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ADHERENCE TO INHALED CORTICOSTEROIDS OF ADOLESCENTS SUFFERING FROM ASTHMA OR RESPIRATORY SYMPTOMS: UNDERSTANDING YOUNG PERSONS’ BEHAVIOUR

Fien DE PORRE
First Master of Pharmaceutical Care

Promoter
Prof. dr. K. Boussery
Co-promoter
Prof. dr. M.L. Bouvy

Commissioners
Prof. dr. J. P. Remon
Dr. E. Mehuys
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May 29, 2013

Promoter
Prof. dr. K. Boussery

Author
Fien De Porre
SUMMARY

Background: Asthma is a chronic illness with a high prevalence amongst children, however a significant amount of adolescents also suffers from it. Treatment of asthma is twofold, consisting of reliever and controller medication. Controller medication, including inhaled corticosteroids (ICS) as the most effective ones, should be taken daily to prevent symptoms and exacerbations. It is known that adherence to ICS is not sufficient and it is assumed that teenagers are even less adherent than children and adults. Knowledge about factors underlying poor adherence in adolescents is rare.

Objectives: The aim of this study was to obtain more information about adherence and related factors to ICS in adolescents suffering from asthma/respiratory symptoms.

Methods: This study was a cross-sectional pharmacy-based study. Patients (12-18 years old) from different pharmacies in the Netherlands, filling of at least two prescriptions for ICS during the past to years, were selected from the pharmacy information system and invited for participating in this study. They were asked to fill in an online questionnaire containing questions about adherence, smoking behaviour, influence of peers and parents, medication beliefs and medication knowledge.

Results: Complete questionnaires were obtained from 74 patients (8,7%). From the participants 62,2% was considered to be non-adherent. A significant difference in adherence was found for the following factors: forgetfulness, symptomatic use of ICS, trying to handle symptoms without medication, denial of asthma severity and difficulties with finding a daily medication routine. Participants not using their ICS in presence of peers (other than friends) were more often non-adherent. Patients, who thought that parental support was to high, usually had a lower adherence. Adherence to ICS was proportional to the users belief in its necessity towards the amount of concerns they had. Finally important reasons for not participating in health research surveys were not using the medication anymore, lack of time, concerns about privacy and the drop by or phone calls of researchers.

Conclusion: Adherence of Dutch adolescents suffering from asthma or respiratory symptoms is not sufficient and there are different factors that can be improved. Because adolescents constitute an individual part of the population, it is important to get more insight in adolescents’ beliefs and attitudes concerning treatment. A greater understanding of teenage usage will affect their adherence by improving both communication and attitudes towards treatment, therefore keeping asthma under control.
SAMENVATTING

Inleiding: Astma is een chronische aandoening die veel voorkomt bij zowel kinderen als pubers. De therapie bestaat zowel uit nood- als onderhoudsmedicatie. Deze laatste, waarvan inhalatiecorticosteroïden (ICS) als meest effectieve worden beschouwt, moet dagelijks worden aangewend ter voorkoming van astma symptomen en exacerbaties. Het is algemeen bekend dat therapietrouw met ICS onvoldoende is. Verder wordt gesuggereerd dat pubers nog minder trouw zijn aan hun therapie dan kinderen en volwassenen. Toch is er weinig gekend over onderliggende factoren van therapieontrouw bij pubers.

Doelstellingen: Deze studie had als doel meer informatie te vergaren over therapietrouw met ICS en verwante factoren bij pubers in Nederland met astma/luchtwegklachten.

Methoden: Dit was een cross-sectionele studie. In verschillende Nederlandse apotheeken werden uit het apotheek informatie systeem volgende patiënten geselecteerd en uitgenodigd voor deelname aan dit onderzoek: 12 tot 18 jarigen die de voorbije twee jaren minimaal twee ICS recepten hebben opgehaald. Hen werd gevraagd een online enquête in te vullen handelend over: therapietrouw, rookgedrag, invloed van leeftijdsgenoten en ouders, opvattingen en kennis over astma medicatie.

Resultaten: Van de patiënten vulden 74 (8,7%) de vragenlijst volledig in. Daarvan werd 62,2% therapietrouw geacht. Er was een significant verschil in therapietrouw voor de volgende factoren: vergeetachtigheid, symptomatisch gebruik, het proberen zonder ICS te leven, ontkennen van astma ernst en problemen met een dagelijkse inhalatie routine. Wie de medicatie niet gebruikte in aanwezigheid van leeftijdsgenoten (andere dan vrienden) was vaker therapietrouw. Patiënten die hulp van ouders als te veel ervoeren, waren minder therapietrouw. Hoe hoger het geloof in de noodzaak van ICS (t.o.v. het aantal zorgen), hoe hoger de therapietrouw. Ten slotte waren de belangrijkste redenen om niet deel te nemen aan onderzoek het niet meer gebruiken van de medicatie, tijdsgebrek, ongerustheid over privacy en het bezocht of opgebeld worden door onderzoekers.

Besluit: De therapietrouw van pubers in Nederland met astma/luchtwegklachten is niet optimaal en verschillende factoren kunnen hierin verbeterd worden. Aangezien pubers een afzonderlijk deel uitmaken van de populatie, is het nuttig inzicht te krijgen in hun opvattingen over en hun houding tegenover de behandeling. Dit kan de communicatie met en de behandeling van pubers verbeteren, wat op zich de therapietrouw en de uitkomst van astma positief kan beïnvloeden.
A WORD OF GRATITUDE

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# TABLE OF CONTENTS

1. **INTRODUCTION** .................................................................................................................. 1
   1.1. **ASTHMA** ..................................................................................................................... 1
       1.1.1. Disease and treatment ............................................................................................... 1
       1.1.2. Asthma in teenagers ................................................................................................. 2
   1.2. **PUBERTY** ..................................................................................................................... 3
       1.2.1. Definition .................................................................................................................... 3
       1.2.2. Puberty and chronic illness ....................................................................................... 4
   1.3. **MEDICATION ADHERENCE** .......................................................................................... 4
       1.3.1. Terminology ................................................................................................................ 4
       1.3.2. The problem of non-adherence ................................................................................ 5
       1.3.3. Measurement of adherence ....................................................................................... 5
       1.3.4. Adherence to asthma treatment: inhaled corticosteroids ........................................... 6
   1.4. **FACTORS RELATED TO ADHERENCE TO ASTHMA TREATMENT** ............................ 7
       1.4.1. Beliefs, attitudes and knowledge ................................................................................... 8
       1.4.2. Fear of side effects ...................................................................................................... 9
       1.4.3. Psychological factors influencing adherence ............................................................ 9
       1.4.4. Smoking behaviour .................................................................................................... 10
       1.4.5. Family support ........................................................................................................... 10
       1.4.6. Influence of peers ....................................................................................................... 11
       1.4.7. Communication with health care providers .............................................................. 11
       1.4.8. Asthma severity ......................................................................................................... 12
       1.4.9. Socio-demographic factors ....................................................................................... 12
       1.4.10. Daily routine, regimen complexity and administration route ................................. 13

2. **OBJECTIVES** ....................................................................................................................... 14

3. **METHODS** ......................................................................................................................... 16
   3.1. **RESEARCH DESIGN** ..................................................................................................... 16
       3.1.1. Study population ....................................................................................................... 16
       3.1.2. Data collection ............................................................................................................ 16
   3.2. **STUDY APPROVAL** .................................................................................................... 17
   3.3. **QUESTIONNAIRE** ........................................................................................................ 17
       3.3.1. Socio-demographic variables ................................................................................... 17
       3.3.2. Respiratory symptoms ............................................................................................... 18
       3.3.3. Smoking behaviour .................................................................................................. 18
       3.3.4. Medication adherence ............................................................................................... 18
       3.3.5. Influence of peers and parents .................................................................................. 19
       3.3.6. Beliefs about medicines ............................................................................................ 19
       3.3.7. Knowledge about asthma medication ........................................................................ 20
3.3.8. Participation in health research ......................................................... 20
3.4. DATA ANALYSIS .................................................................................. 20

4. RESULTS ................................................................................................. 22
  4.1. RESPONSE RATE .............................................................................. 22
  4.2. DESCRIPTION OF THE PARTICIPANTS ............................................ 23
      4.2.1. Socio-demographic variables ..................................................... 23
      4.2.2. Airway symptoms ................................................................... 24
      4.2.3. Medication adherence ............................................................. 25
      4.2.4. Smoking behaviour and influence of peers and parents .......... 25
      4.2.5. Beliefs and knowledge about asthma medication .................... 28
  4.3. ANALYSIS OF THE RESULTS .......................................................... 28
  4.4. PARTICIPATION IN HEALTH RESEARCH ........................................ 31

5. DISCUSSION ............................................................................................ 34
  5.1. INTERPRETATION OF THE RESULTS ................................................ 34
      5.1.1. Adherence ............................................................................... 34
      5.1.2. Smoking behaviour and influence of peers and parents .......... 35
      5.1.3. Beliefs and knowledge about asthma medication .................... 36
      5.1.4. Factors influencing adherence .................................................. 36
  5.2. STRENGTHS AND LIMITATIONS OF THE STUDY ............................ 38
      5.2.1. Strengths ............................................................................... 38
      5.2.2. Response rate ........................................................................ 38
      5.2.3. Analysis .................................................................................. 39
      5.2.4. Reminding of patients ............................................................ 39
      5.2.5. Methodology .......................................................................... 40
      5.2.6. Study sample ......................................................................... 40
      5.2.7. Indistinct of questions ................................................................ 41
  5.3. RECOMMENDATIONS FOR THE FUTURE ....................................... 41

6. CONCLUSION ........................................................................................... 43

7. REFERENCES ............................................................................................ 44
LIST OF USED ABBREVIATIONS

ACQ: Asthma Control Questionnaire
ANOVA: ANalysis Of VAriance
BMQ: Beliefs about Medicines Questionnaire
CI: Confidence Interval
DPI: Dry Powder Inhaler
GINA: Global INitiative for Asthma
ICS: Inhaled Corticosteroids
IRB: Institutional Review Board
MARS: Medication Adherence Report Scale
MDI: Metered-Dose Inhaler
MEMS: micro-electronic Medication event Monitoring System
OCS: Oral Corticosteroids
PIAMA: The Prevention and Incidence of Asthma and Mite Allergy
UPPER: Utrecht Pharmacy Practice network for Education and Research
1. INTRODUCTION

1.1. ASTHMA

1.1.1. Disease and treatment

Worldwide asthma is one of the most common chronic diseases, especially among children (1,2). But also the amount of adolescents suffering from asthma is significant (3). In Europe, the prevalence of asthma in children is around 10% (1). In the Netherlands, it varies between 4% and 7% (4–6). Based on the analysis of five registrations of physicians, the prevalence of asthma on the 1th of January 2007 in the Netherlands was 7.45% for the ages of 10 until 14 years old and 6.47 % for the ages of 15 until 19 years old (4). Information about the trend in prevalence of asthma is rather diverse. There is a higher report of an increase in the prevalence than a decrease, and this more for the ages of 6-7 years old than for the age of 13-14 years old (7).

Asthma is characterized by chronic inflammation of the airways, associated with a condition of hyper responsiveness. Typical are periodic episodes in which the patient has symptoms, such as wheezing, chest tightness, breathlessness and coughing. This occurs mainly at night and in the early morning. Various risk factors can provoke an exacerbation of asthma. Examples of risk factors include allergens (e.g. pollen), tobacco smoke, air pollution, exercise and (mainly viral) respiratory infections. Between those episodes the airway obstruction is reversible, but nevertheless the inflammation is chronic (8).

Treatment of asthma is twofold; the keystone of asthma treatment is controller medication (anti-inflammatory agents), including inhaled corticosteroids (ICS) as the most effective ones. These medicines should be taken every day as a prophylactic therapy to prevent symptoms and exacerbations. On the other hand there is reliever or rescue medication (bronchodilators), used to treat acute symptoms in an attack. The latter should only be taken occasionally. Regular use or overuse of rescue medication should be avoided and is a sign of poorly controlled asthma. Asthma treatment works in two directions as shown in figure 1.1. If asthma is not controlled, a next step in the treatment ladder should be considered. Prior to this, it is important to have attention for the patient’s inhalation technique, adherence and handling of risk factors such as the avoidance of particular allergens or tobacco smoke. On the other side, if the asthma is controlled during a minimum of three months, a descent towards a lower step is permitted. The purpose of asthma treatment is to achieve and keep control with a minimum of medication. Even when asthma
symptoms are controlled, monitoring stays essential, because of the variable nature of the disease. According to the GINA guidelines, patients should be seen by a physician every three months. But when an exacerbation has occurred, patients should return within two weeks to one month (8).

![Management Approach Based On Control](image)

**Figure 1.1:** The ladder of treatment based on asthma control according to the GINA (Global INitiative for Asthma) guidelines (8). Treating of asthma occurs in two directions; in each step rescue medication must be provided. From step two until step five also controller medication on a regular base must be added. There are different possibilities for reliever and controller medication, the shaded boxes are the recommended treatment options.

1.1.2. Asthma in teenagers

It is assumed that making a diagnosis of asthma in teenagers is easier than in children, because there are fewer possibilities in the differential diagnosis and it is easier to measure
lung function. Diseases that can be confused with asthma at this age are mainly hyperventilation, vocal cord dysfunction, psychogenic cough and bronchiectasis. Still a detailed examination leads often to the right differential diagnosis. In spite of those advantages underdiagnosis and undertreatment at this age are sadly not rare (3,9).

Just like in a child, the presence of asthma in an adolescent can interfere with daily activities, is a significant reason for school absence (10,11) and needs an intensive process of self-care, often lifelong (12,13). An important difference in asthma treatment between childhood and adolescence is the responsibility. It is supposed that in childhood parents take most of the responsibility for the child’s treatment. With increasing age, the balance of responsibility shifts more towards the patient himself (14).

Compared to children, asthma in teenagers is much more variable. Furthermore, there is often confusion about the fact that children may or may not outgrow their asthma and also new cases of asthma in adolescence can appear. Exposition to different extrinsic factors can be one explanation why the asthma pattern (symptoms and severity) in adolescence is changing. During puberty, teenagers gain different interests and occupy with different activities and hobbies associated with their age. Exposure to smoke (which is a bigger issue in adolescence than in childhood), both active and passive, can increase the risk of having more severe asthma; not only smoke from cigarettes, but also from inhaled recreational drugs. This risk can increase even more when they are often in closed spaces, which may be filled with smoke, such as a disco. The abuse of alcohol and different feeding habits can also increase the risk (9).

1.2. PUBERTY

1.2.1. Definition

Adolescents go through a period that is called puberty. This is the period between childhood and adulthood (9) in which they have to deal with a lot of changes on various levels; not only physically, but also at emotional, psychological and social level (3,9). The young persons start to look for a own identity, try to make their own decisions and struggle against the dependency on their parents. By contrast, peers will increasingly be playing an important role in their life (3,9,14). As a consequence of all those changes, teenagers often manifest risk-taking behaviour to examine new boundaries in their environment (15).
1.2.2. Puberty and chronic illness

During puberty becoming part of a peer group is crucial. This demands following some rules and behaviour enforced by the group. Having a chronic illness, for example asthma, can interfere with this new lifestyle (12). The presence of a chronic disease and its treatment, causes a permanent change in style of living and demands continual adaptation. Activities are often interrupted by treatment and there is a change in physical appearance (12,13). As a result of that, a chronic disease demands a lot of the young person and harms different aspects of his or her life. Examples are school, work and sport (13). That is why it is not always easy to feel equal to group members and it can create a feeling of being different. Teenagers, suffering from a chronic illness, try to learn being more independent just like normal teenagers do. Paradoxically because of their illness, they often stay dependent emotionally, physically and financially on their parents (12). Thus having asthma and taking medicines each day, can impede with the changes during puberty, making puberty even more difficult than it already is (3).

Fears that chronically ill adolescents experience are being distinct from peers, losing physical intactness, staying dependent on family, losing any control and dying. On top of those fears, chronically ill adolescents are also dealing with the daily worries a teenager normally has to deal with regarding school, friends and family. This also includes concerns about employment and career in the future (16). Also, teenagers’ schedule, compared to children, becomes often more busy and hectic and can be a reason why having a routine with their medicines is a problem (17). It is plausible that adolescents can be compared to older children and adults according to medication recommendations. Even so, they have to be approached in a completely different way regarding communication and organisation of care (3). That is why adolescents deserve extra attention, in this case related to asthma.

1.3. MEDICATION ADHERENCE
1.3.1. Terminology

First it is important to clarify the difference between compliance and adherence, although these two terms are often used together. Compliance is about following treatment as it has been prescribed by the doctor (3). Adherence is quite the same, but is less accusatory than compliance. It has a denotation of having a choice, without accusation, to
be loyal to the therapy or not (12,18). To avoid confusion the term adherence will be used consistently in this thesis.

Non-adherence can be categorized in different ways. First there is a division in absolute and partial non-adherence. Nevertheless, it is seen that adherence is often rather partial than complete. A more significant division of non-adherence in the context of this research is unintentional and intentional non-adherence (14). Unintentional non-adherence is caused by practical barriers, such as: having problems with opening the packaging, forgetting to take the medicine or having difficulties with intake instructions. A more significant part of patients can be categorized in the intentional group. It means that they choose purposefully not to take the medicine as prescribed as a result of weighing up the pros and cons (19). This can give consequence to a separate group of patients who do not even fill their prescription.

1.3.2. The problem of non-adherence

Non-adherence is a worldwide problem for all ages and different diseases (3). The physician prescribing the medicine and the pharmacist delivering it, assume that instructions will be followed as instructed. However, that is not always the case (18,20). Poor adherence is seen in about 50% of chronically ill people (21), inclusive adolescents with a chronic disorder (12,22). Approximately one third of the people in general is adherent to their medication therapy, another third has a more or less adequate adherence and the last third is non-adherent. This is found in several studies about different medical treatments (3). Non-adherence causes higher health care costs and can lead to therapy failure (12).

1.3.3. Measurement of adherence

There are different ways to measure adherence, although not one is perfect. The analysis of blood, urine, saliva and other body fluids is one example. It can demonstrate if the medication is truly taken by the patient. On the other hand it is expensive, often invasive and not free of mistakes. Furthermore evaluation by clinicians, without explicitly asking the patient about it, can give insight in patient’s adherence. This is on the basis of physician’s past experience with the patient, patient’s characteristics and treatment outcome. Still, it is known that physicians often overestimate patient’s adherence. The most common method to assess adherence is self-report by patients. This includes interviews,
questionnaires and medication diaries. It is known that these methods have their limitations too, but they are less expensive. Moreover, self-report can reveal precious information regarding mechanisms underlying (non)-adherence and regarding the patient’s thoughts. Another method in assessing adherence is pill counting or inhaler weighing (more applicable to asthma treatment). This cannot tell us if the patient actually took the medicines or, for example, dumped them just before the doctor’s appointment. Another and high reliable method is the use of a micro-electronic Medication Event Monitoring System (MEMS). Every time the container is opened, date and time are registered. Although in this way medication “dumpers” can be revealed, it still not tells us if the medication is actually taken (14,23,24). Finally another and often used method to assess adherence, is the review of pharmacy records. There are different ways to measure adherence with this information that all give comparable results. According to one study (25), the easiest method to calculate adherence is the Medication Refill Adherence (MRA): The total days of supply must be divided by number of days of study participation and multiplied by hundred. Also used often is the Medication Possession Ratio (MPR). This is the ratio of the total days of supply to number of days of participation per participant. Again it is not possible with this method to find out if the medication is actually taken (25).

1.3.4. Adherence to asthma treatment: inhaled corticosteroids

If ICS are used properly, mild to moderate asthma can be controlled efficiently (26). But it is well known that adherence to ICS is not sufficient. ICS adherence rates vary from 40% to 60% (26–28). In children and adults only 50% or less of the controller medication is taken as prescribed (17,29). In adolescents, it is believed that adherence rates are even lower than in children and adults (14,17). But is this accusation rather a consequence of the difficulties we experience in the treatment of that specific group or is it actually the truth (3)? On the other hand knowledge about the mechanisms underlying poor adherence in adolescents is rare (17).

Poor adherence is related to higher morbidity and mortality of asthma (30). Asthma morbidity is even higher in adolescents than in young children (3,9). The higher morbidity during teenage years is due mainly to underdiagnosis of asthma, although the morbidity stays high in the diagnosed and treated group. Besides poor adherence, a low grade of
adolescents seeking medical help and realizing the purpose of prophylactic therapy, are associated with higher morbidity as well (9).

Adherence to asthma treatment is not only about the intake of medication, but also about the need to avoid circumstances that causes asthma attacks. Adherence to that part of asthma treatment is even lower than to medication. Orders about avoiding pollens, animals and certain food demands a different and regular lifestyle that not always matches with the one an adolescent choose to live. Rather having an attack than being different from their peers, could be a reason why adherence to that part is even lower (12). However in this thesis, the focus will be on adherence to ICS, as the most important and the most prescribed treatment for asthma.

1.4. FACTORS RELATED TO ADHERENCE TO ASTHMA TREATMENT

To analyse and understand the mechanisms underlying poor adherence in adolescents and treatment-related behaviour, we are first going to give a summary of studied factors in literature potentially related to adherence. Some of them are typical in adolescents (with asthma and/or other chronic diseases), others are more general (10). It is also important to know that adherence is not static, but rather a dynamic phenomenon. For example, a person will be taking less as prescribed, mixed with periods in which he or she stops to take the medicine (3). Figure 1.2 gives a summary of those different factors.

![Figure 1.2: Factors potentially related to adherence](image)

- Administration route
- Regimen complexity
- Socioeconomic origin
- Peer support
- Communication with health care providers
- Knowledge
- Fear of side effects
- Education
- Age
- Exercise
- Ethnic/racial status
- Family support
- Anxiety, low self-esteem, anger, fear, guilt...
- Daily routine
- Peer pressure
- Beliefs
- Smoking
- Asthma severity
- Attitudes
1.4.1. Beliefs, attitudes and knowledge

Important and often mentioned are someone’s beliefs about medicines (10,14,18,26,27,31). People make decisions based on their own experiences and the experiences of their environment (18). Those experiences, both negative and positive (26), also affect their beliefs (27). Although adolescents have less experience in life than adults, the reasons on which adolescents’ decisions are made, are not completely different from adults. From the level of mid-teen most of them are able to perform “adult-level cognitive tasks” (17). Beliefs about medicines are also subject to socio-demographic and clinical variables. For example, beliefs are associated with level and type of education (27). People also have often different beliefs about ICS and side effects. The influence of side effects is discussed in more detail in section 1.4.2. Connected with beliefs is the attitude of a patient towards the medication (32,33). An association was found between negative attitudes and morbidity in asthma (10). Having a positive attitude and a good motivation affects adherence in a positive way (12).

Another important factor is knowledge about asthma disease and treatment (10,11,14). Misinformation and false assumptions regarding asthma can lead to poorer adherence (17). Good knowledge affects the attitudes towards medicines in a positive way (27). Unfortunately, knowledge about asthma seems to be poor (9–11). There is often confusion about the role of reliever and controller medication (17). Many people do not understand the need of prophylactic therapy, because of a lack of feeling any immediate difference. Thinking it is only necessary to take medicines when having symptoms (9,30,27) will lead to overuse of rescue medication, resulting in masking the progress of inflammation (9). Furthermore, there is also confusion regarding the fact that someone did or did not outgrow his or her asthma (17,34). To improve the knowledge, not only the patients should be educated, but also their peers. This is because peers and their knowledge have a significant influence on the attitudes and beliefs of adolescents suffering from asthma (10).

Finally, a study that investigated reasons for starting and discontinuing ICS, found out that the majority did not know the specific diagnosis for their ICS prescription. Only about 9% mentioned asthma, the rest of the reasons were: dyspnoea, cough or cold and pneumonia or bronchitis. There is a possibility that patients forgot the doctor’s diagnosis or that the doctor did not discuss the diagnosis with the patient. Although denial of having asthma can be present, despite the doctor’s diagnosis (30).
1.4.2. Fear of side effects

Fear of side effects is a common factor related to adherence (33). Particularly, there are often concerns and misconceptions about the side effects of ICS (9,12). Also mentioned by adolescents are concerns about getting dependent on their medicines and are statements like “drugs are unnatural” (9). According to the GINA guidelines (8), “Inhaled medications are preferred because they deliver drugs directly to the airways where they are needed, resulting in potent therapeutic effects with fewer systemic side effects”. It is important to emphasize this low risk of inhaled medication compared to systematic administering. Also known are concerns about the use of corticosteroids and the interfering with normal growth and puberty (14). Frequently, ICS are accused of the delayed start of puberty that is often seen in asthmatic adolescents (3). Controlled studies about this part of ICS have demonstrated no significant (neither statistical nor clinical) difference in growth, with a daily dose of 100 to 200 µg of ICS. There is a possibility of growth retardation with higher doses of ICS, but interference with growth is more explicit when asthma is severe or uncontrolled. Thereby children between two and ten years old are more subject to the delay in growth of ICS than adolescents are. Finally the influence of ICS on growth is transient and normal length in adolescence will be reached, but at later age (35).

1.4.3. Psychological factors influencing adherence

As with other chronic diseases, denial of having asthma and of the need of medication seems to be a characteristic of teenagers (9,10). This denial can be seen as a part of the period chronically ill teenagers are going trough; thus as a sign that they are trying to adapt oneself (36). Also adolescents suffering from a chronic disease, like asthma, may be facing more with psychological problems than healthy ones. Examples are: depression, low self-esteem, anger, anxiety, fear, guilt and shame. This again could be a potential factor related to adherence (9,13,14). Although many studies implied psychological deviance in chronically ill children and adolescents, other ones showed the opposite for some components on psychological level. Examples of those components are anxiety and self-esteem (36–38). When we talk about mild asthma, the statement of non-psychological deviance seems correct, but yet there seems to be a difference in psychological condition for patients suffering from severe asthma. Anxiety, depression, irrational beliefs and hostility were highly related to this degree of asthma severity (39).
1.4.4. Smoking behaviour

It is common that adolescents start to smoke during puberty (10,15). It is known that the younger the age a child starts to smoke, the more difficult it is to quit (15). You would expect that teenagers suffering from asthma would smoke less than teenagers without asthma. Apparently this is not the case (9). Especially the prevalence of asthmatic girls smoking is comparable to those who do not suffer from asthma (9,40,41). But then the question would be if risk-taking behaviour, such as smoking, is associated with poor adherence and/or if poor adherence is a risk factor to start smoking (9). A study that tried to reveal the attitudes of adolescents towards smoking discovered that those who had asthma in the past were more positive towards cigarettes. In addition this group also had a stronger intention to smoke in the future than adolescents without asthma (42).

In another study there was discovered that more than 50% of asthmatic smoking adolescents, kept on going, even though they had symptoms when they were smoking (10). Although adolescents are aware of the negative consequences of tobacco smoke, this seems not enough to persuade them to give up smoking. There is a change that with recommendations of doctors and nursing staff in early adolescence, the number of asthmatic adolescents who start smoking, will decrease (15).

1.4.5. Family support

Because of the asthma, parents are often more concerned about their teenager and try to protect them more. The teenager, looking for peer acceptance and independency, probably will disagree, resulting in a fight with the parents. Overprotection can delay the development of independent adherence to treatment and can give rise to further tension in the relationship with their teen, resulting in a refusal of taking medicines (14). Still, family support is a crucial factor for adherence in asthmatic adolescents (12–14,23). Good adherence is associated with open relationships among family members and a good family atmosphere. But then again, poor adherence is related with conflicts and weak family relationships (12). In a study with focus group methodology, teens in general said that the role of parents was bigger than that of health care providers. For them, health care providers did not have enough time and/or had poor communication skills towards teenagers (17).
1.4.6. Influence of peers

It was established that the attitudes towards asthma of peers were quite different from asthmatic adolescents, although in the school environment there seemed to be tolerance towards asthma and medication use (10). Nevertheless, adolescents often mentioned that use of the inhaler gave them the feeling to be different from their peers, that it did not come across as something ‘cool’ (9). Embarrassment can be a factor associated with poor adherence, in fact for some, the use of their inhaler was a sign of weakness. As a part of that embarrassment, there was the fear of peers’ reactions on the fact that they had asthma. For example, peers often think that asthma is contagious. Then it is a difficult and annoying task to convince them of the opposite (17).

On the other side, managing asthma in this age group can be more successful if peer support is involved (9). It is seen that friends’ support has an influence on energy and perseverance for care and that those two latters can ameliorate adherence. Furthermore this support can make it easier for the teen to cope with asthma (13). Also participation in support groups can have a positive influence. In those kinds of groups, the adolescent can find some comfort of young persons who are in the same situation. They can learn from each other how to deal with their asthma related to peers, family and attacks (15,16). According to some asthmatic adolescents, talking to someone like a friend or a family member was important. Even tough, it was just as important to meet friends without always being fixed on the illness (16).

1.4.7. Communication with health care providers

Adequate communication between the doctor and the patient is an essential factor, affecting adherence. Communication with a teenager is a challenge and trust plays an important role (9). It is essential that health care providers listen to their needs, thoughts, wishes and fears and that they realize that asthma is only one aspect of their life. The presence of negotiation will give the young persons some authority (13) and apparently in that case, they are prepared to accept health advice (15).

In one study (12) more than 50% of the adolescents had the feeling that health care staff made decisions about their self-care without deliberating with them. As a consequence of that, teens often lie during consultation when they are asked about their medication use (12,27). In a focus-group study (17) participants mentioned that health care providers were
not good at communicating with adolescents; that young patients often lied or withheld information, because they wanted to avoid a doctor who was angry or nagging around. The time staying at the doctor’s office was also shorter, when they just pretended everything was all right. In the same study, adolescents who reported a trusting relationship with their physician were often long-term patients. Finally, according to some teenagers, it was crucial that physicians told them the core messages several times (17).

Besides a patient-centred approach, a simple treatment plan must be draw up. Moreover, this plan must contain information about: what to do when the asthma deteriorates, when the asthma gets better and when there is an asthma attack. As a consequence of that, the young person has an idea when it is necessary to look for help and has a feeling of responsibility and control over his or her asthma (15). This all certainly will improve adherence (3).

1.4.8. Asthma severity

It is known that many teenagers underrate their asthma (3). According to several adolescents who participated in a focus group study (17), adherence to treatment would be better if they saw their asthma as “serious” or “real”. Comparing with peers was a way to define asthma severity. According to those same teenagers, adherence also could improve after an asthma crisis, which may or may not lead to hospitalization (17). Another study showed a statistically significant relationship between level of adherence and asthma severity (12).

1.4.9. Socio-demographic factors

Several studies showed an association between different socio-demographic factors and adherence. A significant association was seen for age (with the ages of 13 and 14 more adherent than the older ones) and exercise (12,13). Others associated to adherence were: lower socioeconomics origin, lower education and less prevalent racial or ethnic status (33). No association was found for sex and family composition (12,13). Association between socio-demographic factors and beliefs about medicines in general were seen for country of birth and level of education. Patients born in the Nordic countries saw medicines as more beneficial and those having a lower education experienced medication as more harmful (27). Also people with an Asian background considered medicines as more harmful than the
European population (43). Furthermore, it is seen that Western immigrants are more adherent than non-Western immigrants (28, 44).

1.4.10. Daily routine, regimen complexity and administration route

The presence of a regular routine could simplify the intake of medicines. Still, because of changing interests of teenagers, their life becomes busier and perhaps even more chaotic, which opposes regular routines. Adolescents mentioned forgetfulness and bad organising skills as factors that could worsen this. An interesting and potential aid to improve forgetfulness is the storage of different inhalers on different locations, although further investigation is needed (17). As a part of that daily routine, a complex drug regimen with different intakes during day makes it more difficult for the patient to follow (3). It is know that adherence decreases with increasing frequency of administration per day. In one study (45) they observed a decrease in adherence from 71% to 18% of days the medication was actually taken, in respectively those with a two times a day and a four times a day treatment. It is obvious that simple treatment plans are the most successful (15).

The use of an inhaler makes it possible to give lower doses compared to oral administration. There are different kinds of inhalers. Although the use of a spacer device is a system that is easy to use, it is not the most pleasant one for teenagers. They cannot use it in a discrete way without someone is noticing it. That is why the pressurized metered-dose inhaler (MDI) and the dry powder inhaler (DPI) are more popular with adolescents. Nevertheless the inhaler is often used in a wrong way, even after inhalation instructions. There is a change that, even when there is knowledge of using instructions, they do not use it in a proper way. Even tough an MDI/DPI is small, it becomes very clear when the adolescent is using it. As already mentioned, this can lead to embarrassment of asthmatic teens towards their peers. It is likely that an oral preventive therapy in a low frequency is more attractive to teenagers than an inhaled one (15).
2. OBJECTIVES

Asthma is a common illness, not only in children, but also in adolescents. One of the most effective controller therapies is the preventive and long-term treatment with inhaled corticosteroids (ICS). It has been shown that treatment with ICS is really effective, nevertheless the morbidity and mortality in asthma is still high. Low adherence to ICS is a major problem in asthma treatment and associated with uncontrolled asthma. In children and adults it is known that adherence to ICS is low, but in adolescents it is assumed that adherence rates are even lower. Furthermore, we do not have good insight in the mechanisms that lay underneath adolescents’ poor adherence. Adolescents cannot be seen as children or adults, as they go through the difficult period of puberty. During that period, becoming member of a peer group is very important. The presence of a chronic illness, like asthma, can create a feeling of being different and can oppose the growing independency on family that is common in teenagers. In other words, they constitute an individual part of the population and that is why it is so crucial to examine this age group in more detail.

The aim of this study was to obtain more information about adherence and factors related to medication use of adolescents suffering from asthma/respiratory symptoms. We formulated the following research questions:

- How adherent to treatment with ICS are adolescents with asthma in the Netherlands?
- What are potential factors related to non-adherence?
- Are adolescents interested in participating in health research? Why or why not? Concerning adherence, we wanted to draw extra attention to the following five factors: Influence of smoking, peers and parents, adolescents’ beliefs about ICS and adolescents’ knowledge about asthma medication.

The first step was to develop a questionnaire, consisting of existing validated questionnaires supplemented with extra questions. Together with that questionnaire a study protocol was written. This protocol, which contained information about the study population, data collection, data analysis and burden of participation, was necessary to obtain permission from the Institutional Review Board (IRB) of the Pharmacoepidemiology and Clinical Pharmacology division of Utrecht University to carry out this research. After IRB permission, different pharmacies were contacted to invite the patients that were eligible for the study. Patients, who were willing to participate, were asked to fill in the online questionnaire. After about two months, the data collection was finished and from then data
analysis was started. First descriptive statistics were used to study the patients’ characteristics. The validated parts of the questionnaire were interpreted according to the general instructions. Furthermore we aimed to give a general overview of the adherence rates of adolescents using ICS. Associations between the different factors and the MARS score were explored to draw conclusions about potentially related factors, if possible. Finally again descriptive statistics were used to get more insight in teenagers’ participation to health research. This study was only a descriptive study that could lay foundation for further research. It succeeded a previous study that investigated adolescents’ medication use in general (46).
3. METHODS

3.1. RESEARCH DESIGN

The study was a cross-sectional pharmacy-based study.

3.1.1. Study population

Adolescents aged 12-18 years old were invited to participate in the study. The participants were patients from different community pharmacies who are part of the UPPER network (Utrecht Pharmacy Practice network for Education and Research)\(^1\). Inclusion criteria were: age 12-18 years and filling of at least two prescriptions of ICS during the past two years in their own community pharmacy. Adolescents were selected from the pharmacy information system by using the prescription records. There are three different pharmacy information systems in the Netherlands that can be used: Pharmacom, Mira and Aposys. This was different in each pharmacy. For each pharmacy information system a protocol was developed to perform the selection of the patients and the extraction of the data.

All the pharmacy clients who met the inclusion criteria were contacted by sending them an information letter or email. This letter or email contained the purpose of the study, as well as extra information about privacy and rights (Appendix I). We aimed at inclusion of at least 150 patients. We expected a 30% response rate and 30 eligible patients per pharmacy; therefore, about 15 pharmacies were recruited from the UPPER-network (inclusion of approximately ten patients per pharmacy). In addition, master pharmacy students of Utrecht University, who were doing an internship in the same period as this project and some bachelor pharmacy students (part of an optional subject: ‘Pharmaceutical Practice Research’), also selected patients in their pharmacy. This occurred in the context of this research project with the aim of enlarging the study sample.

3.1.2. Data collection

The participants were asked to fill in an online questionnaire. In the letter/email there was a link where the participants could find the questionnaire. The questionnaire consisted of different subdivisions, such as therapy adherence, airway symptoms and medication

\(^1\) Upper is a network for research and internships in the pharmaceutical practice and is a part of Utrecht University. Different pharmacies (more than 1200 community pharmacies) in the Netherlands are member of this organisation and can participate in research or internships.
beliefs (part 3.3: QUESTIONNAIRE). To motivate participation, a few ITunes vouchers were raffled of, so interested participants could fill in their e-mail address at the end of the questionnaire. Participants were ensured of the fact that this information would be used for the purpose of the vouchers only.

Each eligible patient received a unique code in his or her invitation letter that was connected to the patient’s ID number in the pharmacy. In this way anonymity was saved. Personal information like name, address and telephone number did not leave the pharmacy. After a while (approximately two weeks), some participants received a phone call to remind them of the questionnaire, if they did not fill it in yet. Data were collected during the months of March, April and May.

3.2. STUDY APPROVAL

This study was approved by the IRB (Institutional Review Board), a panel of different experts of the division Pharmacoepidemiology and Clinical Pharmacy at Utrecht University. They examine studies in which any participation of people is present and in which there will be use of UPPER facilities (47). IRB approval was the only necessary approval for this research. The IRB evaluated the study protocol, the questionnaire and the patient information letter. The development of the study protocol, questionnaire and patient information letter was an important part of this research project.

3.3. QUESTIONNAIRE

The questionnaire consisted of 11 different parts. First, patients had to fill in the unique research code. In a second part they were asked if they wanted to participate. If not, they were asked about their reasons for non-participation and the way they preferred to be approached for health research in general. For those who did not want to participate, the questionnaire ended after this question. The complete questionnaire is added as attachment (Appendix II). The online questionnaire was created with Lime Survey 2.0.

3.3.1. Socio-demographic variables

The first part contained questions about socio-demographic variables, such as gender, date of birth, education (48), religion, origin (49), use of other chronic medication (50,51) and exercise.
3.3.2. Respiratory symptoms

In this part, we asked if the first diagnosis of asthma was actually made or if the patient received ICS for other reasons (8). Furthermore, there were questions about family history of asthma, past use of oral corticosteroids (OCS) and hospitalization. Subsequently there were six questions asked to get an impression of the patient’s asthma severity and asthma control. Therefore the 6-item Asthma Control Questionnaire (ACQ) developed by Juniper et al. was used. This is a validated questionnaire and has proven to be a strong measurement tool (52,53). The questions were scored on a seven point scale and results were calculated as reported by the general instructions (53). Cut-off points for the ACQ score that were used are shown in table 3.1.

<table>
<thead>
<tr>
<th>ACQ score</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACQ score &lt; 0,75</td>
<td>Controlled asthma</td>
</tr>
<tr>
<td>0,75 ≤ ACQ score &lt; 1,50</td>
<td>Partially controlled asthma</td>
</tr>
<tr>
<td>ACQ score ≥ 1,50</td>
<td>Uncontrolled asthma</td>
</tr>
</tbody>
</table>

A last question in this part was about the control they experienced over their asthma or respiratory symptoms over the past year. The division in answers were based roughly on the levels of asthma control by the GINA guidelines (8).

3.3.3. Smoking behaviour

On the basis of the literature, different questions were added about smoking behaviour. Questions were asked about smoking behaviour of family members, but also about the patients’ own smoking behaviour (54). Finally their opinion was asked about the combination of smoking and asthma, to get more insight in their knowledge and thoughts regarding smoking and asthma.

3.3.4. Medication adherence

To measure adherence the Medication Adherence Report Scale (MARS) developed by Horne et al. was used (55,56). We used the 5-item MARS (MARS-5). This is a validated questionnaire that has already been used often to assess self-reported adherence. It consists of five questions about non-adherence behaviour: forgetfulness, dose alteration,
temporary medication discontinuance, dose skipping and quantity lowering (56). Patients were asked to rate the questions on a five point scale (‘always’ until ‘never’). The results were calculated according to the general instructions (26,27). Scores below 23 were considered as non-adherent (27).

Furthermore, the patient was asked about one or more reasons for not being adherent to the medication prescription. Some examples were: forgetfulness, fear of side effects, shame towards their peers, complexity of treatment regime, sign of weakness, lack of support, and lack of routine. Those different answers were based on their appearance and importance in different studies (9,14,17,18,23).

3.3.5. Influence of peers and parents

Different questions were developed to investigate the role of peers and parents in asthma treatment. We included questions about the use of the inhaler in the presence of peers, the role of friends in treatment and the feeling of being excluded because of asthma. Other questions addressed the role of parents in treatment and the amount of parental support teenagers experienced.

3.3.6. Beliefs about medicines

To assess medication beliefs, the Beliefs about Medicines Questionnaire-specific (BMQ-specific), developed by Horne et al. (57), was used. The BMQ-specific has shown to be a valuable measurement tool to discover patients’ beliefs about their prescribed medicines and to have discriminant validity to distinguish between different illnesses or treatment groups (57). The BMQ specific consists of two parts: the necessity and concerns scale. The necessity scale is about patients’ beliefs regarding the need of controller medication to maintain healthy. The concerns scale asks questions about patients’ worries regarding possible adverse effects of using the preventer medication. The answers per scale were rated on a five point scale (‘strongly agree’ until ‘strongly disagree’). Results were calculated according to the general instructions. Higher scores for each scale indicate stronger beliefs of the patient for the notions of each scale. Besides that, a necessity-concerns differential was calculated, with a higher score indicating that the patient experienced ICS more as a necessity and had less concerns about ICS (26).
3.3.7. Knowledge about asthma medication

To test the patient’s knowledge about asthma medication, ten questions were asked. Knowledge about the use of preventer and rescue medication, OCS, spacer devices and antibiotics was examined. Those ten questions were originated from a questionnaire that was used in the PIAMA study (6,58). Each correct answer was scored by one point with a maximum of ten points. A score greater than or equal to seven out of ten was considered as a good knowledge about asthma medication (58).

3.3.8. Participation in health research

In this last part of the questionnaire, participants were asked about one or more important reasons for participating in this study and one or more important reasons for not participating in health research in general. The answer possibilities were based on a study that investigated the factors associated with health research participation (59). A third question in this part was about the way teenagers liked to be approached for health research in general. The two last questions were the same the non-participants were asked in the beginning of the questionnaire.

3.4. DATA ANALYSIS

Descriptive statistics were used to give an overall impression of the patients’ characteristics, medication adherence, beliefs and knowledge. Associations were investigated between the MARS scores and socio-demographic variables, airway symptoms, smoking behaviour, medication adherence (reasons) and influence of friends and parents. In the analysis, the MARS score was used in two ways: as a continuous variable and as a dichotomous variable. We used a cut-off point of 23 to dichotomise the MARS score. In the former situation the association was tested with an independent sample t-test or an ANOVA followed by a post-hoc test, if normality was satisfied. Normality was checked with a QQ-plot, a histogram and a Shapiro-Wilk test. If there was no normal distribution (even after transforming to a logarithmic scale), the following equivalent tests were used: the Mann-Whitney test (or Wilcoxon rank sum test) and the Kruskal-Wallis test. For variables (age and asthma duration) that were numeric instead of qualitative, associations with MARS were investigated trough correlations as described below (e.g. MARS and ACQ). In the other (dichotomous) situation crosstabs were made and association was tested by a Pearson’s
Chi-square test. If more than 20% of the cells had a number lower than five, a Fisher’s exact test was executed as an equivalent for the Chi-square test. Because this last one could only be used with a 2x2 table, variables with more than two categories were dichotomised. Table 3.2 shows the cut-off points used for these variables.

**Table 3.2: Dichotomisation of the variables with more than one category.**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Dichotomisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>12-13,99 ↔ 14-18,99</td>
</tr>
<tr>
<td>Dutch education level</td>
<td>General higher secondary and pre-university education, mixed general higher and pre-university education and University College ↔ practical, vmbo, primary school, intermediate vocational education and special education</td>
</tr>
<tr>
<td>Religion</td>
<td>Protestantism and Catholicism ↔ Islam</td>
</tr>
<tr>
<td>Origin</td>
<td>Native or Western immigrant ↔ non-Western immigrant</td>
</tr>
<tr>
<td>Exercise</td>
<td>Not and occasionally ↔ 1 per week and &gt; 1 per week</td>
</tr>
<tr>
<td>Asthma duration</td>
<td>≤ 10 year ↔ &gt; 10 year</td>
</tr>
<tr>
<td>Duration of airway symptoms</td>
<td>≤ 10 year ↔ &gt; 10 year</td>
</tr>
<tr>
<td>Asthma symptoms during the past year</td>
<td>Not, hardly and a few times per month ↔ a few times per week and daily</td>
</tr>
<tr>
<td>Beliefs about the combination of smoking and asthma</td>
<td>Negative influence ↔ positive influence, no influence and ‘I do not know’</td>
</tr>
<tr>
<td>Amount of parental support</td>
<td>Sufficient and too little ↔ too much</td>
</tr>
</tbody>
</table>

After checking for normality, associations between MARS and the ACQ score, MARS and the BMQ score and MARS and the knowledge score were investigated trough a Pearson’s correlation test (or a Spearman’s rank correlation when not normal distributed). For the ACQ score and the knowledge score, a Chi-square test (or Fisher’s exact test) was also executed, when both variables were managed as a nominal variable. We used a significance level of 5% and calculated p-values were two-sided. It is mentioned explicitly when we used a significance level lower than 5%. To get insight in patients’ (non-)participation again descriptive statistics were used. Statistical analysis was executed with IBM SPSS Statistics version 20 and graphs were created with Microsoft Excel 2011 for Mac.
4. RESULTS

4.1. RESPONSE RATE

For this study 854 patients were invited. Figure 4.1 shows the response and participation rate. The total number of patients who filled in the questionnaire (=study sample) was 74 (8,7%).

![Flow chart of the response of this study. Response was defined as visiting the link where the patients could find the questionnaire. Participation was defined as actually filling in the online questionnaire. Non-participants were those who indicated not willing to participate in this study. Incomplete questionnaires were not used for analysis. The final number of patients used for analysis, is indicated as study sample.](image-url)

Figure 4.1: Flow chart of the response of this study. Response was defined as visiting the link where the patients could find the questionnaire. Participation was defined as actually filling in the online questionnaire. Non-participants were those who indicated not willing to participate in this study. Incomplete questionnaires were not used for analysis. The final number of patients used for analysis, is indicated as study sample.
4.2. DESCRIPTION OF THE PARTICIPANTS

4.2.1. Socio-demographic variables

A summary of the socio-demographic characteristics is shown in table 4.1.

Table 4.1: Socio-demographic characteristics of the participants (N=74)

<table>
<thead>
<tr>
<th>Gender [n (%)]</th>
<th>Male</th>
<th>30 (40,5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age [mean (±S.D.)]</td>
<td>Age group [n (%)]</td>
<td>15,2 (±2,0)</td>
</tr>
<tr>
<td></td>
<td>12≤ age &lt;14</td>
<td>25 (33,8)</td>
</tr>
<tr>
<td></td>
<td>14≤ age &lt;17</td>
<td>34 (45,9)</td>
</tr>
<tr>
<td></td>
<td>17≤ age &lt;19</td>
<td>15 (20,3)</td>
</tr>
<tr>
<td>Dutch education level [n (%)]</td>
<td>vmbo</td>
<td>13 (17,6)</td>
</tr>
<tr>
<td></td>
<td>Practical</td>
<td>1 (7,7)</td>
</tr>
<tr>
<td></td>
<td>Theoretical</td>
<td>12 (92,3)</td>
</tr>
<tr>
<td></td>
<td>General higher secondary</td>
<td>20 (27,0)</td>
</tr>
<tr>
<td></td>
<td>Pre-university</td>
<td>25 (33,8)</td>
</tr>
<tr>
<td></td>
<td>Mixed general higher and pre-university</td>
<td>3 (4,1)</td>
</tr>
<tr>
<td></td>
<td>Intermediate vocational</td>
<td>4 (5,4)</td>
</tr>
<tr>
<td></td>
<td>Primary school</td>
<td>7 (9,5)</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>2 (2,7)</td>
</tr>
<tr>
<td>Active religious [n (%)]</td>
<td>Protestantism</td>
<td>12 (63,2)</td>
</tr>
<tr>
<td></td>
<td>Catholicism</td>
<td>4 (21,1)</td>
</tr>
<tr>
<td></td>
<td>Islam</td>
<td>3 (15,8)</td>
</tr>
<tr>
<td>Country of birth [n (%)]</td>
<td>The Netherlands</td>
<td>71 (95,9)</td>
</tr>
<tr>
<td></td>
<td>Suriname</td>
<td>1 (1,4)</td>
</tr>
<tr>
<td></td>
<td>Other (Great Britain, India)</td>
<td>2 (2,7)</td>
</tr>
<tr>
<td>Origin [n (%)]</td>
<td>Native</td>
<td>62 (83,8)</td>
</tr>
<tr>
<td></td>
<td>Western immigrants</td>
<td>5 (6,8)</td>
</tr>
<tr>
<td></td>
<td>Non-Western immigrants</td>
<td>7 (9,5)</td>
</tr>
<tr>
<td>Other chronic medication [n (%)]</td>
<td>Indication (more than one option possible)</td>
<td>27 (36,5)</td>
</tr>
<tr>
<td></td>
<td>Diabetes</td>
<td>1 (3,7)</td>
</tr>
<tr>
<td></td>
<td>Eczema</td>
<td>9 (33,3)</td>
</tr>
<tr>
<td></td>
<td>Allergy</td>
<td>12 (44,4)</td>
</tr>
<tr>
<td></td>
<td>Oral contraceptives</td>
<td>9 (20,5)</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>7 (25,9)</td>
</tr>
<tr>
<td>Exercise [n (%)]</td>
<td>Not</td>
<td>4 (5,4)</td>
</tr>
<tr>
<td></td>
<td>Occasionally</td>
<td>10 (13,5)</td>
</tr>
<tr>
<td></td>
<td>Once a week</td>
<td>9 (12,2)</td>
</tr>
<tr>
<td></td>
<td>&gt; Once a week</td>
<td>51 (68,9)</td>
</tr>
</tbody>
</table>
The mean age of this group was 15,2 with a range of 12,0 until 18,8 and the highest percentage (45,9%) between 14 and 17 years old. The majority of the patients were higher educated: higher general secondary education (27,0%) or pre-university education (33,8%). The remaining two patients (‘other’) were in University College and special education. Of the participants 27,0% claimed to be active religious and 16,3% was from a foreign origin. In 36,5% of the cases other chronic medication was used, most often for eczema and allergy. Other mentioned chronic medications were: antidepressants, medication for constipation, irritable bowel syndrome, inflammation of para-nasal sinuses and sweating. From the girls 20,5% took oral contraceptives.

4.2.2. Airway symptoms

From the 74 patients, 60 (81,1%) were diagnosed with asthma, while the others received ICS prescriptions for more general airway symptoms, like shortness of breath, cough, chest tightness and wheezing. The mean duration of asthma was 8,8 (±4,9) years, while the majority of the patients without asthma diagnosis used their ICS less than two years. A percentage of 66,2 had one or more family members with asthma, while seven patients (9,5%) did not know the answer on this question. In the past year, seven (9,5%) patients where sure of taking one or more cures of OCS, while two (2,7%) were hospitalized once because of an asthma attack. The mean score of the ACQ was 1,1 (±0,9). Table 4.2 shows how the ACQ score is distributed among the patients, as well as for the total burden of airway symptoms during the past year.

Table 4.2: The distribution of the ACQ score and total burden of airway symptoms during the past year among the patients.

<table>
<thead>
<tr>
<th>ACQ score</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACQ-score &lt; 0,75 (=controlled asthma)</td>
<td>31 (41,9)</td>
</tr>
<tr>
<td>0,75 ≤ ACQ-score &lt; 1,50 (=partially controlled asthma)</td>
<td>15 (20,3)</td>
</tr>
<tr>
<td>ACQ-score ≥ 1,50 (=uncontrolled asthma)</td>
<td>28 (37,8)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Burden of airway symptoms during the past year</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not/hardly</td>
<td>15 (20,3)</td>
</tr>
<tr>
<td>A few times per month</td>
<td>35 (47,3)</td>
</tr>
<tr>
<td>A few times per week</td>
<td>17 (23,0)</td>
</tr>
<tr>
<td>Daily</td>
<td>7 (9,5)</td>
</tr>
</tbody>
</table>
4.2.3. Medication adherence

The mean score of the MARS was 19.5 (±4.8). When the cut-off point of 23 was used, 62.2% of the patients was considered to be non-adherent. Figure 4.1 shows specifically how the participants answered on the five different questions.

![Medication Adherence Report Scale (MARS)](image)

**Figure 4.1: Distribution of the answers on the MARS questions.**

The highest percentage for all the different statements was found in the answer category ‘never’. Table 4.3 shows the different reasons chosen for deviating from the doctor’s prescription advice for ICS use. Reasons mentioned the most often were: forgetfulness, symptomatic use of ICS and testing to handle symptoms without medication. Thereby 28 participants declared not deviating from the doctor’s prescription advice.

4.2.4. Smoking behaviour and influence of peers and parents

Of the 74 patients, five (6.8%) indicated to smoke or to have ever smoked. Of those five smokers, three smoked occasionally, while the other two smoked at least one cigarette a day. Of the patients 40.5 % had one or more family member who smoked, with parents often mentioned.
Table 4.3: Different reasons for deviating from the ICS prescription directions.

<table>
<thead>
<tr>
<th>Reasons (more than one option possible)</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I do not deviate from the doctor’s prescription advice</td>
<td>28 (37.8)</td>
</tr>
<tr>
<td>I forget to take my medication</td>
<td>35 (47.3)</td>
</tr>
<tr>
<td>I only find it necessary to take my medication when I have symptoms</td>
<td>17 (23.0)</td>
</tr>
<tr>
<td>I want to test if I can handle without my medication, maybe my asthma is over</td>
<td>17 (23.0)</td>
</tr>
<tr>
<td>I am ashamed</td>
<td>-</td>
</tr>
<tr>
<td>I do not want to look different than my peers on school</td>
<td>2 (2.7)</td>
</tr>
<tr>
<td>I do not believe I need the medication, it is not that serious</td>
<td>10 (13.5)</td>
</tr>
<tr>
<td>I am concerned about side effects</td>
<td>1 (1.4)</td>
</tr>
<tr>
<td>I do not get enough support</td>
<td>1 (1.4)</td>
</tr>
<tr>
<td>The intake of medication is a sign of weakness</td>
<td>1 (1.4)</td>
</tr>
<tr>
<td>If I move less, I have to take less medication</td>
<td>3 (4.1)</td>
</tr>
<tr>
<td>It is difficult to find a routine, I am quite busy</td>
<td>13 (17.6)</td>
</tr>
<tr>
<td>My treatment schedule is quite complex</td>
<td>-</td>
</tr>
<tr>
<td>I do not really know how to use my inhaler</td>
<td>-</td>
</tr>
<tr>
<td>Other</td>
<td>5 (6.8)</td>
</tr>
</tbody>
</table>

When the question was asked about the combination of asthma and smoking, the majority (93.1%) answered that smoking has a negative influence on asthma. Nobody saw this as a positive combination. There was one patient who did not indicate one of the options and instead answered ‘I do not smoke’ (missing). Figure 4.2 shows the distribution of the answers on this question among the participants.

![Pie chart showing the distribution of patient opinions on the combination of asthma and smoking.](image)

Figure 4.2: Answers given on the question about the combination of asthma and smoking
Not using ICS in the presence of friends was indicated by 17,6% of the patients, while 28,4% did not use their ICS in presence of other peers than friends. A simple reason for the former was the fact that they did not have to use the inhaler on the point of time they were surrounded by friends. Also two participants indicated to be ashamed and two declared that friends think that they put on airs. For not using ICS in presence of other peers, again not needing it on that moment was mentioned now and then. Furthermore, four participants indicated that they were ashamed, one mentioned again that peers think that he or she put on airs and another mentioned that they were not aware of the asthma. Finding it unpleasant when somebody was watching and getting giggles, were two other reasons given. Three participants felt shut out, more specifically during sport or other activities in general. For 6,8%, friends were playing an important role in their medication use, while the role of parents was bigger (63,5%). Table 4.4 shows which role friends and parents play in the medication use of patients (more than one option was possible).

Table 4.4: The role of friends and parents in patients’ medication use. The shaded boxes represent questions that were not applicable to friends or parents.

<table>
<thead>
<tr>
<th>Different roles in the use of asthma medication [n (%)]</th>
<th>Friends</th>
<th>Parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>They collect my medication</td>
<td>40 (54,1)</td>
<td></td>
</tr>
<tr>
<td>They help me remembering to take my medication</td>
<td>2 (2,7)</td>
<td>31 (41,9)</td>
</tr>
<tr>
<td>They encourage me to take my medication</td>
<td>1 (1,4)</td>
<td>18 (24,3)</td>
</tr>
<tr>
<td>They understand why I need them</td>
<td>4 (5,4)</td>
<td></td>
</tr>
<tr>
<td>They help me to fit my medication schedule in my week scheme</td>
<td>3 (4,1)</td>
<td></td>
</tr>
<tr>
<td>I can talk with them when I have problems with my illness</td>
<td>2 (2,7)</td>
<td>16 (21,6)</td>
</tr>
<tr>
<td>Others</td>
<td>3 (4,1)</td>
<td></td>
</tr>
</tbody>
</table>

The role of parents was mainly: collecting and remembering to take the medication, encouraging to take the medication and being someone to whom the teenager can talk to when having problems/difficulties with his or her illness. Concerning parental help 26 (35,1%), 35 (47,3%) and 11 (14,9%) patients respectively did not want to be helped, wanted to be helped without constant control and wanted to be helped as much as possible. One participant did not really care about it and another answered ‘it is fine in the way it is now’. For 69 (93,2%) patients, support from their parents was sufficient, while three (4,1%) indicated parental support as ‘too much’ and two (2,7%) as too little.
4.2.5. Beliefs and knowledge about asthma medication

The different values for the BMQ scores and the knowledge score are shown in table 4.5.

Table 4.5: Mean values of the different BMQ scales and the knowledge score, percentage above the scale midpoint and the distribution of the knowledge score among the patients.

<table>
<thead>
<tr>
<th>Score</th>
<th>Mean (±S.D.)</th>
<th>% Above the scale midpoint</th>
</tr>
</thead>
<tbody>
<tr>
<td>BMQ necessity (5 until 25)</td>
<td>13,5 (±4,7)</td>
<td>36,5</td>
</tr>
<tr>
<td>BMQ concerns (5 until 25)</td>
<td>11,2 (±3,8)</td>
<td>13,5</td>
</tr>
<tr>
<td>BMQ differential (-20 until 20)</td>
<td>2,2 (±5,1)</td>
<td>58,1</td>
</tr>
<tr>
<td>Knowledge</td>
<td>4,8 (±1,9)</td>
<td>N (%)</td>
</tr>
<tr>
<td>Knowledge score</td>
<td>N (%)</td>
<td></td>
</tr>
<tr>
<td>&lt; 7</td>
<td>58 (78,4)</td>
<td></td>
</tr>
</tbody>
</table>

The BMQ-necessity mean value was a little higher than the BMQ-concerning mean value (p<0,001). There was 63,5% that had a necessity score below (or equal to) the scale midpoint, while for 13,5% of the patients the concerns score was above the scale midpoint. The mean BMQ differential was 2,2 (±5,1) and 41,9% of the patients had a score below (or equal to) zero. When a cut-off point of seven was chosen for the knowledge score, 78,4% of the patients seemed to have low knowledge about asthma medication.

The knowledge among participants was the lowest for the use of OCS and the spacer device (for questions 4,5 and 8 more than 80% of the answers were wrong). More than 50% of the participants had a lack of knowledge about the role of rescue medication and antibiotics (question 1 and 10).

4.3. ANALYSIS OF THE RESULTS

Normality was checked and some variables were normal distributed, while others were not. There was no statistical significant difference found (both calculated with MARS as a continuous and dichotomous variable) for gender, age group, education, active religious, religion, origin, other chronic medication, exercise, diagnosis of asthma, duration of airway symptoms, family history of asthma, need of OCS, hospitalization and asthma symptoms during the past year. The range of p-values for these non-significant differences, when MARS was continuous, went from 0,14 until 0,90; while with dichotomous MARS the range went from 0,06 until 1,00. The correlation between MARS and age was negative, but not
statistical significant (p=0,50). A correlation coefficient of -0,378 (p=0,003) was observed between MARS and asthma duration.

There was no statistical significant difference found for own smoking behaviour, frequency of smoking, beliefs about smoking and asthma. Just like there was no difference for the use of ICS in presence of friends, role of friends and parents, feeling of being shut out and amount of parental support. Besides a Chi-square test, relative risks were also calculated with a crosstab. There was a statistical significant difference found for use of ICS in present of peers (friends not included) (p=0,04), with the non-users having a lower adherence, although this was not supported by the Chi-square test (and the relative risk). Table 4.6 shows the relative risks for the variables regarding smoking, peers and parents and the range of non-significant p-values.

Table 4.6: Relative risks with confidence intervals (CI) of variables regarding influence of smoking, peers and family. This is the number of patients being non-adherent (MARS<23) in the ‘no’-group divided by the number of patients in the ‘yes’-group, with no and yes the answers on the relevant questions. For the amount of parental support the same relationship was calculated for too little or sufficient against too much.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Relative risk (CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Smoking behaviour of the patient</td>
<td>1,04 (0,50-2,17)</td>
</tr>
<tr>
<td>Belief about the combination of smoking and asthma</td>
<td>0,75 (0,47-1,22)</td>
</tr>
<tr>
<td>Use ICS in presence of friends</td>
<td>1,30 (0,91-1,88)</td>
</tr>
<tr>
<td>Use ICS in presence of other peers</td>
<td>1,22 (0,86-1,74)</td>
</tr>
<tr>
<td>Feeling of being shut out</td>
<td>0,93 (0,41-2,11)</td>
</tr>
<tr>
<td>Important role of friends</td>
<td>1,59 (0,54-4,73)</td>
</tr>
<tr>
<td>Important role of parents</td>
<td>0,84 (0,57-1,25)</td>
</tr>
<tr>
<td>Amount of parental support</td>
<td><strong>0,61 (0,50-0,73)</strong></td>
</tr>
<tr>
<td><strong>Range of p-values (MARS as continuous and dichotomous)</strong></td>
<td>0,07-0,87 and 0,29-1,00</td>
</tr>
</tbody>
</table>

Because in all cases (except one), one is part of the confidence interval, those relative risks were not significant. On the other hand, the relative risk of ‘amount of parental support’ was significant with a value lower than one.

From the reasons for deviating from prescription advice, which participants could indicate after the five MARS questions, there were some significant differences in adherence. Table 4.7 shows these reasons with their p-values.
Table 4.7: Significant differences in adherence for the different reasons for deviating from the prescription advice. (1)=Mars as continuous and (2)=Mars as dichotomous variable.

<table>
<thead>
<tr>
<th>Reasons for deviating from prescription advice</th>
<th>P-value (1)</th>
<th>P-value (2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I forget to take my medication</td>
<td>&lt;0,001</td>
<td>&lt;0,001</td>
</tr>
<tr>
<td>I only find it necessary to take my medication when I have symptoms</td>
<td>&lt;0,001</td>
<td>&lt;0,001</td>
</tr>
<tr>
<td>I want to test if I can handle my symptoms without medication, maybe my asthma is over</td>
<td>&lt;0,001</td>
<td>0,002</td>
</tr>
<tr>
<td>I do not believe I need the medication, it is not that serious</td>
<td>0,001</td>
<td>0,01</td>
</tr>
<tr>
<td>It is difficult to find a routine, I am quit busy</td>
<td>0,01</td>
<td>0,01</td>
</tr>
</tbody>
</table>

Normality was checked for the ACQ score, BMQ-necessity and BMQ-concerns score, BMQ differential, knowledge score and MARS score. Again not all of them were normal distributed. Correlation coefficients for the different subdivisions together with their p-values are shown in table 4.8.

Table 4.8: Correlation coefficients and p-values for the correlation between the different scores and the MARS score.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Correlation coefficient</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACQ score</td>
<td>-0,13</td>
<td>0,28</td>
</tr>
<tr>
<td>BMQ-necessity score</td>
<td>0,24</td>
<td>0,04</td>
</tr>
<tr>
<td>BMQ-concerns score</td>
<td>-0,21</td>
<td>0,08</td>
</tr>
<tr>
<td>BMQ differential</td>
<td>0,34</td>
<td>0,003</td>
</tr>
<tr>
<td>Knowledge score</td>
<td>0,22</td>
<td>0,07</td>
</tr>
</tbody>
</table>

As an example figure 4.3 shows the correlation of the BMQ differential with the MARS score. Correlation between the BMQ-necessity score and the MARS score was positive, as well as for the BMQ differential. The correlation between the BMQ-concerns score and the MARS score was negative. The correlation coefficient of the ACQ score and the knowledge score with MARS were respectively negative and positive. Although all these values (positive or negative) could give use some insight in the relation between MARS and the different scores, only the correlations of BMQ-necessity and BMQ differential with MARS were statistical significant. When the ACQ score and the knowledge score were used as categorical variables, there was again no statistical significant difference that could be proven (p= 0,17 and p=0,26).
Figure 4.3: Scatterplot showing the correlation between the MARS score and the BMQ differential.

4.4. PARTICIPATION IN HEALTH RESEARCH

From the few non-participants, each of them gave one or more reasons why he or she did not want to participate in this study (table 4.9).

Table 4.9: Reasons for not participating in this study in the ‘non-participants’ group (n=12).

<table>
<thead>
<tr>
<th>Reasons for not participating in this study (more than one option possible)</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The subject does not interests me</td>
<td>2 (16,7)</td>
</tr>
<tr>
<td>I already participated in to many studies</td>
<td>1 (8,3)</td>
</tr>
<tr>
<td>The research questions are to personal</td>
<td></td>
</tr>
<tr>
<td>The research upsets me</td>
<td></td>
</tr>
<tr>
<td>I am afraid of violation of my privacy/confidentiality of data</td>
<td></td>
</tr>
<tr>
<td>I do not want to be called/visited by researchers</td>
<td></td>
</tr>
<tr>
<td>I did not get any compensation (money)</td>
<td></td>
</tr>
<tr>
<td>It demands to much time of me</td>
<td>4 (33,3)</td>
</tr>
<tr>
<td>I will have the risk of negative experience/results</td>
<td></td>
</tr>
<tr>
<td>It is not useful (it is unprofitable for me)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>7 (58,3)</td>
</tr>
</tbody>
</table>
Two of them were not able to participate because of a mental retardation. The other five were not or almost not using the medication. Besides that the reason that was indicated the most was lack of time.

Only three non-participants gave an answer on the question about the preferable way of research approach (nine missing answers). Two of them preferred postal mail and one indicated he did not want to be approached. Because non-participants were not willing to fill in the questionnaire, both questions were not mandatory.

Similar questions were asked to the participating group. In contrast, those questions were mandatory. Table 4.10 shows the reasons why participants chose to participate in this research.

**Table 4.10: Reasons for participation in this study in the ‘participants’ group (n=74).**

<table>
<thead>
<tr>
<th>Reasons for participating in this study (more than one option possible)</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am interested in the subject</td>
<td>27 (37,0)</td>
</tr>
<tr>
<td>Participating does not demands much time of me</td>
<td>40 (54,8)</td>
</tr>
<tr>
<td>The way of approach (online questionnaire)</td>
<td>14 (19,2)</td>
</tr>
<tr>
<td>Research ameliorates health care</td>
<td>49 (67,1)</td>
</tr>
<tr>
<td>Participation in research yields me something in person</td>
<td>10 (13,7)</td>
</tr>
<tr>
<td>Participation in research yields me something in the future</td>
<td>9 (12,3)</td>
</tr>
<tr>
<td>Research helps other people</td>
<td>59 (80,8)</td>
</tr>
<tr>
<td>My participation helps other people</td>
<td>44 (60,3)</td>
</tr>
<tr>
<td>Research informs me about my health/illness/treatment</td>
<td>14 (9,2)</td>
</tr>
<tr>
<td>It is an opportunity to share experiences</td>
<td>16 (21,9)</td>
</tr>
<tr>
<td>Other</td>
<td>3 (4,2)</td>
</tr>
</tbody>
</table>

‘Research helps other people’, ‘research ameliorates health care’ and ‘my participation helps other people’, were the reasons most often chosen for participating in this study. The answers for the option ‘other’ were ‘I do not have something else to do’, ‘I like the ITunes voucher’ and ‘I was obliged’.

The reasons to not participate in health research in general for the participating group are shown in table 4.11. For the participants, lack of time, concerns about privacy and little enthusiasm for receiving visits or phone calls from researchers, were the most common reasons for not participating in health research in general. Another significant part did not see any reason to not participate, while laziness was also mentioned once.
Table 4.11: Reasons for not participating in health research in general in the ‘participants’ group (n=74).

<table>
<thead>
<tr>
<th>Reasons for not participating in health research (more than one option possible)</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am most of the time not interested in the subjects</td>
<td>10 (13,7)</td>
</tr>
<tr>
<td>I already participated in to many studies</td>
<td>5 (6,8)</td>
</tr>
<tr>
<td>The research questions are to personal</td>
<td>1 (1,4)</td>
</tr>
<tr>
<td>The research upsets me</td>
<td>-</td>
</tr>
<tr>
<td>I am afraid of violation of my privacy/confidentiality of data</td>
<td>14 (19,2)</td>
</tr>
<tr>
<td>I do not want to be called/visited by researchers</td>
<td>13 (17,8)</td>
</tr>
<tr>
<td>I did not get any compensation (money)</td>
<td>2 (2,7)</td>
</tr>
<tr>
<td>It demands to much time of me</td>
<td>18 (24,7)</td>
</tr>
<tr>
<td>I will have the risk of negative experience/results</td>
<td>3 (4,1)</td>
</tr>
<tr>
<td>It is not useful (it is unprofitable for me)</td>
<td>9 (12,3)</td>
</tr>
<tr>
<td>I do not see any reason to not participate</td>
<td>14 (18,9)</td>
</tr>
<tr>
<td>I do participate</td>
<td>4 (5,4)</td>
</tr>
<tr>
<td>Other</td>
<td>4 (5,4)</td>
</tr>
</tbody>
</table>

Figure 4.4 illustrates the preferable medium of research approach, but now for the participants. The majority preferred to be approached by postal mail, while another significant part preferred email as the way to be approached.

Figure 4.4: The way in which participants want to be approached for health research
5. DISCUSSION

5.1. INTERPRETATION OF THE RESULTS

When discussing the results, it is important to keep the relative small study sample in mind, therefore results have to be interpreted with care.

5.1.1. Adherence

When using a cut-off point of 23 for the MARS questionnaire, 62,2% of the patients was considered to be non-adherent. This is near the upper range of previously reported adherence rates (40%-60%) (26–28). The mean MARS score in this study was 19,5. This was lower than the score reported in a previous study about adolescents’ medication use performed by students of Junior College Utrecht (JCU) (46). In that study a mean score of 20,9 was calculated, but participants were adolescents both with and without different chronic diseases. When we take the scale-midpoint in the MARS score as cut-off point (26), 79,7% had a score above 15. In a study involving 18-45 years old participants (26), a comparable result (79%) was observed.

In other studies (28,60) a cut-off point of 21 instead of 23 was used. We wanted to examine if the difference in cut-off point would have a significant impact on our most important results (not shown in the result section; socio-demographic and airway variables were not included). When using the lower cut-off point, 51,4% was considered to be non-adherent. A higher percentage (57,3%) was demonstrated in a study involving children (28). We could conclude that using the cut-off point of 21 had no extreme impact on our results: associations and relative risks stayed most of the time not significant.

Forgetfulness was one of the most elected reasons for not following the doctor’s prescription advice. This was indicated most often in the MARS questionnaire in another study (55). Furthermore, participants also indicated that by discontinuing ICS use for a while, they could maybe substantiate the idea that they did not have asthma anymore. The belief that someone outgrew his or her asthma is a common thought among people. Although a lot of children feel improvement in their asthma, bronchial hyper-reactivity seems to endure and there is often a return of symptoms (17). So, it is still not 100% clear if a person actually can outgrow his or her asthma (34). Remaining and often mentioned reasons for not taking medication as prescribed were: ‘I only find it necessary to take my medicines when I have symptoms’, ‘I have trouble with finding a routine, because I am quite
busy’ and ‘I do not believe I need my ICS, it is not that serious’. Again, similarity was seen with other studies (9,12,17,18). Unfortunately, three participants indicated the statement ‘if I move less, I need less medication’. In a focus-group study, this answer was also mentioned once (17), but a number of three is even more disturbing if we keep in mind that asthma and obesity are comorbidities (61).

5.1.2. Smoking behaviour and influence of peers and parents

In our study sample, only five patients indicated themselves as smokers. This is in contrast with the high percentage of asthmatic smokers in other studies (10,13). Thereby it is not possible to give answer to the question if risk-taking behaviour, such as smoking, is associated with poor adherence and/or if poor adherence is a risk factor to start smoking, with only five smokers in our sample. Fortunately the majority (including three smokers) indicated smoking as having a negative influence on asthma, while nobody saw it as a positive combination. There was only one patient who thought that smoking has no influence on asthma, but he or she was a non-smoker. The remaining part did not know the answer.

The percentage of patients that experienced problems with using their ICS in the presence of friends was lower than in presence of other peers. But, there were only three patients that sometimes felt shut out because of asthma. The role of friends in the use of ICS was low in comparison with parents’ role. Apparently parents still play an important role in the medication use of teenagers, although teenagers are struggling against the dependency on their parents (3,9,12,14). This role included mainly collecting the medication and remembering to take the medication. Although the role of friends seems to be very low, literature declares that the management of asthma can ameliorate if peers are involved (9,13). The majority of the participants indicated that they wanted to be helped by their parents without constant control, while another significant part did not want to be helped at all. After examining the data in detail, we could not find a trend with those answers and age, because both old and young ages gave mixed answers (statistical analysis about this topic is not shown). In contrast, the majority was still satisfied with the support of their parents.
5.1.3. Beliefs and knowledge about asthma medication

More than half of the patients were not convinced of ICS’ necessity (score below the scale-midpoint), while only a small percentage had high concerns about ICS use (score above the scale-midpoint). Finally, less than half of the patients had higher (or equal) numbers of concerns about ICS use, than that they perceived it as a necessity (score below (or equal to) zero). In a study with adults (18-45 years old), the doubt about ICS’ necessity was lower, but at the same time they had more concerns (26).

More than 75% of the patients had limited knowledge about asthma medication. If we looked in more detail to the different questions, we saw that knowledge was the lowest regarding the use of OCS and the spacer device, followed by the role of rescue medication and the role of antibiotics. The low knowledge about OCS can possibly be explained by the fact that only seven participants were aware of taking OCS (more than) once. It is known in general that there is still much confusion about preventer and reliever medication (9,17,30,27). On the other hand, literature mentions more often that the knowledge about exercise-induced asthma (10,18,19) and prevention of environmental factors and certain types of food is particularly low (19). The questions concerning knowledge were originally used to test the mothers of asthmatic children, so maybe these questions were to hard for adolescents.

5.1.4. Factors influencing adherence

There were barely any associations found between adherence and the different factors. In contrast, previous studies showed associations between adherence and age (12,13,29), exercise (12,13), asthma severity (12), smoking (12,13) and ethnic minority status (29,33). We found a negative (and significant) correlation between adherence and duration of asthma: how longer the participants had asthma, how more non-adherent they were. This is in contrast with another study (12) that did not find any association.

Non-smokers were more often non-adherent than smokers. Participants, who saw smoking as a negative influence on asthma, were less non-adherent than participants with other beliefs. Patients, who did not use their ICS in the presence of friends or other peers, were often less adherent than patients who did. A lot of patients just did not need to use their ICS when friends or other peers were around and did not indicate a ‘real’ reason, like a feeling of shame. That is why this relation is somewhat confusing. Although, this was not
supported by the Chi-square test or relative risk (all the relative risks stated above were not significant), participants not using their ICS in presence of peers (friends not included), had a significant lower adherence than those who did.

The few patients that felt shut out were more often non-adherent. When friends played an important role, non-adherence was often lower, while non-adherence was higher when parents were playing an important role. Indeed there was no association found between adherence and support from friends in another study (12), but by contrast that study demonstrated a positive association between parental support and adherence. There were a lower number of patients who were non-adherent, when experiencing parental support as sufficient and too little, in comparison with too much parental support. This implies that a to high degree of parental support decreases the teenagers’ adherence. Can this be explained by adolescents’ independency struggle on their parents? Only this last relative risk was significant, but the others can point us in a certain direction.

There was a significant difference in adherence for the following reasons: forgetfulness, symptomatic use of ICS, trying to handle symptoms without medication, denial of asthma severity and difficulties with finding a daily medication routine. The relative risks (<1, but not shown in the result section) imply that patients indicating those reasons, were often more non-adherent. These factors were also cited in a focus-group study with adolescents using ICS (17), as mentioned in other literature as well (9,18).

A higher value of the ACQ score matched with a lower MARS score (negative correlation). Although this correlation was not significant, this direction would imply a better adherence with better-controlled asthma (lower ACQ score). This correlation was proven in a study involving adults (62). Adherence increased when participants experienced their ICS more as a necessity, decreased when they had more concerns about it and decreased when there were increasingly more concerns towards necessity beliefs. Only the correlations with the BMQ-necessity scale and the necessity-concerns differential were significant, but again the value (positive or negative) can point us in a certain direction. Those trends were similar to another study involving adults (26). Finally, a positive correlation of knowledge and MARS implies that adherence ameliorates when the knowledge about asthma medication is better. Nevertheless this correlation was not significant. In contrast, it is known that education of the patients is important in improving patients’ adherence (9,30).
5.2. STRENGTHS AND LIMITATIONS OF THE STUDY

5.2.1. Strengths

In the Netherlands, there was not much research done about adolescents and adherence to asthma medication. In contrast, low adherence to ICS is a topical subject. Although there were not many associations found, this descriptive study revealed interesting information. Therefore, this study can serve as an interesting foundation for further research. All this information gives other researchers the insight, which of the factors can be important to investigate in more detail. Finally, this study just taught us an important aspect: the way we used to approach teenagers was not the most profitable one.

5.2.2. Response rate

We already knew before starting this research project that teenagers are difficult to contact for health care research, although we did not expect a response as low as this. Recruiting a sufficient number of teenagers into research studies is actually a common problem. This is illustrated in studies about adolescents and obesity (63,64). Previous studies in adolescent populations concluded that recruitment of adolescents is one of the most challenging aspects of research, especially if those teenagers participate in risk-taking behaviour (smoking) (65). Response rates of previous performed studies involving adolescents varied from 17% until 88% (13,46,63).

Adolescents are not really focussed on their health, unless they observe an immediate effect of it. It seems also that adolescents are concerned about their privacy, because they are often not informed about the ethical rules in research. The presence of an incentive appears to be important as well (65). It is known that the length of a questionnaire has an important influence on the response rate (66). In the patient information letter the average spending time was mentioned, but unless they started to fill in the questionnaire, the actual length of the questionnaire could not be observed. Surprisingly, after about one month, we still received some questionnaires of patients from pharmacies that were visited in the beginning of the period. So, it seemed that some patients just put the invitation letter aside for a while instead of throwing it away.

When we asked non-participants to indicate one or more reasons for not participating in this study, not/almost not using their medication and lack of time were mentioned the most often. The participants also confirmed lack of time as a reason. A similar result was
found in the literature (59). Besides lack of time, participants were concerned about their privacy and did not want to be called or visited by researchers. Concerns about privacy appears to be typical of adolescents (64). In contrast, research as a tool to help other people and to ameliorate health care were reasons to participate in this research.

Another factor that can be important is the way in which we approached the teenagers. In most pharmacies, email addresses were not available and invitation letters where send by postal mail. Only in one pharmacy two patients were send an email. Although we cannot conclude anything with only two patients as a try-out, sending an email instead of a letter by postal mail can be another useful medium. Nevertheless, when patients were asked about the way they want to be approached, the majority indicated postal mail as the preferred medium. One study (66) that compared postal mail with internet surveys showed that postal mail surveys produced higher participation rates than e-mail surveys, while web-based surveys had comparable rates. Although we sent our invitation out by postal mail, we made an online questionnaire, with the idea that this was a better method for the age of adolescents. This mixed design is not investigated in the study stated above. There are some studies (67,68) that investigated the use of social networking sites, such as Facebook, to recruit adolescents in research. This seemed to be an advantageously technique that can be added to traditional techniques, for both recruitment and reminding of participants. Nevertheless, this needs further research.

5.2.3. Analysis

Because of the low response it was not simple to perform a valuable analysis. Dichotomisation of the variables could raise the power of this study partially, but at the same time this resulted in a loss of information.

5.2.4. Reminding of patients

Sending of a reminder is a common procedure in research. In our case, we did not have any personal information of the participants and therefore return to the pharmacy was necessary. Only in two pharmacies patients were called to remind them of the questionnaire. This was used as a try-out to discover if a reminder by telephone was actually effective. In both pharmacies some patients could not be contacted. When the patient himself was not home, a message was passed on to a family member. Although some
indicated not to participate, there was still a significant number that promised to fill in the questionnaire. Only one actually did it. Because, it seemed that reminding patients by telephone was not the best technique for this study population, no other phone calls were made.

5.2.5. Methodology

It is known that self-report is subject to bias. Furthermore over-reporting of medication use seems to be more common than under-reporting (69). Thereby it is important to known that the MARS arranges the participants according to their “relative standing on the adherence dimension”. This means that it does not give us exact information about the way and time of medication intake (26). More of this information can be achieved by reviewing pharmacy records.

The study is still ongoing, therefore selection and invitation of patients was still running when this thesis was written. It is important to keep in mind that not all the patients, included in this study, had the allowed time of two weeks to fill in the questionnaire. Because of complexity, all the patients were included who received a letter two days before finishing the data collection. The result being that the final response ratio is approximately correct.

The study was hindered from the start because there were only four months to design, conduct and compile this research.

5.2.6. Study sample

When we look at the description of the study sample, we see that the majority of the patients were from native origin. Literature confirms that inhabitants, who are born in a foreign country, are less eager to participate in health research (59). On the other side, the number of immigrants in the Netherlands is significant (70) and in certain pharmacies the amount of foreign patients that were send a letter was quite large. Furthermore, the biggest proportion of participants had a higher educational level. There is a change that responders difference from non-responders, but this should be investigated.

It seemed not always clear to the patients what the purpose of this study was. From the patients who took the effort to indicate that they did not want to participate, five of them gave as reason that they did not or almost not use their medicines anymore. One of them
even wrote that he or she always collected his medicines, but never used them. Those patients (low adherence) are the ones we wanted to approach and recruit for the study. Probably, a part of the non-responders have the same attitude, because teenagers with low adherence seems to have difficulties to participate in research (12). Because we were not able to assess those non-responders, there is a risk that our study sample lacks some important patients, who are probably a significant contribution to the image of adolescents’ medication adherence.

5.2.7. Indistinct of questions

When asking the questions about the use of patients’ inhaler in the presence of friends or other peers, we aimed to discover if potential shame and/or bullying could be a reason for low adherence. Unfortunately, many of these questions were answered by the fact that they only needed to use their inhaler in the morning or evening when there were no peers around. Thereby, we emphasized in the beginning of the questionnaire that the majority of the questions were about ICS and not about reliever medication. So now we experience that those questions were not flawless to discover our earliest ideas underlying those questions.

When patients were asked to indicate different reasons for deviating from their prescription, they saw the following first option: ‘I do not deviate from my prescription, I use my medication as I was enforced’. We created this option in the context of a situation that a MARS score of 25 (=no deviation from prescription) would be reached. In this situation, there would be no reasons for deviation from prescription. Nevertheless, participants, who indicated this option, did not all have a score of 25 and sometimes chose other options on top. As a consequence, the percentage for this answer option is not fully reliable.

For some participants, the question about reasons to not participate in health research caused some confusion, because they did participate in this study. Apparently it was not clear that that question was about health research in general.

5.3. RECOMMENDATIONS FOR THE FUTURE

When performing a study in which adolescents are involved, the way of approaching participants must be considered carefully. Sending invitations by letter seemed not to be the golden standard to approach teenagers. There can be a perspective for the use of social
networking sites in health research (67,68), although this needs further investigation. It may be interesting as well to compare non-responders with responders in some way.

The questionnaire contained a lot of information, so for further research it is maybe better to focus on a few of these topics. This limits the amount of questions, what makes it more pleasant for the participant as well. For obtaining more information, the MARS-score must be treated as much as possible as a continuous variable and a logistic model must be considered, when the amount of participants is sufficient. When achieving a higher participation rate, there can be a change to reveal even more useful information about teenagers and ICS use. A focus-group study can be useful as well.

When this questionnaire will be reused in the future, extra explanation can be necessary to clarify that the purpose is also to reach patients, who are not/not fully complying with their medication prescription advice. Questions leading to confusion must be clarified as well.
6. CONCLUSION

The purpose of this study was to learn more about Dutch teenagers suffering from asthma/respiratory symptoms and their adherence to ICS. We have shown that more than half of the participating adolescents in this study had a low adherence.

Factors associated with poor adherence were: forgetfulness, symptomatic use of ICS, trying to handle symptoms without medication, denial of asthma severity and difficulties with finding a daily medication routine. Furthermore, the longer participants had asthma, the less adherent they were.

Results showed that patients, who were not using their inhaler in front of peers (friends not included), were more likely to deviate from prescription directions. Teenagers, who thought that parental support was too high, usually had a lower adherence. In addition, adherence to ICS was proportional to the users belief in its necessity towards the amount of concerns they had. Although, it is accepted that having a good understanding of their own therapy is important, more than 75% of the patients possessed a low knowledge about asthma medication.

Finally, many adolescents claimed that they were unwilling to participate in research, primarily for the following reasons: lack of time, privacy concerns and little enthusiasm for receiving visits or phone calls from researchers.

There are a lot of factors that can be improved regarding adherence to ICS in teenagers suffering from asthma/respiratory symptoms. A greater understanding of teenage usage could be obtained from further research. Such research will affect teenage adherence by improving both communication and attitudes towards treatment, therefore keeping asthma under control.
7. REFERENCES

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APPENDIX I: PATIENT INFORMATION LETTER (Dutch version)

UITNODIGING
voor deelname aan:

Onderzoek naar medicatiegebruik bij jongeren met luchtwegklachten

Informatie voor jongeren van 12 tot 18 jaar

Wij willen je namens de apotheek uitnodigen om deel te nemen aan een onderzoek - het invullen van een korte online vragenlijst - naar medicatiegebruik bij jongeren met luchtwegklachten. Dit onderzoek wordt uitgevoerd door onderzoekers van de Universiteit Utrecht.
In deze folder vertellen we je meer over dit onderzoek en wat het betekent als je hieraan meedoet.

Ben je jonger dan 16 jaar, laat dan ook je ouders deze informatiefolder lezen, zodat je samen kan beslissen of je mee gaat doen aan dit onderzoek.

Waarom dit onderzoek?
We weten al veel over het gebruik van inhalatiecorticosteroïden* voor astma en luchtwegklachten door kinderen en volwassenen. Maar hoe jongeren van 12 tot 18 jaar deze medicijnen gebruiken weten we niet. Met dit onderzoek willen we te weten komen wat jongeren van hun luchtwegmedicijnen vinden en hoe zij deze gebruiken.

*Inhalatiecorticosteroïden zijn de medicijnen die je dagelijks gebruikt om te voorkomen dat je luchtwegklachten krijgt. Deze puffers zijn meestal bruin, rood, oranje of paars van kleur.

Waarom ben jij uitgenodigd?
Voor dit onderzoek zoeken wij jongeren van 12 tot 18 jaar die in de afgelopen 2 jaar minimaal twee recepten voor een inhalatiecorticosteroïd hebben opgehaald in de apotheek. Volgens de gegevens van jouw apotheek ben jij één van deze jongeren.

Wat betekent deelname aan dit onderzoek voor jou?
Deelname aan dit onderzoek is vrijwillig. Je kan meedoen door het invullen van een online vragenlijst. Dit duurt ongeveer 15 minuten. De vragenlijst bestaat uit algemene vragen en vragen over hoe jij je medicijnen gebruikt en wat jouw mening is over je medicijnen.
Daarnaast vragen we je om toestemming om een overzicht van jouw medicatie op te vragen bij de apotheek. Deze informatie gebruiken we om te kijken of mensen die verschillende meningen hebben ook andere geneesmiddelen gebruiken.
Onder de deelnemers verloten we een aantal iTunes waardebonnen, om hier kans op te maken moet je aan het einde van de vragenlijst je e-mailadres achterlaten.

_Hoe gaan we met jouw gegevens om?_
Al jouw gegevens worden vertrouwelijk behandeld. Alleen de onderzoekers krijgen jouw gegevens te zien en zij verwerken deze informatie met de onderzoekscode die hieronder vermeld staat. Jouw apotheker krijgt geen toegang tot de antwoorden die je hebt ingevuld en jouw naam zal nooit ergens worden vermeld.

Ja, ik wil deelnemen aan dit onderzoek.*
Hoe nu verder?
Als je besluit om mee te doen, dan vragen we je om de online vragenlijst binnen 2 weken in te vullen.
Ga naar de vragenlijst met de volgende link:
_http://tinyurl.com/puffer123_
Je start de vragenlijst met het invullen van de volgende persoonlijke onderzoekscode:

Nee, ik wil niet deelnemen. Hoe nu verder?
Als je besluit om niet mee te doen aan dit onderzoek, zouden we graag willen weten waarom je niet meedoet. Dit kan je aangeven door naar de vragenlijst te gaan, jouw persoonlijke onderzoekscode in te vullen en alleen aan te vinken waarom je niet deelneemt (zie de link en code hierboven).
*Ben je jonger dan 16 jaar, overleg deelname met je ouders.

_Krijg je bericht over de uitslag?_
Het is niet mogelijk om je over jouw persoonlijke gegevens te informeren. Als het onderzoek is afgelopen kan je via jouw apotheker een samenvatting van de uitkomsten ontvangen.

_Vragen_
Voor (technische) vragen en problemen bij het invullen van de vragenlijst, bijvoorbeeld wanneer je de link niet kan openen, stuur je een e-mail naar upper@pharm.uu.nl

Als je vragen hebt over de **inhoud van dit onderzoek** dan kan je terecht bij dr. Ellen Koster (onderzoeker Universiteit Utrecht) of bij je apotheker.

_Apotheek_

Stamp of the pharmacy

Universiteit Utrecht, UPPER
Dr. Ellen Koster / e.koster@uu.nl
Postbus 80082, 3508 TB Utrecht
APPENDIX II: QUESTIONNAIRE (Dutch version)

**Comment:** Not all the questions were asked. It depended on the answers given by the patients, which other questions followed. This is shown with following sign: ‘→’. Extra comments about specific questions are shown in red; those comments were not present in the online questionnaire. Sometimes, questions were clarified to the patient. These are shown in blue and were present in the online questionnaire.

**Onderzoek naar medicatiegebruik bij jongeren met luchtwegklachten**

Dit onderzoek gaat over de medicatie die je dagelijks gebruikt voor jouw luchtwegklachten (inhalatie corticosteroïden), de zogenaamde preventie puffers. Deze hebben meestal een bruine, rode, oranje of paarse kleur. We bedoelen dus **NIET** de rescue medicatie (blauwe puffer). Indien het toch zou gaan over de rescue medicatie, zullen we dit vermelden. Hieronder vind je enkele afbeeldingen en namen als voorbeeld van inhalatiecorticosteroïden:

![Inhalers](image_url)

Voorbeelden: Flixtide, Beclometason, Pulmicort, Budesonide, Qvar of Aerobec.

**WAT VRAGEN WE VAN JOU?**

Meestal hoef je slechts 1 van de vakjes aan te vinken. Het kan voorkomen dat je het lastig vindt om een keuze te maken, kies dan toch altijd het antwoord dat het beste van toepassing is. Indien je meerdere antwoorden kunt aankruisen, wordt dat vermeld bij de vraag.

Het invullen van deze vragenlijst duurt ongeveer 15 minuten.
VERTROUWELIJKHEID
De ingevulde gegevens worden alleen onder onderzoeksnummer verwerkt. In de informatiefolder die je hebt ontvangen staat dit nummer vermeld, dit moet je zo meteen invullen.

Meer informatie over dit onderzoek kun je vinden in de folder die we jou hebben toegestuurd.

Deelnemers aan het onderzoek maken kans op een iTunes waardebon. Als je kans wilt maken op deze waardebon, kun je aan het einde van de vragenlijst je emailadres achterlaten. Deze gegevens zullen alleen gebruikt worden voor de verloting van de prijs.

1. ONDERZOEKSNUMMER
Vul hier het onderzoeksnummer in dat je terug vindt in de informatiefolder (4 cijferige code):

2. DEELNAME
Voor jongeren tot 16 jaar moeten de ouders/verzorgers ook toestemming geven voor deelname aan het onderzoek. Overleg dus van tevoren en laat je ouders ook de folder lezen.

1. Deelname aan het onderzoek?
- Als je WEL wilt deelnemen aan het onderzoek, vink dan dit vakje aan om te bevestigen dat je de informatie in de folder hebt gelezen en begrepen.
- Als je NIET wilt deelnemen aan het onderzoek, vink dan dit vakje aan.

\[\rightarrow\] 1a. Je hebt aangegeven dat je niet mee wilt doen. Wat is/ zij de belangrijkste reden(en) dat je NIET wilt deelnemen aan dit onderzoek?
(Je mag meerdere antwoorden aankruisen)
- Het onderwerp interesseert mij niet
- Ik heb al aan te veel studies deelgenomen
- De onderzoeksvragen zijn te persoonlijk
- Het onderzoek maakt mij van streek
- Ik ben bang voor schending privacy/vertrouwelijkheid van gegevens
- Ik wil niet dat onderzoekers mij bellen/mij bezoeken
- Ik heb geen compensatie aangeboden gekregen (geld)
- Het kost teveel tijd
- Ik loop risico op negatieve ervaring/resultaten
- Niet zinvol (deelname levert mij persoonlijk niets op)
- Andere: ......................................................
1b. Op welke manier zou jij het liefst in het algemeen benaderd worden voor deelname aan onderzoek?
- Per brief (post)
- Per mail
- Via sociale-media: Facebook, Twitter,...
- Per telefoon
- Andere: ....................................................

Comment: Only patients who indicated not to participate were asked questions 1a and 1b stated above (those questions were not mandatory). For them the questionnaire ended here. Patients, who indicated to participate, went from question one straight to part three.
3. ALGEMEEN

1. Wat is je geslacht?
   □ Man □ Vrouw

2. Wat is je geboortedatum?
   .................

3. Welke opleiding volg je?
   □ Praktijkonderwijs
   □ vmbo
   □ havo
   □ vwo (atheneum, gymnasium)
   □ Middelbaar beroepsonderwijs (mbo)
   □ Andere: ........................................

   → 3a. Indien vmbo, is dit praktisch of theoretisch gericht?
   □ Praktisch (basis, kader of gemengd)
   □ Theoretisch

4. Maak je actief deel uit van een geloofsgemeenschap?
   □ Ja □ Nee

   → 4a. Indien ja, wat is dan je geloof?
   □ Protestants
   □ Katholiek
   □ Joods
   □ Islam
   □ Andere: ........................................

5. In welk land is je moeder geboren?
   □ Nederland
   □ Turkije
   □ Marokko
   □ Suriname
   □ Antillen
   □ Andere: ........................................

6. In welk land is je vader geboren?
   □ Nederland
   □ Turkije
   □ Marokko
□ Suriname
□ Antillen
□ Andere: .............................................

7. In welk land ben je zelf geboren?
□ Nederland
□ Turkije
□ Marokko
□ Suriname
□ Antillen
□ Andere: .............................................

8. Gebruik je naast je luchtwegmedicatie nog andere chronische medicatie voorgeschreven door een arts?
(met chronische medicatie bedoelen we medicatie die je voor een langere tijd/altijd moet innemen (vrijwel dagelijks). Bv. voor suikerziekte, maar bv. ook de anticonceptiepil.)
□ Ja □ Nee

→8a. Gebruik jij de anticonceptiepil? (This was asked only when the patient was a girl)
□ Ja □ Nee

→8b. Voor welke andere aandoening(en) gebruik jij nog chronische medicatie?
(je mag meerdere antwoorden aankruisen) (when gender=female)
□ Ik neem naast de anticonceptiepil geen andere chronische medicatie in
□ Diabetes (suikerziekte)
□ Epilepsie
□ ADHD
□ Eczeem
□ Reuma
□ Andere: .............................................

→8c. Voor welke andere aandoening(en) gebruik jij nog chronische medicatie?
(je mag meerdere antwoorden aankruisen) (when gender=male)
□ Diabetes (suikerziekte)
□ Epilepsie
□ ADHD
□ Eczeem
□ Reuma
□ Andere: .............................................

9. Hoe vaak sport je?
□ Niet
□ Af en toe
1. Is de diagnose astma bij jou daadwerkelijk door een arts gesteld?
   □ Ja     □ Nee

→ 1a. Indien ja, op welke leeftijd was dat?
   .................................................................

→ Indien nee:
1b. Voor welke klacht(en) heeft jouw arts luchtwegmedicatie voorgeschreven?
   (Het gaat hier over de onderhoudsmedicatie (inhalatiecorticosteroïden). Dit zijn de
   medicijnen die je dagelijks gebruikt om te voorkomen dat je luchtwegklachten krijgt. Deze
   puffers zijn meestal rood, oranje, bruin of paars.)
   (je mag meerdere antwoorden aankruisen)
   □ Kortademigheid
   □ Hoesten
   □ Benauwdheid
   □ Piepende ademhaling
   □ Andere: .........................................................

1c. Hoe lang gebruik je al medicatie voor luchtwegklachten?
   □ 1 jaar of minder
   □ 1-2 jaar
   □ 3-5 jaar
   □ 5-10 jaar
   □ > 10 jaar

2. Heeft iemand anders in de familie astma?
   □ Ja     □ Nee     □ Weet ik niet

→ 2a. Indien ja, wie? (je mag meerdere antwoorden aankruisen)
   □ Moeder
   □ Vader
   □ Zus
   □ Broer
   □ Andere: .........................................................
3. Heb je in het afgelopen jaar **orale corticosteroïden** moeten innemen?  
(Dit is een korte stootkuur (1-2 weken) van prednis(ol)on die je in moet nemen in pil vorm, vaak om een ernstige astma aanval te behandelen.)  
☐ Ja  ☐ Nee  ☐ Weet ik niet

→ 3a. Indien ja, **hoeveel kuren** heb je gehad in het **afgelopen jaar**?  
...........................................................................................................

4. Ben je het afgelopen jaar opgenomen in het **ziekenhuis** als gevolg van een astma-aanval?  
☐ Ja  ☐ Nee

→ 4a. Indien ja, **hoeveel ziekenhuisopnames** waren dat in het **afgelopen jaar**?  
.............................................................................................................

5. Hier volgen enkele vragen omtrent jouw **luchtwegklachten**:  

5a. Hoe vaak ben je per nacht gemiddeld **wakker geworden door astma/luchtwegklachten** in de afgelopen week?  
☐ Nooit  
☐ Bijna nooit  
☐ Een paar keer  
☐ Verscheidene keren  
☐ Vaak  
☐ Heel vaak  
☐ Kon niet slapen vanwege astma

5b. Hoe **ernstig waren de astma-/luchtwegklachten bij het ’s morgens wakker worden** gemiddeld in de afgelopen week?  
☐ Geen klachten  
☐ Heel lichte klachten  
☐ Lichte klachten  
☐ Matige klachten  
☐ Vrij ernstige klachten  
☐ Ernstige klachten  
☐ heel ernstige klachten

5c. In welke mate werd je over het algemeen in de afgelopen week door astma/luchtwegklachten **beperkt bij activiteiten**?  
☐ Helemaal niet beperkt  
☐ Nauwelijks beperkt  
☐ Een beetje beperkt  
☐ Tamelijk beperkt
5d. In welke mate heb jij je over het algemeen **kortademig** gevoeld in de afgelopen week ten gevolge van astma/luchtwegklachten?
- Helemaal niet
- Nauwelijks
- Een beetje
- Middelmatig
- Vrij ernstig
- Ernstig
- Heel ernstig

5e. Hoe vaak had je in de afgelopen week over het algemeen een **piepende ademhaling**?
- Nooit
- Zelden
- Af en toe
- Geregeld
- Vaak
- Meestal
- Altijd

5f. Hoeveel **pufjes/inhalaties van een kortwerkend luchtwegverwijzend middel** ((bijvoorbeeld Ventolin®, Bricanyl®) heb je op de meeste dagen genomen de afgelopen week? *(Het gaat hier over de rescue medicatie, deze puffers zijn meestal blauw. Voorbeelden: Ventolin, Salbutamol, Airomir, Serevent, Atrovent, Foradil, Bricanyl, Berodual, Oxis of Ipratropium.)*
- Geen
- 1-2 pufjes op de meeste dagen
- 3-4 pufjes op de meeste dagen
- 5-8 pufjes op de meeste dagen
- 9-12 pufjes op de meeste dagen
- 13-16 pufjes op de meeste dagen
- meer dan 16 pufjes op de meeste dagen

6. Hoeveel **last** had je van jouw **astma/luchtwegklachten** het afgelopen jaar?
- Niet/nauwelijks
- Enkele keren in de maand
- Enkele keren in de week
- Dagelijks
5. ROOKGEDRAG

1. Heb je familieleden die roken?
   - Ja
   - Nee

   → 1a. Indien ja, wie dan? (je mag meerdere antwoorden aankruisen)
   - Vader
   - Moeder
   - Zus
   - Broer
   - Andere: ..............................................

2. Rook je of heb je wel eens gerookt?
   - Ja
   - Nee

   → 2a. Indien ja, hoeveel rook(te) je?
   - Ik heb gerookt, maar ben er mee gestopt
   - Ik rook slechts af en toe (niet dagelijks)
   - Ik rook minimaal 1 sigaret per dag

   → 2b. Indien je eerder bij vraag 2a hebt aangegeven dat je hebt gerookt, maar bent gestopt, kun je hiervoor dan ook een reden aangeven? (je mag meerdere antwoorden aankruisen)
   - Het was te duur
   - Vanwege mijn luchtwegklachten
   - Ik vond het niet meer lekker
   - Mijn vrienden en/of familie hadden er last van
   - Andere: ..............................................

3. Wat denk je over de combinatie roken en astma?
   - Roken heeft een positieve invloed op astma
   - Roken heeft een negatieve invloed op astma
   - Roken heeft geen invloed op astma
   - Ik weet het niet
   - Andere: ..............................................

6. HOE GEBRUIK JIJ JOUW MEDICATIE?

Wij willen graag weten hoe jij jouw inhalator gebruikt. Kun je voor iedere bewering aangeven in welke mate deze voor jou geldt? Dit doet je door aan te klikken wat voor jou het meest van toepassing is.
(Het gaat hier opnieuw over de onderhoudsmedicatie (inhalatiecorticosteroïden). Dit zijn de medicijnen die je dagelijks gebruikt om te voorkomen dat je luchtwegklachten krijgt. Deze puffers zijn meestal rood, oranje, bruin of paars.)

<table>
<thead>
<tr>
<th>Hoe gebruik jij je inhalatiecorticosteroïden?</th>
<th>Altijd</th>
<th>Vaak</th>
<th>Soms</th>
<th>Zelden</th>
<th>Nooit</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Ik <strong>vergeet</strong> mijn geneesmiddelen te gebruiken.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Ik <strong>wijzig de dosering</strong> van mijn geneesmiddelen.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Ik <strong>stop een tijdje</strong> mijn geneesmiddelen te gebruiken.</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>4. Ik besluit een <strong>dosing over te slaan.</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Ik neem <strong>minder</strong> dan is voorgeschreven.</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

Indien je afwijkt van het voorschrift van jouw arts, **om welke reden(en) gebeurt dit dan?** (je mag meerdere antwoorden aankruisen, indien jouw antwoord er niet tussen staat, kun je dit aanvullen bij ‘andere’)

- Ik wijk niet af van het voorschrift, ik gebruik mijn medicatie zoals het is voorgeschreven
- Ik vergeet mijn medicatie te gebruiken
- Ik vind het alleen nodig mijn medicatie in te nemen als ik klachten heb, anders zie ik het nut er niet van in
- Ik wil testen of ik zonder mijn medicatie kan, misschien is mijn astma wel over
- Ik schaam mij tegenover anderen
- Ik wil niet anders zijn dan mijn leeftijdsgenoten op school
- Ik geloof niet dat ik de medicatie nodig heb, zo ernstig is het niet
- Ik maak me zorgen om bijwerkingen
- Ik krijg onvoldoende steun
- Het innemen van medicatie is een teken van zwakte
- Indien ik minder beweeg, hoef ik ook minder medicatie in te nemen
- Het is moeilijk een regelmaat te vinden, ik heb het nogal druk
- Mijn behandelingsschema is te complex
- Ik weet niet goed hoe ik mijn inhalator moet gebruiken
- Andere: ..........................................................

### 7. LEEFTIJDGENOTEN EN OUDERS

1. Gebruik jij jouw inhalator in de **aanwezigheid van je vrienden?**

- Ja
- Nee
1a. Indien nee, waarom niet? (je mag meerdere antwoorden aankruisen)
   □ Ik schaam me
   □ Ze lachen me uit
   □ Ze stellen er vrevelende vragen over
   □ Ze denken dat astma besmettelijk is
   □ Ze denken dat ik me aanstel
   □ Ze weten niet dat ik astma heb en ik wil dat ook zo houden
   □ Andere: .....................................................

2. Gebruik jij jouw inhalator in de aanwezigheid van anderen dan je vrienden, bv. klasgenoten?
   □ Ja   □ Nee

2a. Indien nee, waarom niet? (je mag meerdere antwoorden aankruisen)
   □ Ik schaam me
   □ Ze lachen me uit
   □ Ze stellen er vrevelende vragen over
   □ Ze denken dat astma besmettelijk is
   □ Ze denken dat ik me aanstel
   □ Ze weten niet dat ik astma heb en ik wil dat ook zo houden
   □ Andere: .....................................................

3. Spelen je vrienden een belangrijke rol in het gebruiken van je medicatie? (Bijvoorbeeld: ophalen, innemen, organisatie.)
   □ Ja   □ Nee

3a. Indien ja, welke rol dan? (je mag meerdere antwoorden aankruisen)
   □ Ze helpen mij eraan herinneren mijn medicijnen in te nemen
   □ Ze moedigen me aan om mijn medicijnen in te nemen
   □ Ze begrijpen waarom ik ze nodig heb
   □ Ik kan met hen praten als ik het moeilijk heb/problemen heb met mijn ziekte
   □ Andere: .....................................................

4. Voel je je wel eens buitengesloten omwille van je astma?
   □ Ja   □ Nee

4a. Indien ja, waarom dan? (Not mandatory)
   ..................................................................................................................................................................................
5. Spelen je ouders een belangrijke rol in het gebruiken van je medicatie?
(Bijvoorbeeld: ophalen, innemen, organisatie.)
☐ Ja ☐ Nee

→ 5a. Indien ja, welke rol dan? (je mag meerdere antwoorden aankruisen)
☐ Ze halen mijn medicatie op bij de apotheker
☐ Ze helpen mij eraan herinneren mijn medicijnen in te nemen
☐ Ze moedigen me aan om mijn medicijnen in te nemen
☐ Ze helpen me mijn medicatieschema in te passen in mijn weekschema
☐ Ik kan met hen praten als ik het moeilijk heb/problemen heb met mijn ziekte
☐ Andere: ..........................................................

6. Vind je hulp van je ouders bij het gebruiken van de medicatie belangrijk?
(Gebruiken heeft hier een brede betekenis: ophalen, innemen, organisatie.)
☐ Ja, ik heb graag dat ze me zo veel mogelijk helpen
☐ Ja, maar ze hoeven me niet constant te controleren
☐ Nee, ik wil niet dat ze me helpen, ik kan best wel zelfstandig zijn
☐ Andere: ..........................................................

7. Eervaar je de steun van jouw ouders als te weinig, voldoende of te veel?
☐ Te weinig
☐ Voldoende
☐ Te veel

8. HOE DENK JIJ OVER JOUW MEDICATIE?

<table>
<thead>
<tr>
<th>Hoe denkt je over jouw inhalatiecorticosteroïd? (meestal rode, oranje, bruine of paarse puffers)</th>
<th>Helemaal niet mee eens</th>
<th>Niet mee eens</th>
<th>Geen duidelijke mening</th>
<th>Mee eens</th>
<th>Helemaal mee eens</th>
</tr>
</thead>
<tbody>
<tr>
<td>Op het moment hangt mijn gezondheid af van mijn geneesmiddelen.</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Ik maak me zorgen over het feit dat ik geneesmiddelen moet nemen.</td>
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</tr>
<tr>
<td>Mijn leven zou erg moeilijk zijn zonder geneesmiddelen.</td>
<td></td>
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</tr>
<tr>
<td>Soms maak ik me zorgen over de effecten die mijn geneesmiddelen op de lange termijn kunnen hebben.</td>
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<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Helemaal niet mee eens</td>
<td>Niet mee eens</td>
<td>Geen duidelijke mening</td>
<td>Mee eens</td>
<td>Helemaal mee eens</td>
</tr>
<tr>
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</tr>
<tr>
<td><strong>Zonder</strong> mijn geneesmiddelen zou ik heel ziek zijn.</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td><strong>Ik ben onvoldoende op de hoogte</strong> van wat mijn geneesmiddelen doen.</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td><strong>Mijn toekomstige gezondheid hangt af van mijn geneesmiddelen.</strong></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td><strong>Mijn geneesmiddelen ontwichten mijn leven.</strong></td>
<td></td>
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<td></td>
</tr>
<tr>
<td><strong>Soms ben ik bang</strong> dat ik <strong>té afhankelijk</strong> zal worden van mijn geneesmiddelen.</td>
<td></td>
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<td></td>
</tr>
<tr>
<td><strong>Mijn geneesmiddelen voorkomen dat ik verder achteruitga.</strong></td>
<td></td>
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</tr>
<tr>
<td><strong>Deze geneesmiddelen hebben onplezierige bijwerkingen.</strong></td>
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</tbody>
</table>

**9. KENNIS OVER ASTHMA BEHANDELING**

*In dit een-na-laatste onderdeel willen we je nog een paar vragen stellen waarmee we jouw kennis nagaan over jouw luchtwegmedicijnen. Dit is geen test, wij willen gewoon achterhalen of je voldoende op de hoogte bent van jouw eigen medicatie. Vul dit zo goed mogelijk in en pak gerust de medicatie erbij als jou dit kan helpen.*

<table>
<thead>
<tr>
<th></th>
<th>Juist</th>
<th>Onjuist</th>
<th>Weet ik niet</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Luchtwegverwijdende medicijnen</strong> <em>(blauwe puffer)</em>, zoals bijvoorbeeld Ventolin en Salbutamol pakken de <strong>oorzaak</strong> van luchtwegklachten aan.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Luchtwegbeschermende medicijnen/ontstekingsremmers (inhalatiecorticosteroïden; meestal rode, oranje, bruine of paarse puffers)</strong> geven <strong>gewenning</strong>, dus heb je steeds meer medicijnen nodig.</td>
<td>Juist</td>
<td>Onjuist</td>
<td>Weet ik niet</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
</tbody>
</table>

**Luchtwegbeschermende medicijnen/ontstekingsremmers** om te inhaleren hebben vrijwel **geen bijwerkingen**.

**Prednis(ol)on** in de vorm van een korte stootkuur (1-2 weken) geeft meestal **veel bijwerkingen**.

**Prednis(ol)on** helpt bij **acute benauwdheid** binnen 15 minuten.

Het is altijd nodig om de **mond te spoelen** na het inhaleren van **luchtwegbeschermende medicijnen/ontstekingsremmers**.

**Luchtwegbeschermende medicijnen/ontstekingsremmers** moet je **altijd** gebruiken, óók als het **goed gaat**.

Een **voorzetkamer** (Volumatic, Nebuhaler), voor het inhaleren met verstuiver/aërosol, zorgt ervoor dat **meer medicijn de longen** bereikt.

Bij gebruik van een **voorzetkamer** mogen niet alle pufs tegelijk in de voorzetkamer worden gedaan, maar moeten ze **één voor één** worden geïnhaleerd.

**Antibiotica** zijn **belangrijk** bij de behandeling van astma.
10. DEELNAME AAN DIT ONDERZOEK

Je bent nu bijna aan het einde van de vragenlijst. Wij willen nog een paar vragen stellen over onderzoek in het algemeen.

1. Wat is/zijn de belangrijkste reden/redenen waarom je hebt deelgenomen aan dit onderzoek? (Je mag meerdere antwoorden aankruisen)
   - Het onderwerp spreekt mij persoonlijk aan
   - Deelname kost niet veel tijd
   - De wijze van benadering (online vragenlijst)
   - Onderzoek verbetert de gezondheidszorg
   - Meedoen aan onderzoek levert mij persoonlijk iets op
   - Meedoen aan onderzoek levert mij in de toekomst iets op
   - Onderzoek helpt anderen
   - Mijn deelname helpt anderen
   - Onderzoek informeert mij over mijn gezondheid/ziekte/behandeling
   - Het is een mogelijkheid om ervaringen te delen
   - Andere: ..........................................................

2. Wat zijn voor jou belangrijke redenen om NIET deel te nemen aan onderzoek (Je mag meerdere antwoorden aankruisen)
   - De meeste onderwerpen interesseren mij niet
   - Ik heb al aan te veel studies deelgenomen
   - De onderzoeksvragen zijn te persoonlijk
   - Het onderzoek maakt mij van streek
   - Ik ben bang voor schending van privacy/vertrouwelijkheid van gegevens
   - Ik wil niet dat onderzoekers mij bellen/mij bezoeken
   - Ik heb geen compensatie aangeboden gekregen (geld)
   - Het kost teveel tijd
   - Ik loop risico op negatieve ervaring/resultaten
   - Niet zinvol (deelname levert mij persoonlijk niets op)
   - Andere: ..........................................................

3. Op welke manier zou jij het liefst benaderd worden voor deelname aan onderzoek?
   - Per brief (post)
   - Per mail
   - Via sociale-media: Facebook, Twitter,…
   - Per telefoon
   - Andere: ..........................................................
11. ITUNES WAARDEBON

Vul hier je emailadres in, wanneer je kans wil maken op een iTunes waardebon:
(Deze gegevens zullen alleen gebruikt worden voor de verloting van de prijs.)

..................................................