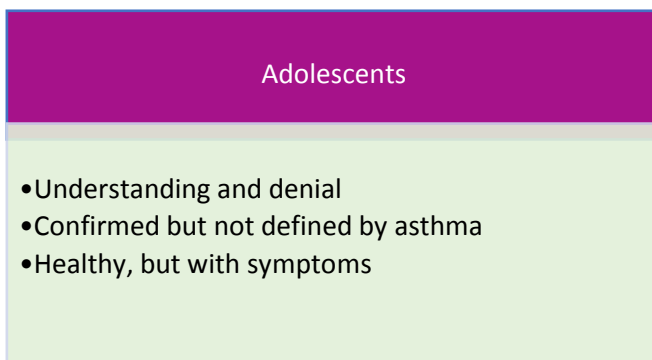


Figure 10: Summary of “struggling with ambivalence”

5.3.6 Limitations during exercise (study IV)

Almost all adolescents in the individual interviews mentioned limitations during activity and most mentioned difficulties in breathing during exercise and that having access to fresh air and oxygen was critical. They expressed limitations in that they could not perform like their friends.

Limitation during exercise

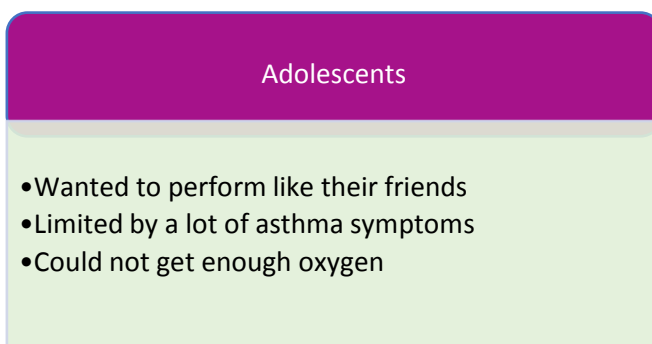


Figure 11. Summary of “limitations during exercise”.

5.3.7 Summary of aspects of living with an asthma disease

Table 6

Experiences	Parents	Adolescents
Feelings of frustrations	Feelings of anxiety and inadequacy Lack of knowledge Feelings of not being believed Feeling lonely	Unfair to have asthma Not being believed by teachers Not being define by the asthma Interrupting vigorous exercises
Treatment strategies	Were as alert as possible Used PEF to check their child's asthma	Developed their own ways of self-management Wanted regular check-ups Developed strategies to prevent asthma symptoms through understanding (insight, taking responsibility, seeing consequences, maturity)
Adaptions strategies	Adapting to the child every day Communicating well	Ignoring or denying symptoms Being like others Not attributing symptoms to asthma
To be met with competence and understanding	Achieving correct diagnoses Getting emergency help Understanding and support regarding asthma management Need of support based on individual needs	Need of support based on individual needs Possibility to tell about own experiences To be confirmed by family, friends, teachers and coaches To be seen as everyone else
Struggle with ambivalence		Understanding and denial Confirmed but not defined by asthma Healthy but with symptoms
Limitation during exercise		Wanted to perform like their friends Limited by a lot of asthma symptoms Could not get enough oxygen

6 DISCUSSION

The overall aim of this thesis was to evaluate health care professionals' adherence to national guidelines in asthma care and to explore experiences of living with a chronic disease like asthma. The main results show that there is a gap between the pediatric asthma care provided at PHCs and the recommendations in national guidelines. Adolescents with asthma reported a lower HRQoL than adolescents without asthma especially, when asthma was partly controlled or uncontrolled. Many adolescents with asthma reported limitations in physical activities and developed their own strategies for managing asthma. Furthermore, daily living with asthma in adolescence showed ambivalence between *understanding* and *denial*, *confirmed but not defined by asthma*, and *healthy but with symptoms*. Parents of children with asthma expressed frustration and lack of knowledge regarding how to treat and take care of their children with asthma. Parents have to struggle and communicate well to be understood. Both parents and adolescents wanted to be met with knowledge and competence.

6.1 ADHERENCE TO GUIDELINES (STUDIES I, II, III AND IV)

Health care professionals' adherence to national guidelines at PHCs showed shortcomings, especially as regards non-pharmacological treatment.

The spirometry test is an important tool for both correct diagnosis and monitoring of pediatric asthma and has a high priority in national and international guidelines (3, 33). In study I, only a minority of the children older than 6 years of age had ever undergone a spirometry test, even though all PHCs had access to a spirometer. A similar low proportion of performance has been shown in other countries (117, 118). It has also been discussed that there are differences in performance and interpretation of spirometry tests and therefore a need for standardization of performance in clinic practice (119). In study III, adolescents wanted to perform a spirometry test to check if they were getting better or worse compared with in previous tests.

In Sweden, asthma nurses perform spirometry tests at PHCs and are responsible for non-pharmacological treatments. At PHCs with access to an asthma nurse, spirometry tests were performed at a higher proportion, but still among only 14 % of the children older than 6 years. Study I also showed shortcomings in other non-pharmacological actions, such as patient education and demonstration of inhalation technique. This may depend on barriers in organization or inter-professional collaborations at PHCs, which are important factors for providing optimal asthma care (3, 33, 120, 121). For successful inter-professional collaborations, the interplay between nurses and physicians is of importance (122), where knowledge and trust of competence among colleagues can support the feeling of being a team (123).

In the focus group study (III), both parents and adolescents emphasized their contact with the asthma nurse as she could tailor their education and give support. They mentioned that she had competence and understanding of their needs. This has been shown in another qualitative study, where parents valued the nurses' availability and responsiveness (74). Nurses as

educators can generate significant reductions in the cost for asthma care, for example through decreased emergency department visits and improved self-management of asthma exacerbations (124). Having access to an asthma nurse in primary care in Sweden and internationally has been shown to increase patient knowledge, improve asthma control and reduce costs (125-127).

From the focus group study (study III) we learned that the adolescents developed their own strategies of self-management, e.g., they used asthma medication in different ways; sometimes before exercise or as prescribed, but sometimes they just adapted and waited until the symptoms disappeared. This was despite the fact that they were all prescribed regular treatment with inhaled steroids. However, the different adherence to medication among the adolescents in the focus group interviews could have many underlying reasons. A review of asthma management suggests that adolescents deny, hide or ignore symptoms and thereby their need for medication because of their desire not to be different from other adolescents (14). This was also seen in the individual interviews (study IV), where adolescents denied their asthma by ignoring symptoms in an attempt to interact socially. Consequently, the strong desire to be liked by their peers may lead to denying or ignoring asthma symptoms. Similar behaviors, as well as underreporting symptoms, have been described elsewhere (128, 129) and may lead to poor symptom control (10).

Only a few children and their parents had received patient education in study I. In both study III and study IV, parents and adolescents asked for further education on asthma. However, the need for patient education to support self-management of asthma is well recognized (130). It has been shown that evidence-based nursing practice will benefit adolescent asthma self-management education by providing coping strategies, family problem-solving support, regular health professional reviews, and methods to promote quality of life (130). However, the authors of that paper suggested that more research was needed to evaluate the efficacy of asthma education programs among adolescents (130). Web-based educational programs for children with asthma may have positive influences on pediatric patients' asthma-related knowledge and use of asthma preventer medications, but not on frequencies of reported asthma symptoms (131). Barriers for providing self-management support to patients with asthma according to guidelines have been suggested to be mainly professional (132). This could involve doubt about the evidence base and relevance to primary care, lack of knowledge or skills, misconceptions, lack of time or resources, or poor team work between doctors and nurses (51, 132). A study with video-taped patient consultations at nurse-led (COPD) clinics showed that nurses seldom planned consultations on an individual basis and seldom used motivational discussions in self-management education (133).

Adherence to pharmacological treatment is essential for asthma management, but the results in study I showed that 58 % of children were prescribed with inhaled steroids at PHC. This is not in line with guidelines, where it is estimated that 80 % require treatment with inhaled steroids or leukotriene antagonists at PHCs (134). Achieving good adherence is a complex task, requiring interventions not covered in current guidelines of managing asthma in children

(48). The conflict between *what to do* according to guidelines and *how to* organize health care so that support is, in practice, provided in accordance with guidelines may be essential.

Of the 58 % of children treated with inhaled corticosteroids (study I), only 14 % had been given demonstration of inhalation technique. Teaching a proper inhalation technique is essential and should be done at each visit (135) as supported in all guidelines (3, 33). Additionally, in study III parents reported lack of knowledge regarding how to help their child inhale in a correct way. In order to achieve and maintain a correct inhalation technique, the procedure involves both demonstration and letting the patient show how they inhale (136). It has also been shown that child's inhalation technique improves when he/she receive instruction in inhalation technique (137, 138). In younger children it may be necessary to demonstrate to the parents how to hold a child securely to receive treatment administration, particularly with a spacer and facemask (139). It is also recommended not to change to a new device without the patient's/parents' involvement or without follow-up education on how to use the new device properly (140). One of the most common reason for poor asthma control is poor inhalation technique (141).

Exposure to tobacco smoke is one of the major causes of deterioration in children with asthma (142, 143). Documentation on exposure to tobacco smoke or questions on active smoking were uncommon in study I. Studies have shown that children with wheeze who visited emergency departments were more likely to be exposed to second-hand tobacco smoke (144). Educational programs for smoking parents could have an effect on children's asthma exacerbations and frequencies of emergency visits due to acute asthma symptoms (145, 146).

Furthermore, in study II we saw that adolescents with asthma were as likely to smoke as those without asthma. Smoking among adolescents both with and without asthma is associated with physical and psychosocial risk factors (147, 148). In study II, current smoking was an independent risk factor for impaired HRQoL when adjusting for confounders in the regression analysis. As smoking is the most common cause of long-term health problems, it is important that health care professionals are aware of how to prevent smoking among adolescents (both with and without asthma) and how to support smoking cessation. Studies have shown that educational programs and smoking bans can reduce smoking rates among adolescents (149).

In study I, only half of the children had a planned follow-up. Follow-ups are one of the central areas highlighted in both national and international guidelines (3, 33). Follow-ups should be performed with different regularity depending on whether asthma is controlled or not and if the patient is on a regular or as-needed medicine. The follow-up should also include adequate patient education, demonstration of correct inhalation technique and implementation of a self-management plan and a routine medical examination (3, 150)

Our results regarding adherence to guidelines have been commented on by Bush and Fleming, suggesting that asthma care requires the KISS approach (Keep It Simple, Stupid)

(151). This approach includes getting the diagnosis right, giving an appropriate level of treatment and making sure the child and family know what it is all about, especially how to use the medication delivery device and eliminate trigger factors in the environment.

6.2 DAILY LIFE WITH ASTHMA (STUDIES III AND IV)

Being a parent of a child with asthma or being an adolescent with asthma affects daily life in both positive and negative ways. Both parents and adolescents highlighted the importance of being seen and understood and wanted to receive support from health care professionals who had competence and understood their needs. This has also been presented in other studies, where the parents' need for support and empathy was expressed (69).

To be seen in adolescence meant to be confirmed by family, friends, teachers and health care professionals. The adolescents wished to talk about their own experiences of living with asthma when visiting health care professionals. Similarly, younger children with diabetes or asthma also expressed that they wished to communicate their own experiences in their daily life (16).

The adolescents in study IV had developed an insight, learned to live with their disease and took responsibility for their actions. These are responsibilities which adolescents likely did not have in childhood and which align with normal cognitive development during this period of life (9, 82). Applying this to asthma management, adolescents are capable of developing strategies and goals for their asthma and generate different solutions for how they want to achieve control (9). Having asthma poses challenges in achieving these developmental tasks and requires adolescents to balance between their normative developmental needs and their disease adaptation (152). Unlike children, who think in the present, adolescents are able to think about the future and consider consequences or compare and evaluate different situations. Adolescents can to a greater extent understand the limitations that asthma imposes and see how the diagnosis challenges their autonomy and independence (10). This insight was not seen clearly in the focus group study (III) among adolescents, where the adolescents had developed their own strategies of self-management. Sometimes they took medication before exercise or as prescribed, but sometimes they just adapted to the symptoms and waited until they disappeared. One reason for differences in self-management could be that the adolescents in the focus groups were a bit younger than the adolescents in the individual interviews.

The adolescents with asthma described their daily life as a struggle with ambivalence. They struggled with self-management balanced against a strong desire to interact socially with their friends. Such ambivalence was also shown in a study of adolescent boys with asthma, who described feeling disadvantaged because of their asthma, which contrasted with the statement that asthma was an insignificant part of their lives (153).

This ambivalence may be a part of normal adolescent development, but may also underscore the conflict of adapting in social life, in order to be like others and to feel "normal" (154). Peer interactions have an important role in adolescence and social support for those with

chronic conditions is important (155). Having the ability to openly discuss their illness with other peers can also have a positive influence on asthma self-management in adolescents (156).

The parents in the focus group (study III) felt frustrated and presented feelings of loneliness, anxiety, and inadequacy relating to how they took care of their children. Similar frustration has been reported by other parents of children with asthma in a focus group interview where parents feared and worried about their children's safety especially during asthma exacerbations (157). Having a child with asthma has also been shown to impair the parents' quality of life and put pressure on families (158). In the focus group interviews (study III), parents also had difficulties adapting to their children's everyday life. They wanted their children to participate in the same activities as children without asthma. These results are comparable to results in other studies where parents were often worried when their children were participating in various activities (159, 160).

Feelings of frustration were also expressed by both parents and adolescents relating to not being believed by the teachers in school. Parents mentioned a lack of understanding among teachers in pre-schools and schools. The parents expressed that the teachers did not seem to understand the specific needs of children with asthma and their asthma symptoms were sometimes not taken seriously enough. They expected to be listened to and believed by teachers. Therefore, parents wanted the asthma nurse to visit schools and educate teachers about asthma and its consequences for children. In 2013, the National Board of Health and Welfare in Sweden reported on the situation for children with allergic diseases (161). The report showed limitations in the school environment as well as in teachers' knowledge about allergic diseases. More education was suggested.

Many of the adolescents reported asthma symptoms during exercise both in study II and in study IV and almost half of them avoided activities due to asthma symptoms (study II). They strongly articulated limitations due to asthma and thought it was unfair that they had this disease. A multi-center study involving six countries showed that almost half of children and adolescents with asthma felt that their asthma affected their ability to play sports, and this had a substantial impact on their daily lives (7). These limitations seemed to be a common feature among adolescents with asthma and showed that it is important that health care professionals focus on physical function when providing asthma care in adolescence. Studies have shown that physical activity improves quality of life among children and adolescents with asthma (162, 163).

6.3 HAVING ASTHMA AFFECTS HRQOL (STUDY II)

Adolescents with asthma reported lower HRQoL, especially in the EQ-5D dimension of pain or discomfort and in the EQ VAS, and there was a negative association with the level of asthma control. Impaired HRQoL as measured by the EQ-5D has also been found among adults with asthma, especially among those with impaired asthma control (164-166). In addition, impaired asthma control and impaired quality of life in adolescence have been

observed in a study using an asthma disease-specific instrument (167). The association was mostly seen in subjective control domains such as night-time and day-time symptoms, as well as limitations in physical activity (167). The psychological impact that asthma has on adolescents is well documented (168) and in our study (study II) the majority of adolescents with asthma reported problems in the EQ-5D dimensions pain or discomfort and anxiety or depression. There were also a higher proportion of adolescents with asthma as reported problems in both dimensions pain or discomfort and anxiety or depression than in those without asthma. Psychiatric comorbidity in adolescents with asthma increases with the severity of asthma (169).

Sex differences in the EQ-5D dimension of pain or discomfort were seen. Several other studies have also shown that girls with asthma report lower HRQoL (170-172). However, when we adjusted the analyses for sex in a regression model using EQ VAS score, the reduction in HRQoL for girls was no longer statistically significant, which highlighted the importance of performing adjusted analyses.

Allergic asthma or asthma with allergic comorbidity was not associated with additional impact on HRQoL. A previous study showed no significant differences in quality of life when patients aged ≥ 20 years with both asthma and atopy were compared with age-matched patients with asthma but without atopy (173). Adolescents with non-allergic asthma had impaired HRQoL in both the EQ-5D dimension of pain or discomfort and the EQ VAS score, as compared with those with only asthma. Other studies have shown that non-atopic asthma was associated with more depression in girls (174) and more emotional symptoms in school-aged children than atopic asthma (175). The fact that non-atopic asthma in adult may be more severe than atopic asthma (176) provides some indication that the same may apply to adolescents with non-atopic asthma.

Utilization of the EQ-5D in other studies has shown that younger children with asthma report higher EQ VAS scores than adolescents with asthma (63, 177) and supported that adolescence is a sensitive period for clinical to take into account.

There is a lack of literature regarding minimal clinically meaningful differences in EQ VAS scores among adolescents with asthma. However, our results showed that adolescents with asthma had significantly lower EQ VAS compared with adolescents without asthma and this was especially clear among adolescents with partly controlled or uncontrolled asthma compared with controlled asthma. The association was persistent when performing a quantile regression adjusting for potential confounders and other allergy-related diseases.

6.4 PROVIDE OPTIMAL ASTHMA CARE (STUDIES I, II, III AND IV)

The findings of this thesis give support to the fact that asthma care need to be improved in both a medical and a nursing perspective. There is a need for children and adolescents with asthma to be met by a health care professional with expertise in the asthma field, so that care can be provided according to guidelines and on an individual basis. A nursing perspective focuses on trying to understand how a person experiences his/her situation, a prerequisite in

order to identify needs and establish goals together with a patient and take appropriate actions. Involving patients in treatment decisions and individualizing educational support also seems to have a favorable effect on adherence (178) which is supported by guidelines (3). Both medical and nursing perspectives enable and support the patients to reach asthma control and wellbeing.

Person-centered care includes treating people as individuals, respecting their rights as people, and building mutual trust and understanding so that therapeutic relationships are created, as well as working on the basis of what health means for them, which should be a helpful way to manage asthma (43, 179). Health-promoting nursing is based on a holistic existential approach with a humanistic view and focuses on understanding a patient's life in relation to health, illness and suffering instead of focusing on problems and diagnoses (180).

Asthma care should be built on a partnership between a child, his/her parents and health care professionals, in order to be successful. There are four essential components of asthma management stated in international guidelines: assessment and monitoring, control of factors contributing to asthma severity, pharmacotherapy and education for a partnership in care (181).

6.4.1 Clinical implications

Based on the results of this thesis, several aspects of clinical practice care of children and adolescents with asthma can be improved.

By using quality registers for asthma care (182) in clinics, asthma care can be improved. When using the registers, the clinics can measure the quality of care given and thereby patients with asthma can obtain equal asthma care across the country. The quality registers can be used for both children and adults.

Training, resources and financial incentives are required to ensure that children and adolescents receive asthma care from health care professionals with expertise in the asthma field. One way forward could be to establish asthma and COPD clinics that work according to current guidelines (183). This requires development of cooperation between nurses and physicians or pediatricians to work in teams with patients and involve other professionals as needed.

There is a need for teachers and coaches in pre-schools and schools to understand what it is like to live with an asthma disease, which should be apparent in knowledge, understanding and actions. An asthma nurse coordinator may be a link between home, clinic and pre-school/school for providing education to teachers and coaches.

Good communication skills on the part of health care professionals are essential for providing optimal asthma care (184) and can result in increased patient satisfaction (185). Training health care professionals to provide and support self-management of asthma is crucial (34, 186). The importance of taking patient beliefs into account when providing asthma care

have been supported by others (187) and communication between professionals, children and parents is seen as an essential component of children's asthma care (74, 188). It is important to communicate with both a child and its parents, since children have their own experiences of living with asthma and their own views of what is of importance (189).

The fact that adolescence is a sensitive period means that health care professionals should listen to the specific needs that adolescents with asthma have. The process of transferring responsibility for treatment and care from parents to an adolescent should include involvement of the adolescent in decisions related to his/her disease and in discussions with health care professionals (10). One way to accomplish this would be for adolescents to meet health care professionals without their parents. This may give them the opportunity to express their own experiences of living with asthma, in addition to taking more responsibility and making their own decisions regarding their disease (190). Confidentiality is also essential for establishing trusting and open communication when working with adolescents (14, 74).

Health care professionals, parents, coaches and teachers ought to anticipate conflicts between adolescents' desire for normalcy and the daily demands of asthma, and are thus encouraged to reflect on how this conflict may impact on adolescents' self-management (152, 191). Appropriate support and strategies that take these issues into consideration are needed to promote the adolescents' sense of normalcy and to facilitate their ability to cope with demands imposed by asthma while living as "normal" adolescents (191).

Children, adolescents and parents need a basic understanding of asthma, including the nature and treatment of the disease, which can be further developed as children grow up to an adolescents and take more responsibility for their asthma self-management (14). The education should be repeated as regards treatment issues, new updated information about asthma and demonstrations on inhalation technique.

As reported elsewhere (192, 193), individual written asthma action plans or protocols are resources for self-management of asthma in both childhood and adolescence. A written asthma action plan should include information on medical treatment, but also advice about physical activity and what to do when exacerbations and trigger factors affect them. Moreover, it is important that sport coaches understand how children and adolescents with asthma want to be treated. Clinicians are encouraged to take a genuine interest in the impact of asthma on daily life, including how asthma interferes with and limits physical activity (191).

Many of chronically ill children and adolescents will continue managing their chronic illness into adulthood, so involving measurements of health status is of importance as a subjective reported outcome of wellbeing (194). By using questions about HRQoL as well as questions about markers associated with asthma control (ACT) (26, 195) in the clinic, adolescents with an increased risk for impaired HRQoL and those with partly controlled/uncontrolled asthma (196) can be identified.

Providing optimal asthma care

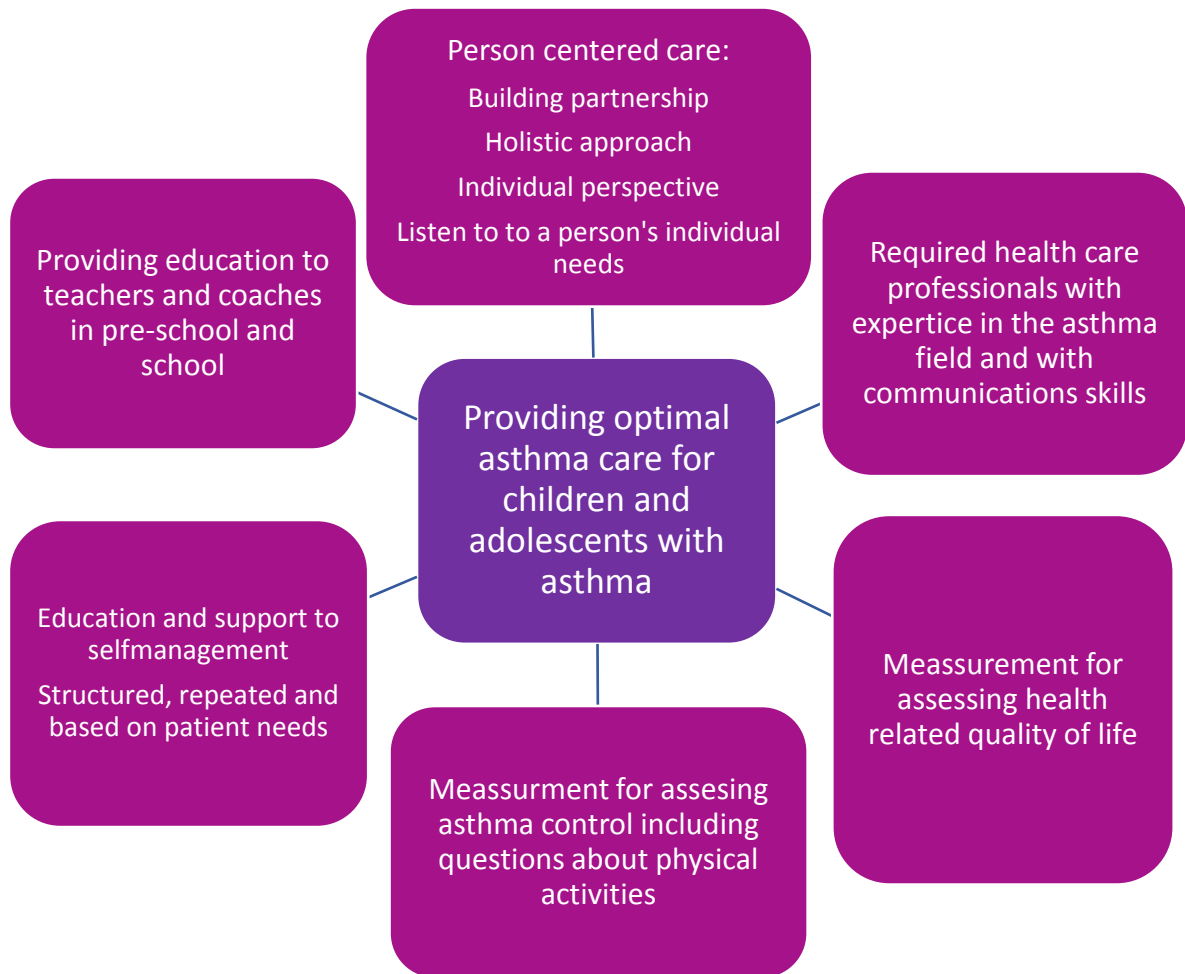


Figure 12: Summary of how optimal asthma care may be provided

6.5 METHODOLOGICAL CONSIDERATIONS

This thesis involves both qualitative and quantitative methods to reach a deeper understanding of asthma care. Combining qualitative and quantitative methodologies can provide more comprehensive explanations for health and medicine science than can be derived from either approach alone (90). Researchers' background and position often affect what they choose to investigate and how they angle their research (92). My background as a pediatric nurse has probably affected my research questions to some extent.

In Study I, we were aware that not all actions might have been documented in medical records, even though Swedish law (197) clearly states that all health care professionals shall provide such documentation to ensure high quality, safe care. Avoiding or being aware that bias may have affected the result is a form of reflexivity. To reduce the risk of bias in study I, we let external research nurses with training in asthma care scrutinize the medical records. The nurses had no other connection to the research group.

There are various ways of classifying asthma control in children and adolescents, and in study II we tried to construct a variable as much in accordance with GINA guidelines as possible (192). However, our questions about markers associated with asthma control reflected a period of 12 months in contrast to GINA's recommended 4 weeks and thereby might result in recall bias over- or underestimating the frequencies of self-reported symptoms.

Further, our results showed that only a small proportion of adolescents had controlled asthma. Most adolescents were partly controlled which may be due to the fact that many reported limitations in physical activities. However, the fact that limitations during exercise are an important issue to take into account when treating adolescents with asthma was apparent from both study II and study IV.

In study III, there were two nurses who identified and listed the recruited participants. One was an asthma nurse, which may have influenced the results regarding the participants' positive experiences of asthma nurses.

The asthma definitions used in this thesis was constructed according to the aims and the method used in the different studies. In study I and III we used ICD codes to asthma to select children and adolescents with an asthma diagnosis. In study I we also selected ICD codes on obstructive bronchitis and cough to see if there was an asthma diagnosis beyond, according to the evidence criteria for asthma. In study III the included participants should also have prescription on regular treatment with inhaled corticosteroids. In study II and IV, we used reported asthma symptoms, episodes of wheeze or/and in combination with a doctor's diagnosis (study IV) or/and pharmacological treatment with inhaled corticosteroids (studies II and IV). These relatively strict definitions of asthma were to be ensuring that the examined children and adolescents really did have an asthma diagnosis.

The fact that some authors in both study III and study IV have clinical experience of working with patients with asthma could be a potential source of bias. The authors' preconceptions may have influenced the results both in the interview situations and in the analysis process, but to mitigate this risk the authors tried to bracket their preconceptions. However, previous knowledge could also contribute to deeper understanding. To validate these circumstances, all authors discussed the analyses together to achieve new perspectives and illuminate the purpose.

A review of the validity and reliability of EQ-5D in studies of asthma has shown that EQ-5D is useful for helping clinicians to understand the impact of respiratory diseases (198).

However, it is possible that a ceiling effect could occur in study II, because the majority of the adolescents reported full health in the dimensions of mobility, self-care, and usual activities, indicating that some health problems might not be detected by the instrument. A ceiling effect may indicate that there is not a wide enough range of response alternatives in the questionnaire (58).

We have also reflected on the fact that although many of the adolescents with asthma reported that they avoided activities due to asthma, the majority still reported full health in the dimension of usual activities in the EQ-5D instrument. It may depend on that adolescents have adapted to their situation and deny their asthma symptoms. These questions might also have been perceived differently among the adolescents, if the questions had specifically asked whether *asthma* limited them in their physical activities. Moreover, we used the EQ-5D 3L with three levels of seriousness per dimension and maybe the results would have differed if we had used the EQ-5D 5L version with five levels of seriousness per dimension (199).

A potential weakness may be that we did not combine the generic instrument with an asthma-specific instrument; we might have failed to focus on the specific symptoms and experiences that would be obtained in an asthma-specific instrument (58). On the other hand, the generic instrument covers a wide range of conditions and has the advantage of reflecting disease burden in general. Additionally, the EQ-5D seems to be suitable for children with chronic diseases (200-203).

The adolescents with asthma in the focus group interview (study III) sometimes had difficulties in expressing their thoughts and interacting with each other. This could be countered through individual interviews (study IV), where the adolescents were more open and expressed their thoughts as well as providing rich and varied stories. However, in the focus group interview with parents the interaction between the parents was clear and visible: they turned to one another, listened carefully and encouraged what others described.

The use of phenomenological inspiration in study IV gave us the possibility to get deeper into the adolescents' own lives (95). Based on the phenomenological perspective, experiences of illness, suffering and treatment should be understood in terms of what they meant to each individual (114). Throughout both the interview process and the analysis process the authors

tried to bracket their preconceptions, so it was possible for the phenomenon to become apparent and be described.

Transferability refers to the generalizability of the data, i.e., whether conclusions made on the basis of the data can be transferred to other settings or groups (204). In study I, the study population was relatively small, but the medical records were selected randomly from PHCs serving a wide range of neighborhoods and socio-economic groups. Further, the children were randomly included and stratified by age groups. With the Huber-White sandwich estimator (104, 105), we adjusted for the risk that the observations were more similar within each PHC. With these adjustments made, we could state that adherence to guidelines seems low at PHCs in the Stockholm region in Sweden.

In study II, strengths include the population-based design with the use of self-assessed information on HRQoL, the large study sample, and the high response rate, which bring generalizability to the results.

In studies III and IV, we were aware that the qualitative studies had a limited number of participants. However, the important thing is to collect answers rich and varied enough to illuminate the aim. We cannot generalize the results, but instead we receive a deeper knowledge of experiences of living with asthma and these results may be transferrable to other contexts and research fields, including adolescents or parents of children with other chronic diseases.

7 CONCLUSIONS

Based on the results of this thesis, asthma care of children and adolescents with asthma needs to be improved both in a nursing and in a medical perspective.

- There is a gap between the care provided for pediatric asthma and the recommendations in national guidelines.
- Asthma during adolescence impairs health-related quality of life, especially when asthma is partly controlled or uncontrolled.
- Parents of children with asthma feel frustrated and report a lack of knowledge about how to treat and take care of their children in daily life. They have to communicate well to be understood by health care professionals and teachers in pre-schools and schools.
- Adolescents with asthma and parents of children with asthma need to be met with competence and understanding by health care professionals.
- Adolescents with asthma develop their own strategies for self-management and struggle with an ambivalence between the strong desire to interact socially and the need to manage their asthma.
- Limitations in physical activities affect adolescents with asthma which stress the importance of health care professionals to give advice on strategies to perform physical exercise.

8 FUTURE STUDIES

- This thesis produced less knowledge about the younger children themselves, so to gain further insights about pediatric asthma care from a patient perspective, we need more knowledge regarding what it is like to live with an asthma disease from younger children's perspective. One way forward could be to perform individual interviews with school children with asthma.
- Adherence to national guidelines was low, so it would be interesting to conduct a new study in PHC to scrutinize the medical record (to compare with study I) and examine if the new updated national guidelines on asthma have affected asthma care in PHCs.
- Adolescents with asthma have impaired HRQoL, especially when asthma is partly controlled or uncontrolled. Further, many adolescents reported impact on physical activities. There is a need to further investigate if there is a correlation between physical activities, HRQoL and asthma control among young adults with asthma. One way could be to collect data by questionnaires on HRQoL, questions about physical activities and ACT to young adults with asthma and thereby investigate if there are any associations between those factors. This study may be possible in the new planned follow up in BAMSE.
- Adolescents with asthma developed their own strategies for pharmacological treatment. We need more and deeper knowledge about adherence to pharmacological treatment in adolescents and young adults. This can be done using individual interviews and asking adolescents and young adults about barriers and facilitators to adhering to pharmacological treatment.

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11 SVENSK SAMMANFATTNING

Astma är en av de vanligaste kroniska sjukdomarna hos barn och ungdomar. Sjukdomen förekommer med en prevalens om cirka 8-10 % i Sverige.

Att uppnå astmakontroll är en viktig faktor för att må bra i sin sjukdom. Astmakontroll kan definieras som den grad av symtom och aktivitetsbegränsning patienten har och det behov av luftrörsvidgande medicinering som påvisas hos patienten. Kontroll av astma baseras också på den risk man har att drabbas av försämring och exacerbationer vid ex försämrad lungfunktion, medicinbiverkningar, dålig följsamhet, inkorrekt inhalationsteknik etc.

Studier har visat att de som har astma kan i de allra flesta fall uppnå astmakontroll om de erhåller rätt vård och behandling. Ändå ser man att många barn och ungdomar med astma inte uppnår kontroll, utan rapporterar både dagliga och nattliga symtom, och ökad skolfrånvaro. Vi har idag begränsad kunskap kring hälso- och sjukvårdspersonalens följsamhet till de riktlinjer som finns för vård och behandling av barn och ungdomar med astma.

Behandlingen syftar till besvärsfrihet, utan dagliga symtom och utan akuta försämringsperioder. Lungfunktionen ska vara näst intill normal och patienten ska ha få eller inga biverkningar av sina mediciner. Den farmakologiska behandlingen styrs av graden av astmakontroll. Behandling handlar också om de icke- farmakologiska delarna. Patienten behöver få utbildning om sin sjukdom samt få demonstration om inhalationsteknik, vad man skall göra vid försämringar och vilka utlösande faktorer som finns i vardagen och försämrar sjukdomen. Denna behandling ska baseras på patientens behov och i en ömsesidighet mellan sjukvårdspersonal och patient.

Att leva med en astmasjukdom kan påverka vardagen fysiskt, psykiskt och socialt. Tonårstiden är en sårbar tid då mycket händer i kroppen, både fysiologiskt och psykologiskt. Att då också ha en astmasjukdom kan ställa särskilda krav på ungdomar och vi vet att ungdomar med astma kan vara svåra att behandla ur ett kliniskt perspektiv. Att vara förälder till ett barn med astma påverkar också hela familjens situation. Därför behöver vi mer kunskap om hur personal som tar hand om barn med astma följer gällande riktlinjer och hur vardagen ter sig för den som lever med en astmasjukdom.

Det övergripande syftet med denna avhandling var att undersöka personalens följsamhet till riktlinjer och undersöka konsekvenserna av att leva med en astmasjukdom för barn och ungdomar med astma.

Detta utfördes genom fyra delstudier:

Studie 1 undersökte personalens följsamhet till riktlinjer genom journalgranskning. Journaler granskades gällande 366 barn och ungdomar i åldern sex månader till 16 år med läkardiagnostiserad astma samt för 281 barn med diagnos på hosta eller obstruktiv bronkit vid 18 vårdcentraler i Stockholms län. Av dessa exkluderades 223 journaler, då dessa barn inte

uppfyllde kriterierna för en astmadiagnos, vilket gav en total studiepopulation på 424 barn med astma.

Journalgranskningen utfördes av sjuksköterskor med erfarenhet och kunskap inom astmaområdet. Journalernas dokumentation granskades med avseende på prioriterade kvalitetsindikatorer i gällande nationella riktlinjer för astma både i sin helhet och under de sista 12 månaderna; allergianamnes, förskrivning av inhalationssteroider, utförd spirometri, genomförd patientutbildning, demonstration av inhalationsteknik, tobaksexponering samt om patienten erhållit en planerad uppföljning.

Resultatet visade att följsamheten till riktlinjerna uppvisade brister. Tobaksanamnes rapporterades i endast 14 % av fallen. Den farmakologiska behandlingen rapporterades också i högre utsträckning (58 %) än patientutbildning och demonstration av inhalationsteknik som dokumenterades i 14 % av fallen. Totalt 22 procent (n=49) av barnen från sex års ålder hade någon gång blåst en spirometri och 14% (n=37) hade utfört spirometri de sista 12 månaderna. Spirometri utfördes i högre grad om man hade tillgång till en astmasjuksköterska på vårdcentralen (P=0.003).

Studie II undersökte livskvalité hos ungdomar utifrån BAMSE studien, en populationsbaserad födelsekohort. Studiepopulationen (n = 2 946) i denna studie bestod av ungdomar som deltagit i 16-årsuppföljningen och besvarat frågor om bl.a. hälsorelaterad livskvalité, allergisjukdom, bakgrundsfaktorer och medicinering. Hälsorelaterad livskvalité undersöktes i relation till astmasjukdom och grad av astmakontroll. Det instrument som användes var ett generiskt instrument, EQ-5D, som kan mäta livskvalité inom en population men också möjliggör jämförelser med olika patientgrupper. Instrumentet består av 5 dimensioner (rörelse, hygien, aktivitet, smärta/ obehag och oro/depression) i tre allvarighetsgrader och en VAS-skala där man skattar sin hälsa mellan 0 till 100, där 0 är den sämsta upplevda hälsa och 100 den bästa.

Resultatet visade att ungdomar med astma rapporterade mer problem i EQ 5D dimensionen smärta och obehag än ungdomar utan astma (P<0.001). Ungdomar med astma visade också en lägre EQ VAS median än de som inte hade astma (85 vs 90, P=0.002). Detta resultat kvarstod efter justering för möjliga confounders såsom för kön, rökning och eksem. Flickor hade lägre livskvalité än pojkar, men efter vår justering var denna skillnad inte längre signifikant. De markörer som användes för att mäta astmakontroll visade att många tonåringar rapporterade besvär vid ansträngning (82 %) och att en tredjedel undvek ansträngning p.g.a. sin astma. Ungdomar med en delvis kontrollerad eller okontrollerad astma hade lägre EQ VAS median än unga med kontrollerad astma (85 vs 90, P = 0.04 and 70 vs 90, P = 0.003). Ungdomar med kontrollerad astma hade samma upplevda hälsorelaterade livskvalité som de utan astma. Detta resultat visar att det är viktigt att mäta astmakontroll och livskvalité på ungdomar med astma och att fler studier skulle behövas för att visa sambandet.

Studie III Här utforskade vi upplevelser av att leva med en astmasjukdom bland föräldrar till barn med astma och bland ungdomarna med astma genom fyra fokusgruppsintervjuer.

Föräldrarna och tonåringarna rekryterades från två barn- och ungdomsmedicinska mottagningar tillhörande Astrid Lindgrens barnsjukhus i Stockholm, en i norr och en i söder. Barnen till de rekryterade föräldrarna och tonåringarna hade en läkardiagnostiserad astma och skulle vara ordinerade regelbunden behandling med inhalationssteroider. De fyra fokusgruppsintervjuerna bestod totalt av 9 tonåringar och 11 föräldrar. Intervjuerna analyserades med en kvalitativ metod, systematisk textkondensering, som systematiskt bearbetar intervjutexten genom att man flera gånger varvar texten mellan helhet och delar för att inte missa något ur kontexten. Slutligen sammanfattas essensen i kategorier eller teman som bildar rubriker i resultatdelen.

De teman som framkom ur resultatet var frustrationer, strategier och förväntningar. Föräldrar kände sig frustrerade och osäkra på hur de skall ta hand om sitt barn med astma. De kände sig ensamma och blev ibland inte betrodda av lärarna och pedagogerna i skolan eller förskolan. Föräldrarna kände inte alltid att de möttes av kompetent personal som kunde förstå hur det är att leva med en astmasjukdom. Att kommunicera väl var en viktig faktor för att bli förstådd. De hade förväntningar på att få möta personal som förstod och hade kompetens för att ta hand om barn med en astmasjukdom. När de fick träffa en astmasjuksköterska kände de att detta var möjligt: sjuksköterskan var kompetent och förstod och kunde också skraddarsy behandlingen. Trots att samtliga var ordinerade regelbunden behandling med inhalationssteroider utvecklade tonåringarna egna behandlingsstrategier: tog ibland ingen medicin, ibland vid ansträngning, och ibland väntade de tills astmaattacken gick över. De ville vara som sina kompisar och de tyckte inte kompisarna behövde veta att de hade astma. Att få komma och utföra spirometri för att se hur bra de mårde i sin astma var viktigt för att se om de blivit bättre eller sämre jämfört med tidigare test; om det var idé att fortsätta med medicinerna. Ungdomarna vill också träffa personal som förstod dem och hade kompetens inom astmaområdet.

Studie IV utforskade ungdomarnas uppfattningar av att leva med en astmasjukdom genom 10 djupintervjuer. Dessa ungdomar rekryterades från den populationsbaserade BAMSE-studien. Samtliga hade en läkardiagnostiserad astma; hälften hade haft sin astma sedan de var små och hälften hade debut i skolåldern. Även i denna studie analyserades materialet med den kvalitativa metoden, systematisk textkondensering, men denna gång med inspiration från fenomenologin. Fenomenologin är en ansats som möjliggör att försöka nå djupare in i människors liv och förstå hur det är att leva med en astmasjukdom, med känslor, tankar och handling i fokus. Man försöker här nå människors livsvärld, vilket betyder att man försöker fånga upplevelser/uppfattningar/innebörden av att ha en astmasjukdom i det dagliga livet, vardagen, minnen, framtid m.m.

Resultatet visade att tonåringar med astma lever med en ambivalens mellan att behandla sin sjukdom och att interagera socialt, att få vara som alla andra, prestera som alla andra etc. Ambivalens framkom i tre olika kategorier: *Förståelse och förnekelse*, *Att bli bekräftad men inte definierad av sin astma* och *Att känna sig frisk, men ha ganska mycket astmasymtom speciellt vid ansträngning*. Att ha astma under tonåren innebär att man har lärt sig leva med

sin sjukdom, och utvecklat en insikt, man vet ofta hur man ska hantera den och man tar ansvar för sina symtom. Men å andra sidan ignorerar man också sina symtom, man vill inte visa att man har astma, man förnekar sjukdomen och ibland säger man att det beror på dålig kondition när det är astmasymtomen som är orsaken till besvär exempelvis vid ansträngning. Som tonåring med astma vill man också bli bekräftad – det är viktigt att familjen, kompisarna och syskonen förstår hur det är att leva med en astmasjukdom. Att ha lärare som förstår är också viktigt, däremot beskrevs lärare som inte förstod som frustrerande för ungdomarna. Den andra sidan av detta var att inte vilja bli definierad av sin astma, man ville bli behandlad som en ”vanlig tonåring”. Som tonåring ville man inte att man skulle ta för stor hänsyn vid t.ex. träningar och matcher för att man hade astma eller att lärarna skulle berätta för hela klassen vilka hänsyn man bör ta till ungdomen med astma. De intervjuade ungdomarna kände sig ganska friska i sin sjukdom. De tyckte inte att astman utgjorde en särskilt stor del av deras liv men ändå beskrev de att de hade mycket symtom, speciellt vid ansträngning. Att ha astma vid ansträngning kändes begränsande: att inte kunna prestera som sina kompisar, att inte kunna vara bäst, att behöva avbryta eller ta pauser.

Slutsatsen av dessa studier är att astmasjukvården behöver förbättras både utifrån ett medicinskt- och ett omvårdnadsperspektiv. Sjukvårdspersonalen behöver ha kompetens inom astmaområdet för att kunna möjliggöra att unga med astma uppnår astmakontroll och kunskap för att skapa förståelse för hur det är att leva med en astmasjukdom. De behöver lyssna mera på patienten för att se vilka behov och mål som patienten har för att sedan tillsammans upprätta en behandlingsplan. Att bl.a. mäta astmakontroll genom ACT formulär och även be patienten fylla i livskvalitéformulär kan vara en möjlig väg för att försöka uppnå ett välbefinnande hos barn, ungdomar och föräldrar till barn som lever med en astmasjukdom.

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