



Long-term adherence to inhaled corticosteroids in children with asthma: Observational study



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ABSTRACT

Introduction: Non-adherence to daily controller medication in childhood asthma is strongly dependent on potentially modifiable factors such as parental illness perceptions and medication beliefs. The extent to which adherence in children can be improved by addressing modifiable determinants of non-adherence has not been studied to date, however. We assessed long-term adherence and its determinants in children with asthma enrolled in a comprehensive asthma care program employing shared decision making with parents.

Methods: Observational study in 135 children 2–12 years of age with asthma attending a hospital-based outpatient clinic. One-year adherence to inhaled corticosteroids was measured by electronic devices. Parental illness perceptions and medication beliefs, and asthma control were assessed by validated questionnaires.

Results: Median (interquartile range) adherence was 84% (70–92%). 55 children (41%) did not achieve the pre-defined level of good adherence ($\geq 80\%$) and this was associated with poorer asthma control. Parental perceived medication necessity was high, with a median (interquartile range) BMQ necessity score of 17 (16–20). Parents' replies to the five key questions on the core issues of the program showed high concordance of their illness perceptions and medication beliefs with the medical model of asthma and its treatment. Differences in these perceptions between adherent and non-adherent families were small and non-significant.

Conclusions: Poor adherence may persist in children despite a high level of concordance between medical team and parents on illness perceptions and medication beliefs, even in the absence of socio-economic barriers to good adherence. Achieving good adherence in all children is a complex task, requiring interventions not covered in current guidelines of managing asthma in children.

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1. Introduction

Adherence to daily medication is of critical importance in determining the success of treating chronic conditions such as childhood asthma [1–3]. Poor adherence to maintenance medication is the rule rather than the exception, however [2,4]. This may

be the result of patients and their parents not understanding the rationale for treatment (unwitting non-adherence) [5,6], which should be remediable by health care professionals providing information on the mechanisms of disease, the beneficial effects of medication, and the importance of daily use of controller medication. Studies, however, have shown that such education alone is insufficient to improve adherence [4,7], indicating that other factors are more important in driving non-adherence. These have been divided into two groups. Unplanned non-adherence relates to disorganized family (medicine taking) routines and child raising issues [6,8,9], and intentional non-adherence refers to patients (or their parents) who deliberately choose not to follow the doctor's

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recommendations [5,6]. Intentional non-adherence, strongly driven by illness perceptions and medication beliefs, has been proposed as the most important form of non-adherence, both in qualitative and quantitative studies [10,11].

Because of the accumulating evidence on the behaviors responsible for medication taking, non-adherence is now increasingly being viewed as 'a condition that can be diagnosed and treated' [12]. The extent to which adherence in children can be improved by addressing modifiable determinants of non-adherence has not been studied to date, however. If parental illness perceptions and medication beliefs are indeed the strongest determinants of adherence, excellent adherence should be expected in patients whose parents express beliefs concordant to the medical model of asthma.

We previously reported a very high median level of adherence to inhaled corticosteroids (ICS) over 3 months in 2–6 year old children with asthma enrolled in a comprehensive, guideline-based asthma management program [13]. Even in this group with high median adherence levels, the degree of adherence was strongly related to medication beliefs [13].

The aim of the present study was to assess one-year adherence to ICS and its determinants in 2–12 year old children with asthma. We focused on the role of illness perceptions and medication beliefs, hypothesizing that these would be different between families with high and those with lower levels of adherence.

2. Methods

2.1. Design and setting

This was an observational study with one year follow-up of asthmatic children aged 2–12 years, receiving asthma care in our hospital-based outpatient center with comprehensive self-management education and close follow-up. Details of our asthma management program have been described previously [13,14]. Briefly, children with troublesome or difficult to control asthma symptoms can be referred to our center by their primary care physician (which, in the Netherlands, is always a family physician). Our center is situated in a large secondary care general teaching hospital serving a mixed urban-rural population of approximately 350,000 inhabitants. Our strategy is to reach consensus with patients and parents on the treatment plan including daily use of ICS controller therapy through shared decision making [15]. We aim to achieve this by providing comprehensive self-management education and counseling, specifically eliciting, addressing and discussing parental illness perceptions and medication beliefs, instructing and checking correct inhalation technique, and providing scheduled close follow-up, with low-threshold accessibility to both pediatricians and asthma nurses for questions, concerns, and check-ups [14,15]. All children referred to our center in whom the diagnosis of persistent asthma is made are being prescribed daily ICS therapy. Patients are being seen at the center at least quarterly during the first year of the program, and at least twice a year afterwards (at least once a year by the attending pediatrician, and at least once a year by the pediatric asthma nurse).

2.2. Inclusion

Inclusion criteria for this study were a diagnosis of asthma made by the attending pediatrician based on national Dutch guidelines for the diagnosis and management of asthma (which are comparable to international guidelines) [16], and use of ICS for at least three months. Exclusion criteria comprised limited knowledge of the Dutch language, severe comorbidity and a sibling participating in the study.

Over a one-year period, parents of all 2–12 year old children with asthma visiting our outpatient clinic for a scheduled follow-up visit were asked to participate in the study. We aimed to include at least 100 patients to allow analysis of determinants of adherence, as a representative sample of all patients visiting our hospital-based secondary care pediatric asthma clinic, as previously reported [13].

2.3. Follow-up and assessment of adherence to ICS

Throughout the 12-months follow-up, adherence was monitored by electronic devices logging date and time of each ICS actuation: Smartinhaler® for MDI/spacer combination, SmartTracker® for MDI with dose counter, and SmartDisk® for Diskus/Accuhaler [13,17]. At each follow-up visit, or during home visits when time to the next scheduled follow-up visit exceeded 5 months, data recorded by the electronic devices were uploaded and proper recording function checked. 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. Adherence data were not fed back to patients and parents, and remained unknown to the attending physician. To assess physicians' ability to recognize their non-adherent patients, the attending pediatrician was requested at each follow-up visit to estimate the patient's adherence on a visual analogue scale ranging from 0% to 100%. The primary investigator (TK) was the only person with access to the adherence data, and he was not involved in the medical care of study patients.

2.4. Putative determinants of adherence

We collected information on a range of putative determinants of adherence in all participating children. A complete list of these determinants is presented in e-Table 1 in the online repository. Briefly, the following determinants were assessed.

- *Clinical and demographic data* were collected by structured interview and chart review. At baseline, lung function was assessed before and after inhaling salbutamol 400 µg: flow-volume curves in children 5 years of age and older, and respiratory resistance (Rint) by MicrorintR in children < 5 years of age (MicrorintR; Micro Medical Ltd, Rochester, UK), following international guidelines [18,19]. Results were expressed as Z-scores [20].
- *Parental illness perceptions and medication beliefs* were assessed upon entry into the study by a number of validated questionnaires: the Brief Illness Perception Questionnaire (B-IPQ) [21], the Beliefs about Medicines Questionnaire (BMQ) [22], and the Treatment Satisfaction Questionnaire for Medication (TSQM) [23]. In addition, we applied the 'I Worry scale' (scoring parental worries about their child having asthma and using daily ICS) [24], and a locally developed asthma knowledge questionnaire to assess parental knowledge about the use of medication. The BMQ consists of 10 questions measured on a 5-point Likert-scale, five on necessity and five on concerns about ICS (sum scores of both items 5 to 25). The balance between these parent-perceived necessity and concerns can be calculated by subtracting the individuals' concerns score from the individuals' necessity score leading to a range of -20 to 20. Higher scores indicate stronger perceived necessity and/or lower concerns towards ICS use.
- To assess the *effectiveness of our asthma self-management program and the achieved concordance with parents* through shared decision making, the members of our asthma team a priori identified the five key questions from these questionnaires reflecting the core issues of the program (Table 2). Parents

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