

ADHERENCE

Every parent tells a story: why non-adherence may persist in children receiving guideline-based comprehensive asthma careTed Klok, MD, PhD¹, Susanne Lubbers, MD¹, Adrian A. Kaptein, PhD², and Paul L. Brand, MD, PhD^{1,3}¹Princess Amalia Children's Clinic, Isala klinieken, Zwolle, the Netherlands, ²Unit of Psychology, Leiden University Medical Center, Leiden, the Netherlands, and ³UMCG Postgraduate School of Medicine, University Medical Center and Groningen University, Groningen, the Netherlands**Abstract**

Objective: Effective self-management and adherence to inhaled corticosteroids are issues of particular interest in comprehensive asthma care. In spite of this care, however, a number of parents and children remain non-adherent. The reasons for this non-adherence have up till now been unknown, because previous adherence studies have based their findings either on populations with poor adherence or on unreliable self-reported adherence. This study was designed to explore factors that contribute to persistent non-adherence to inhaled corticosteroids in children ranging between 2 and 12 years of age receiving comprehensive asthma care, with adherence assessed objectively. **Methods:** This qualitative study was based on in-depth interviews which took place in the homes of parents whose children had completed a one-year follow-up of electronically measured adherence to inhaled corticosteroids. Rich and comprehensive descriptions of parents' own accounts of self-management behavior were obtained using active listening techniques. Each interview was recorded and transcribed verbatim followed by data analysis using standard methodology for qualitative studies. **Results:** Twenty children's parents (mean age 5.9 years) were interviewed. Distinctive patterns of modifiable barriers to adherence emerged, including a novel finding of parents misjudging their child's ability to manage the daily use of medication by him/herself. Persistent non-adherence appeared to be caused by a number of maintaining factors. Most noticeable factors were unawareness of non-adherence by both parents and health care providers, a lack of parental drive to achieve high adherence and ineffective parental problem-solving behaviour. **Conclusions:** This study has identified modifiable barriers to adherence in families participating in a comprehensive asthma care programme. Future studies are needed to verify our novel findings and to investigate whether interventions around these barriers are needed to increase the effectiveness of asthma care programs

Keywords

Adherence, quality of care, qualitative study, self-management, shared decision making

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Over the last decade, several studies have explored determinants of adherence to inhaled corticosteroids (ICS) in children with asthma [1]. In most studies, children only received between 30% to 70% of the prescribed doses. Adherence appeared to be particularly poor in ethnic minorities from lower socioeconomic status [1–4]. These fixed demographic determinants of poor adherence, however, are largely mediated by modifiable risk factors for low adherence, such as parental illness perceptions and medication beliefs [1–3,5]. If these modifiable risk factors are addressed in guideline-based comprehensive asthma care [6], high adherence and good asthma control can be achieved even in this group of underprivileged children with asthma [7].

We have recently shown a comparable pattern of high median adherence in pre-school children from middle class

families receiving regular, comprehensive, multidisciplinary asthma care [8]. This was associated with most parents expressing illness perceptions and medication beliefs in accordance with the medical model of asthma [9]. However, even in populations with such high median adherence, variability in adherence remains. In our study in pre-school children whose median adherence was 92% over a three-month period, a third of the children received less than 75% of the prescribed doses of ICS [8]. Reasons for such "persistent non-adherence" in spite of comprehensive guideline-based asthma care are unknown. Previous adherence studies have focused on populations with a high rate of non-adherent patients, or have relied on parental or patients' self-reported adherence which highly overestimates objectively measured adherence [10].

This study was designed to explore determinants of persistent non-adherence to inhaled corticosteroids in parents and children receiving comprehensive guideline-based asthma care. We used electronically measured adherence, which ensures capturing unreported and unwitting non-adherence. We intended to explore every potential reason for non-adherence and did not want to limit ourselves to

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identifying established barriers to adherence. We therefore chose a qualitative study design, allowing for a rich and detailed description of determinants of adherence [11].

Methods

Setting and design

We have recently completed a one-year observational follow-up study of electronically measured adherence to ICS maintenance therapy. We followed a group of 2-to-12-year-old children with pediatrician-diagnosed asthma and persistent ICS use in our pediatric asthma outpatient clinic (Zwolle, the Netherlands) [8,9]. Patients can only be seen in this hospital-based clinic after referral by their family physician because of uncontrolled asthma despite the prescription of ICS. In the Netherlands, all children with medical problems are first seen by a family physician, all pediatricians are hospital-based. To ensure optimal asthma management and adherence, our asthma care comprises repeated teaching of tailored asthma self-management, including: [6,12]

- Discussing parents' perceptions about asthma and its treatment.
- Establishing and maintaining a partnership between health care providers and the patient/parent dyad.
- Ensuring concordance on treatment and its goals with parents and those children old enough to participate in the discussion.
- Stressing the importance of adherence to daily ICS treatment.

To achieve this, patients and their parents visit the clinic four to six times during their first year of follow-up, and two to four times per year afterwards. With this strategy, most children achieve high levels of adherence to ICS and good asthma control [8,13]. Throughout the 12-month follow-up, adherence was monitored by SmartInhaler[®] (Auckland, New Zealand) for metered dose inhaler (MDI)/spacer combination, SmartTracker[®] (Auckland, New Zealand) for MDI with dose counter, and SmartDisk[®] (Auckland, New Zealand) for Diskus/Accuhaler, electronic devices logging date and time of each ICS actuation [8,14]. At each follow-up visit to the clinic, the data recorded by these electronic devices were uploaded by the primary investigator (who was not involved in the clinical care of these patients) who also checked proper recording function. The uploaded adherence rates were available to neither the treating physicians, asthma nurses, nor to the parents and children. To prevent loss of data in the case of malfunctioning devices and to assess asthma control regularly, a home-visit was made by a researcher to upload the adherence logger data and record parental assessment of asthma control if time to the next scheduled follow-up visit exceeded 5 months. We aimed at obtaining a minimum of four visits per patients during the study period. The efforts to minimize loss to follow-up by planning home visits contributed to a high number of patients completing the study (135 of the initial 147 patients). Adherence was calculated as the number of electronically recorded inhaled doses expressed as a percentage of the number of doses prescribed, censored at 100% of the prescribed dose [15].

Our study aimed to explore determinants of non-adherence persisting in spite of such comprehensive care. In order to

achieve this, we interviewed parents about their medicine-giving behavior (based on data obtained through electronic adherence measurements) during the follow-up study. Although we focused on non-adherence, we included children's parents from the whole adherence spectrum. The interviews with adherent parents served the purpose of enriching our analysis by allowing us to contrast the ways medicines were used between parents with low and high adherence.

Selection of eligible patients and parents

For this qualitative study, all 2-to-12-year-old children who had completed a one-year follow-up of electronically measured adherence to ICS (details of which were published previously) [8] were eligible for inclusion. The consecutive eligible children's parents were asked to allow de-blinding of the results of long-term adherence measurements and to participate in an in-depth interview on their (non-)adherence behavior. Based on the results of electronically measured adherence over the completed one-year follow-up period, parents who had given informed consent were divided into two groups of at least 10 parent couples. These groups represented those with adherence below 75% and those with adherence above 75%. In the case of ICS in children with asthma, an adherence level of 80% is commonly used as threshold value of low adherence [13]. However, this average long-term adherence level of 80% reflects periods with adherence both above and below 80% because adherence varies over time. As we wanted to identify children whose adherence was consistently low during follow-up, we lowered the threshold value of "low adherence".

In both groups, random number tables were used to rank the children, stratified for age (younger than 6 and 6-to-2-year-olds). From the top of each of these ranked lists, parents were included for interviews until saturation for each group had been reached (i.e. additional interviews were not expected to yield new information on patterns of non-adherence). Parental educational level was assessed by recording the highest level of education completed.

Interviews

Two researchers (TK and SL) visited parents at their homes for a semi-structured in-depth interview lasting approximately one hour. We started each interview by asking the parents to estimate the one-year ICS adherence achieved in their child, after which we revealed the results of one-year electronically measured adherence. The similarity or difference between the parent-estimated and actually measured adherence was used as a starting point to explore parental (non-)adherence behavior without passing judgment. Active listening techniques were used to obtain a rich and comprehensive description of the parents' explanation for following or deviating from the health care team's recommendations of ICS dose and dosing frequency. As the character of the interviews was home-based, children aged 8–12 commonly engaged in the interview themselves. When the interviewers felt they had obtained a comprehensive and accurate overview of parental and children's (non-)adherence behavior, they summarized it, inviting modification by parents until they

accepted it as accurate and complete. Following the principle of grounded theory methodology, findings of previous interviews were used to guide subsequent interviews in exploring patterns of adherence behavior [11]. Explanations for non-adherent behavior were also specifically discussed with parents with high adherence. This served the purpose of finding out if such explanations were less prevalent in adherent families. It also improved understanding of the reasons why parents confronted with the same problem (e.g. a child unwilling to take medication) showed different behaviors.

Analysis

Each interview was recorded and transcribed verbatim and analyzed using standard methodology for qualitative studies [8,9,11]. The transcripts of the first two interviews were coded independently by two researchers (TK, SL) using qualitative analysis software (Kwalitan[®], Kwalitan advice, Malden, the Netherlands) with good agreement (Cohen's kappa values 0.80 and 0.90, respectively). Subsequent transcripts were coded by one researcher (SL) and cross-checked by another (TK). Differences in coding were resolved by consensus. Based on the coded transcripts, three distinct patterns of non-adherence behavior were identified. All transcripts explaining families' non-adherent behavior could be categorized into these three patterns, suggesting we did not miss any important pattern of non-adherence behavior. Further analysis of field notes and transcripts was used to reveal differences between adherent and non-adherent families with respect to these patterns. Conceptual ideas underlying the persistence of each of the non-adherence behaviors were based on these differences and cross-checked with the transcripts. These concepts were modified and extended during discussions between all authors.

Ethical considerations

This study was approved by the hospital ethics review board of the Isala klinieken, Zwolle, the Netherlands; all parents provided written informed consent.

Results

Forty-two out of 69 children's parents (61%) who had been asked to participate in our study gave informed consent to de-blind study results for the interview (Figure 1). Refusal of de-blinding consent was equal in adherent and non-adherent parents. Saturation was reached after 10 children's parents with poor adherence (below 75%) and 10 with high adherence (above 75%) had been interviewed. The mean age of the children whose parents were interviewed was 5.9 years (Table 1). Median education level of parents was 5 (i.e. secondary vocational degree, range 3–7). On average, therefore, this was a middle-class Caucasian population of parents.

Individual stories, recognizable patterns

All interviews took place around a kitchen or dinner table, allowing for a low-profile atmosphere. All parents were happy to discuss the way they managed giving medicine in detail.

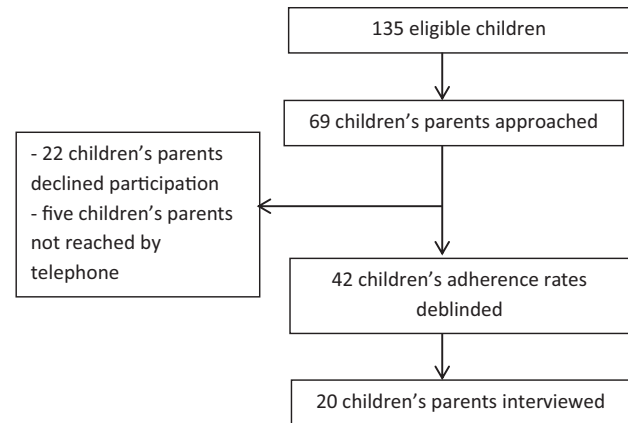


Figure 1. Inclusion of patients.

All but one of the 8–12-year olds contributed to the interview. As we wanted parents to speak freely about their children, we also interviewed parents without their child being present.

Each single interview provided us with a unique story about how parents and children cope with the child's asthma and the recommendation of daily ICS use. With the exception of one family, all interviews could be summarized with a clear and mutually agreed description of how medication was taken. All of the parents reported that they had been recommended to provide daily ICS to their child. Even though some parents reduced the dose, all expressed the intention to use ICS regularly in order to achieve good asthma control in their child. We identified three distinct patterns of non-adherence behavior (Table 2). Within these patterns, a number of barriers as well as factors contributing to the persistence of these barriers were identified (Table 2).

Intentional non-adherence

Parents of four children deliberately deviated from the pediatrician's advice. They adjusted the ICS dose according to what they thought was the desired or obtained level of asthma control in their child. Based on their own experience, these parents increased the dose during a "bad" season, or when their child showed increased symptoms. These parents were all convinced that they were self-managing their child's asthma well.

Most commonly, children were given a single daily ICS dose instead of the recommended two. In these children, electronically measured adherence could thus be as low as 50%, with parents readily confirming the accuracy of this number. They did not discuss their dose-reducing behavior with the pediatrician, unless the pediatrician explicitly asked them about their ICS use. Parents' main reasons for lowering the ICS dose were concerns about ICS side effects or resistance against medication in general. These parents were convinced their child needed ICS treatment, but their aim was to optimally balance the pros and cons of ICS. Parents of two children achieved well-controlled asthma in their child with this strategy. Two other children, however, had persistent asthma symptoms. In one child, the parents repeatedly tapered the dose of ICS after a short period of well-controlled asthma. For the parents of the other child, the persistence of mild

Table 1. Characteristics of patients and their parents who were interviewed ($n = 20$) and those who declined participation ($n = 27$).

Demographic and clinical characteristics	Interviewed	Declined	p Value
Age (mean; range; yrs)	5.9 (2.4–12.7)	4.8 (2.3–11.0)	0.089
Male gender (%)	17 (85%)	17 (23%)	0.114
Parental diagnosis of asthma (%)	10 (50%)	12 (44%)	0.773
Household smoking (%)	8 (40%)	8 (30%)	0.541
Maternal educational level ^a	5 (4–6)	5 (4–6)	0.235
Hospitalisation ever for asthma exacerbation (n, %)	10 (50%)	9 (33%)	0.368
Duration of outpatient clinic asthma care before study (months)	18 (12–35)	13 (7–21)	0.343
ACQ	0.5 (0.2–1.2)	0.3 (0.0–1.0)	0.979
PACQOL	6.2 (5.3–6.8)	6.5 (5.3–6.9)	0.605
Level of adherence in adherent families (mean, range) $n = 10$ and 16	88% (81%–97%)	94% (82%–99%)	
Level of adherence in non-adherent families (mean, range) $n = 10$ and 11	51% (15%–74%)	47% (15%–72%)	

Data are presented as median (interquartile range) unless otherwise stated. ACQ: Asthma Control Questionnaire (<0.75 = well-controlled asthma, >1.5 = not well-controlled asthma); PACQOL: pediatric asthma caregiver quality of life questionnaire (1 is low and 7 is high quality of life) [38,39].
^a7-point scale, ranging from 1 (high school drop-outs; only completed primary education) to 7 (completed college or university education).

Table 2. Patterns of barriers to adherence and factors contributing to the persistence of these barriers.

Patterns of barriers	Quotes from the interviews
Intentional non-adherence:	
<ul style="list-style-type: none"> concerns about medication resistance against meds in general 	<p>“I was rather skeptical about the meds, but I also saw my daughter’s breathlessness. Well, then you weigh your options in your mind”</p> <p>“No, I don’t follow each of the pediatrician’s recommendations. I look at my child, whether he needs the meds or not.”</p>
Unplanned non-adherence associated with family-related barriers:	
<ul style="list-style-type: none"> Child raising issues Missing family routines 	<p>“Do I have to upset him completely, only for such an inhalation? How hard should you push? That’s a difficult decision sometimes.”</p> <p>“I have this experience with my daughter (also an asthmatic), of controlling her like a cop. That’s something I don’t want to go through again.”</p> <p>“I should stick to the rules that we decided on, but that’s not what happens”</p>
Unplanned non-adherence associated with self-management of children.	
<ul style="list-style-type: none"> Parental misperceptions about children’s capacity of self-management Children incapable of self-managing daily use of medication 	<p>“When he received the powder inhaler, when he was eight, we thought he could take the meds on his own.”</p> <p>“He’s already 9 years; he has to figure out for himself what he wants, and how to get things done.”</p> <p>“The meds are just annoying. I see the inhaler when I go to bed, but I don’t take it”</p>
Maintaining factors	
Parent related:	
<ul style="list-style-type: none"> unawareness of non-adherence not reporting of non-adherence lack of motivation to achieve high adherence ineffective problem-solving behavior 	<p>“That he takes his meds only half of the time, that’s quite shocking to me.”</p> <p>“Giving the meds every day once a day, that’s so obvious to me, and the right thing to do. I think that’s the reason I don’t report this to the pediatrician.”</p> <p>“Well, I do notice he doesn’t take his meds. I see the counter of the inhaler still on the same number, just like some days before. Then you think: okay... but, you know, I have to deal with a lot of problems...”</p> <p>“In the evening, he usually falls asleep on the couch. Then I don’t wake him up for his meds.”</p>
Physician related:	
<ul style="list-style-type: none"> unawareness of non-adherence not (specifically) asking about the use of ICS unawareness about young children self-managing their medication 	<p>“He (the pediatrician) never informed about the details of using the medication: about who is responsible, and how we are doing it”</p>

symptoms did not outweigh their concerns about ICS side effects.

Parents with good adherence differed from these non-adherent parents in two ways. Some of these highly adherent parents expressed few if any concerns about (side effects of) ICS and therefore did not deliberately balance pros and cons of ICS. Other highly adherent parents did express a high level of concerns about ICS use, but were convinced that their child needed the ICS two times a day nevertheless.

Family-related barriers

Parents in this group tended to give a higher estimation of the level of adherence than the electronically measured adherence would show. Unaware of their non-adherence, these parents would not discuss this with their pediatrician. Different families were confronted with different sets of barriers that kept them from regular ICS use. Barriers such as relational or economic issues or parental psychiatric illnesses seemed fixed or difficult to modify at first sight. After exploring

parental and children's adherence behavior in more detail, however, barriers appeared modifiable in most families. Child raising issues, for example, were found to be important barriers in three families, for example where parents would skip a dose when children refused the use of their inhaler simply to avoid upsetting their child. Other parents deliberately skipped the morning dose, because overcoming the resistance of the child would take too much of their time to arrive at school on time. Augmented by the absence of daily medicine taking routines, at least four families were prone to simply forgetting giving the medication altogether. Parents were aware of these barriers, but accepted them to avoid family stress.

Compared to the self-management of parents with good adherence, two differences emerged. First, parents with good adherence were dedicated to use ICS regularly, whereas parents with poor adherence regarded the achieved adherence rates as the best they could possibly do. Highly adherent parents put giving medication before avoiding upsetting their child. Second, parents with good adherence showed good problem-solving skills by having developed medicine taking routines to avoid forgetting the medication.

Transferring excessive responsibility to children

In this group, children 8–10 years of age were given full responsibility for taking their own medicine, without parental supervision. Two of these children's parents were astonished to find out that the adherence rates that had been recorded for a year turned out to be much lower than they had expected. These parents had been convinced that 8 to 10 years old children could take such a responsibility. In families struggling with relational or economic problems, children were given the responsibility for taking their own medicine at an even younger age, in order to reduce the number of issues that needed tackling. Even though aware of their child's non-adherent behavior, some parents decided to ignore it in their wish to avoid a fight about taking medicine. Their decisions to do so were either based on the assumption that too much pressure on the child would lead to more resistance, or on the belief that giving the child full responsibility would foster their independence. Lacking the drive to achieve good adherence as well as ineffective ways of solving problems, however, underlie these problems. Parents who were aware of their child's non-adherence relied on the pediatrician to try and change their child's behavior.

In children with high adherence, children's wish for independence was accepted more gradually. Parents were much more involved in supervising their children's ways of taking medication. These parents were more dedicated to achieve good adherence and expressed the view that children could not be expected to self-manage their own medication before the age of 12. To prevent a fight about independence, some parents have developed subtle tactics to keep an eye on their child's medicine taking behavior such as being within earshot of the child on the times the inhaler should be taken.

Discussion

Through in-depth interviews, which took place in the domestic environment of children with asthma that remained

non-adherent in spite of receiving guideline-based comprehensive asthma care, we gained insight into three categories of barriers that kept these patients from being adherent and into determinants that explained why these barriers could not be overcome. Some parents faced non-adherence even though they were conscientiously dealing with medication. They were self-managing medication by giving the lowest possible ICS dose. Other parents, however, poorly planned medication. They were either overwhelmed by complex family, social or child-raising issues, or gave responsibility for medication to the children themselves without supervising them. Further probing suggested that in those parents a lack of drive or ineffective problem-solving skills underlay barriers not been overcome. These factors, together with parental as well as health care provider's unawareness of the degree of non-adherence were identified as the underlying causes of persistent non-adherence.

Parents who deliberately balanced the pros and cons of prescribed medication use, based on their own illness perceptions and medication beliefs, formed the group of "intentional non-adherers". Previous studies have described this as a cause of problematic non-adherence: not taking medication at all or only if symptomatic [16–18]. This is the first study to demonstrate that intentional non-adherence may also be associated with continuous use of ICS, aiming to achieve good asthma control with the lowest possible dose of daily ICS. The parents in this group in our study expressed constructive illness perceptions and medication beliefs, concordant with the medical model of asthma, after receiving comprehensive self-management education [9]. Although in some children this parental medicine taking behavior was associated with persistent asthma symptoms, in other children parents achieved well-controlled asthma. To avoid misclassifying such parents as being problematically non-adherent, physicians and parents need to reach concordance on the ICS dose and on the desired level of asthma control [19]. Finally, physicians should actively check the current dose being given at each follow-up visit.

This study confirmed previous findings that unplanned non-adherence is common, in particular in families with relational or economic issues [2,20]. As reported by previous studies, this relationship is mediated by potentially modifiable barriers, including a lack of medication taking routines and ineffective child raising strategies [2,15,16,20,21]. Given that parents and physicians are usually unaware of the degree of unplanned non-adherence, current guideline-based comprehensive asthma care is not sufficient [10,15,22]. Factors contributing to the persistence of these potentially modifiable barriers emerged in our study. These included the lack of motivation to achieve good adherence and the presence of ineffective problem-solving behavior. The latter has been noted in a survey of diabetes educators. They reported that appropriate problem-solving was the most difficult skill to teach patients [23,24]. A large trial in asthmatic adults showed no benefits of problem-solving education, and the authors suggested that patients' lack of motivation to achieve high adherence was the main reason for this failure [25]. Similarly, an asthma outreach program in inner-city children with asthma in the USA was of limited benefit when parents lacked the motivation to

participate [26]. Apparently these maintaining factors represent determinants of self-management that are difficult to modify, supporting our analysis about the role of such underlying factors in the persistence of modifiable barriers.

Perhaps the most striking novel finding of our study was the excessive responsibility given by parents to children at a relatively young age to self-manage the daily use of their own medication, without parental supervision. This represented a major cause of non-adherence. An increase in shared responsibility for asthma self-management has been reported from the age of 8 years [27–29], particularly for daily preventer medication use [30,31]. This practice has shown to be related with deficient inhalation technique [29], however until now, the effect of this practice on adherence has been largely unknown. One of the two previous studies investigating this effect (reporting no effect) used parental-reported adherence [27]. Results were highly unreliable for two reasons. Both parents and children are generally hesitant to disclose poor adherence and parents can also be unaware of their child's poor adherence [32]. The second study, which was based on electronic monitoring of adherence, showed lower adherence in children with more responsibility [21]. In contrast to common belief [16], children below the age of 10–12 years seem to be unable to take responsibility for their own taking of medicine [33,34]. To identify and overcome this barrier to adherence, parental beliefs about the self-management responsibility of their child should be discussed during follow-up visits, along with the associated lack of motivation to achieve good adherence and ineffective problem-solving behavior. Parents should likewise receive counseling in supervising their child's taking of medicine at least until their child reaches the age of 12.

Clinical implications

This study has shown the importance of assessing non-adherence objectively in some patients. Many parents and physicians appear to be unaware of the extent of non-adherence. Non-adherence needs to be identified before barriers underlying it can be discussed and modified. It has been shown that feeding back results of objectively measured adherence improves adherence, but only for a short period [35,36]. This may reflect a lack of parental motivation or ability to control asthma, in particular in families with competing priorities and problems. Whether motivation enhancing techniques such as motivational interviewing may change long-term adherence in such patients remains to be established. Short-term benefits of this approach have been established in inner-city asthmatic adolescents [37]. In families struggling with many and complex daily life issues, a child's asthma may be a minor problem not getting priority. An open discussion about the complex issues of coping with daily life and about the child's ability to self-manage the daily use of their medication may help to achieve concordance with parents on the degree of achievable asthma management and control in these patients. Our experience in interviewing these parents suggests that reproaching parents' non-adherence should be avoided.

Strengths and limitations

The main strength of this study lies in the qualitative design, which allowed for an in-depth exploration of barriers to adherence during guideline-based comprehensive asthma care. A home-based environment for the interviews appeared to be the ideal environment to explore and discuss parental explanations for following or deviating from the pediatrician's recommendation to give daily ICS to their child. The use of electronic devices ensured detection of unwitting non-adherence. The limitation of this study is that it is still impossible to make generalizations. This study population receiving high quality asthma care was characterized by a high level of adherence associated with a high level of asthma control (Table 1) [13]. Whether our findings, in particular our finding of excessive medication responsibility given to children, are applicable to populations of children with asthma in different settings, and with different levels of adherence and asthma control remains to be established.

The electronic monitoring of adherence and the home visits made by a researcher may have improved medicine taking behavior of both parents and children (Hawthorne effect, http://en.wikipedia.org/wiki/Hawthorne_effect), limiting the possibility to detect patterns of non-adherence. In designing our long-term follow-study, however, we aimed to minimize this effect by ensuring a 12-month follow-up period. We assumed that the Hawthorne effect would be strongest during the first few months of monitoring adherence, and would diminish over time. This hypothesis is supported by the finding that long-term adherence was highest during the first three months of follow-up [8], and some 10% lower during the remaining 9 months of follow-up [13]. As previous work showed improved adherence when results of electronically measured adherence were fed back to parents [35], we refrained from providing such feedback because we wanted a real-life assessment of adherence.

Conclusions

This study in families participating in a comprehensive asthma care program shows that persistence of non-adherence in spite of comprehensive asthma care can be related to both adequate and inadequate asthma self-management. Adequate self-management that nevertheless leads to non-adherence is related to parents' intentions to achieve optimal asthma control with the lowest possible ICS dose. Inadequate self-management is caused by potentially modifiable barriers, of which parental medication beliefs, child-raising issues and lack of family routines have been identified previously. In this study, a novel barrier to adherence was identified: full responsibility given to children at a young age to self-manage their daily use of ICS. The persistence of barriers was related to limitations in parental problem-solving behavior and a lack of motivation to achieve high adherence as well as unawareness of non-adherence with both parents and health care providers. Future studies are needed to verify our novel findings and to investigate whether interventions around these barriers are needed to increase the effectiveness of asthma care programs. Effectiveness of interventions to improve adherence may well prove limited if parental motivation and problem-solving skills are not addressed.

Declaration of interest

The authors report no conflicts of interest.

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