

# Adherence to therapy regimen by children with asthma and their parents

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## Abstract

**Introduction:** Strict compliance with medical advice is a prerequisite for complete asthma control. Inadequate compliance with recommendations reduces the effectiveness of treatment, increases the costs of therapy and the number of related complications.

**Aim:** To try to answer the question: To what extent is it, and what determines the adherence to therapy by children suffering from bronchial asthma and their parents?

**Material and methods:** The survey was conducted in 2019 among 109 children with bronchial asthma aged 7–18 years (mean age: 12.5 ±0.97) treated at the University Children's Hospital in Lublin and their parents. The research applied the Morisky-Green test and the VAS Scale for self-assessment of the degree of cooperation, as well as an original questionnaire.

**Results:** The conducted research demonstrated that a large percentage of parents (91.74%) declare that their child complies with the therapy throughout the disease, but 44.44% of them express the fear of medicating their children with GCSs. Non-compliance with the therapy by the children subject to our analysis was mainly due to: resolution or alleviation of symptoms of the disease (45.83%), reluctance to take medications every day (44.43), and difficulties in using the inhaler (16.67%).

**Conclusions:** In the investigated group of children with asthma and their parents, compliance with medical recommendations and, consequently, the therapy used, was not optimal and depended mainly on the severity of the disease, the child's age and knowledge about the treatment. There is a need for continued education of asthmatic children and their parents about recommended therapy.

**Key words:** asthma, children, parents, treatment, compliance.

## Introduction

Compliance with medical recommendations preconditions effective therapy. This is important especially in chronic diseases, requiring the use of drugs over a long period of time. Failure to comply with the recommendations increases the costs of treatment and the number of related complications [1]. Failure to comply with medical orders is the main reason for the failure of treating diseases of affluence such as asthma, diabetes, hypertension or lipid disorders.

Bronchial asthma is one of the most common chronic respiratory diseases in both adults and children. In European countries, the incidence of this disease increased and is currently higher in children than in adults. Various

sources state that in Poland, about 10–15% of school-age children are affected. The number of children hospitalized for this reason is also growing. Data on the prevalence of asthma in Poland does not coincide with the data from the Western countries, and the reason for that is most likely the underdiagnosis of asthma, predominantly in children. In our country, asthma is diagnosed too rarely and too late in the paediatric population, which poses a risk of inadequate therapy and the development of irreversible changes in the respiratory system and, consequently, respiratory disability [2–11].

Modern recommendations for the treatment of asthma emphasize the need to adapt it to specific conditions, e.g. the age of the child. In addition, treatment must be personalized and intensified and modified throughout

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the disease, and the patient should be the center of attention. The therapy of asthma in children and adolescents is particularly difficult because it has to take into account the differences of this particular age. Teenagers need to emphasize their maturity and independence, which can influence their decisions concerning therapy. Reluctance to accept advice, interpreted as a violation of the principles of their sovereignty, may lead to risky behaviours in the form of partial or complete cessation of therapy [12–16].

Asthma cannot be cured, but its proper management, involving a partnership between the therapeutic team and the patient and their family, usually allows to control the disease [1, 17, 18].

### Aim

The aim of the present study was to answer the question: To what extent is the therapy of children suffering from bronchial asthma and their parents followed and what does it depend on?

### Material and methods

Research using the diagnostic survey method was conducted in 2019 among children suffering from bronchial asthma and their caregivers. The selection of the study group was deliberate, i.e. we invited all children with asthma treated in the period subject to our research at the University Children's Hospital in Lublin, who met the following criteria and expressed their consent, as well as their parents, to participate in the study. The selection criteria were: diagnosis of bronchial asthma, duration of the disease of at least 1 year, age of the child over 6 years (it is only at this age that it becomes possible to apply various types of inhalers in therapy). A total of 117 questionnaires were distributed, of which 8 were discarded due to incomplete data. A hundred and nine questionnaires were qualified for the final analysis. The research tools applied were the Morisky-Green test [18] and the VAS scale (Visual Analogue Scale) [17] for self-assessment of the degree of cooperation and an original questionnaire designed for the purposes of the work. The Morisky-Green test consisted of 4 questions regarding the use of prescribed drugs by the subjects. In the case of VAS, the respondents assessed their adherence to the therapy on a 10-point scale (0–10 points). The scoring has a positive direction, i.e. the more points the respondents scored, the better their compliance was. It is a simple and repeatable test for multiple assessment of a variable of subjective trait or attitude. The proprietary questionnaire consisted of 32 closed and open-ended questions and was divided into 2 parts. The first part was addressed to parents and concerned the course of the child's disease, compliance with treatment, possible fears and reasons for non-compliance, and their sociodemographic data.

The second part was aimed at children and concerned their acceptance of the recommended therapy, their compliance therewith and possible difficulties related to it and reasons for non-compliance.

Among the respondents there were 69 (63.3%) boys and 40 (36.7%) girls aged 7–18 (mean age:  $12.5 \pm 0.97$ ) and 97 (89%) mothers and 12 (11%) fathers, with a mean age of  $36.91 \pm 5.74$  years. 63.3% of them resided in urban areas, whereas 36.7% in rural ones. Almost all children came from complete families (98.17%) and only 1.83% had single-parent families. Most of the children (78.9%) also had siblings, while 21.1% were the only children. The financial situation of the respondents, in their subjective opinion, was mostly good (44.95%) or average (41.28%) and only 6.24% assessed it as not very good, and not a single respondent assessed it as bad. Most of the surveyed parents had higher (43.12%) or high school (33.94%) education.

On average, the examined children had suffered from bronchial asthma for  $4.68 \pm 2.77$  years (min. 1 year – max. 15 years). The data on the disease were taken from the medical records, in which the severity of asthma in children was determined according to GINA 2014: the criteria in force at that time. Moderate chronic asthma accounted for 60.55% of the cases, mild chronic asthma for 36.7%, and severe chronic for 2.75%. 19.27% of the children had other chronic diseases, such as allergic rhinitis, atopic dermatitis or food allergies. Almost all children (92.66%) have recently experienced exacerbation of their asthma. All the children were hospitalized for asthma in the last year. A large percentage of them left school (62.39%) and used additional medical assistance (63.3%) due to exacerbation of the disease, while a small percentage of children measured their PEF (31.2%) on their own, and kept a self-monitoring diary (18.35%).

### Statistical analysis

The database and statistical research were carried out using the Statistica 13.0 software suite (StatSoft, Poland). The  $\chi^2$  test was used to test the existence of differences or relations between the examined characteristics. We adopted the significance level of  $p < 0.05$ .

### Results

The analysis of the research results using the proprietary questionnaire demonstrated that most, i.e. 73.39% of the examined children with asthma were treated chronically with inhaled glucocorticosteroids (GCSs), which were administered with either pressurized metered dose (pMDI) or dry powder (DPI) inhalers (36.7% each), and during hospitalization by nebulization (37.61%). A small percentage of the respondents reported side effects of therapy, mainly local ones such as: hoarseness (21.1%), cough (20.18%), sore throat (8.26%) and oral thrush (7.34%). The side effects of therapy that the

parents most often feared in their children were: uncontrolled weight gain (42.2%), slower growth rate (27.52%) or tooth decay (33.03%). The self-assessment of compliance in children with asthma using the VAS scale for the group was  $7.5 \pm 2.45$  points (min. 5 – max. 8) on average and thus located it in the high score category. Their self-assessment of the degree of cooperation with the Morisky-Green test was slightly lower. It is true that the vast majority of the surveyed children (77.98%) stated that they accepted the recommended therapy, but in the abovementioned test, as many as 40.37% of them admitted that they had forgotten to take a dose of the drug. Among 24 children who did not accept the prescribed medications, the most common cause was the resolution or reduction of symptoms of the disease. The acquired results are presented in Tables 1 and 2.

The subsequent stage of the research involved determining the compliance of parents of sick children with the doctor's recommendations. The self-assessment of compliance by parents of children with asthma using the VAS scale was on average  $9 \pm 0.35$  points for the entire group (min. 7 – max. 10) and was higher than in children. The analysis of the data demonstrated that only a small percentage of parents adhered to the recommendations only during the initial treatment period or disease exacerbation. The acquired results are presented in Table 3.

The most common cause of parents' non-compliance with medical recommendations was the remission or alleviation of the child's asthma symptoms (88.89%), fear of side effects of therapy (44.42%), the child's reluctance to take medications every day (44.43%), no visible effects

of the treatment (11.93%) and the lack of knowledge about the benefits of treatment (11.11%).

The vast majority of the surveyed parents believe that the recommended therapy works with good results (88.07%). Parents consider the lack of disease exacerbation (67.89%) and normal physical activity of the child (51.38%) to be the greatest benefits of adhering to the recommended therapy.

When asked whether the costs related to asthma therapy in a child have a negative impact on the financial situation of the family, more than half of the surveyed parents (51.38%) answered yes, and 11.93% admitted that it did happen that they did not buy their child's medications due to their high costs in the past.

The conducted research also analyzed whether clinical variables such as the duration of the disease, the severity of asthma, the occurrence of exacerbation periods and other chronic diseases in a child influenced the adherence to therapy by the respondents. It turned out that only the severity of asthma had a significant impact here, as compliance with medical recommendations increased with the severity of the disease ( $p = 0.02$ ) (Table 4).

In the presented research, it was assumed that socio-demographic variables may influence the adherence to therapy by the respondents. The research analyzed 7 variables: age, gender, place of residence, family structure and financial situation, as well as parents' education. Statistical analysis revealed that only the age of sick children had a significant impact on their compliance with medical recommendations. Older children were more likely to forget to take their medication ( $p = 0.003$ ) (Ta-

**Table 1.** Self-assessment of the degree of compliance of children with asthma in the treatment process according to the Morisky-Green test

Adherence to therapy	Yes		No	
	Number (n)	Percentage* (%)	Number (n)	Percentage* (%)
Have you ever forgotten to take your medicine?	44	40.37	65	59.63
Does it happen that you do not observe your medication times?	34	31.19	75	68.81
Do you skip your next dose of medication if you feel well?	11	10.9	98	89.1
Do you skip the next dose of medication if you feel unwell and link it to the medication?	9	8.26	100	91.74

\*Percentages do not add up to 100% as the respondents could mark multiple answers.

**Table 2.** The reasons for the child's reluctance to take medications

Reasons discouraging the child from therapy	Number (n)	Percentage* (%)
Difficulty in handling the inhaler	4	16.67
No health improvement (treatment effects)	2	8.33
Abolishment of symptoms or improvement	11	45.83
Fear of the side effects of drugs	1	4.17
Other cause	9	37.50

\*Percentages do not add up to 100% as the respondents could mark multiple answers.

**Table 3.** Parental adherence to therapeutic recommendations of their child

Parental adherence to child therapy	Number (n)	Percentage (%)
Throughout treatment	100	91.74
Only in the initial period of treatment	1	0.92
Only during the exacerbation of the disease	8	7.34
Never	0	0.00
Total	109	100

**Table 4.** Influence of the severity of asthma on the adherence to therapy by the subjects

Severity of asthma	Light (n)	Percentage (%)	Moderate/severe (n)	Percentage (%)	Total
Forgetting to take medication:					
Does not happen	23	57.50	42	60.87	65
Can happen	17	42.50	27	39.13	44
Total	40	100%	69	100%	109
$\chi^2 = 0.0204679, p = 0.88624$					
Acceptance and willingness of the child to take prescribed medications:					
Accepting	26	65.00	59	85.51	85
Not accepting/hard to say	14	35.00	10	14.49	24
Total	40	100	69	100	109
$\chi^2 = 5.064989, p = 0.02442$					
Strict compliance with doctor's orders:					
All the time	35	87.50	65	94.20	100
Other	5	12.50	4	5.80	9
Total	40	100	69	100	109
$\chi^2 = 0.7473016, p = 0.38733$					

**Table 5.** Impact of the child's age on adherence to the recommended therapy

Child's age	≤ 12 years (n)	Percentage (%)	≥ 13 (n)	Percentage (%)	Total
Forgetting to take medication:					
Does not happen	42	73.68	23	44.23%	65
Can happen	15	26.32	29	55.77	44
Total	57	100%	52	100%	109
$\chi^2 = 8.614293, p = 0.00334$					
Acceptance and willingness of the child to take prescribed medications:					
Accepting	42	73.68	43	82.69	85
Not accepting/hard to say	15	26.32	9	17.31	24
Total	57	100%	52	100%	109
$\chi^2 = 0.8140217, p = 0.36694$					
Strict compliance with the doctor's orders:					
All the time	51	89.47	49	94.23	100
Other	6	10.53	3	5.77	9
Total	57	100%	52	100%	109
$\chi^2 = 0.3057300, p = 0.58031$					

**Table 6.** Influence of parents' knowledge about the benefits of therapy on adherence to it

Forgetting to take/administer the drug	Does not happen (n)	Percentage (%)	Can happen (n)	Percentage (%)	Total
Knowing about the benefits of therapy:					
No	34	52.31	12	27.27	46
Yes	31	47.69	32	72.73	63
Total	65	100	44	100	109

$\chi^2 = 5.754688, p = 0.01645$

ble 5). The remaining characteristics did not have a significant impact ( $p > 0.05$ ).

Then, we went to analyze the impact of knowledge about the benefits of the therapy on compliance of respondents. Parents who had no knowledge about the benefits of the therapy ( $p = 0.01$ ) were more likely to forget about giving/reminding their children to take the drug (Table 6).

## Discussion

Bronchial asthma is an inflammatory disease of the respiratory tract and requires long-term treatment. It may significantly affect the quality of life of school children and youth, cause frequent absences from school and exemptions from physical education lessons, which was further confirmed by the results of our own research (62.39%). Untreated or improperly treated asthma leads to irreversible changes in the bronchial tree (its remodeling), which later leads to chronic respiratory failure. On the other hand, a properly treated and well-controlled disease allows a child to function normally in a peer environment and to play sports [6–10, 12–16, 19–21].

The primary objective of bronchial asthma pharmacotherapy is to reduce the inflammatory process in the bronchi. Proper treatment of asthma is associated with the need for long-term medication, also in asymptomatic periods. Inhalation is the preferred route of drug administration for the treatment of asthma, regardless of age. Inhaled glucocorticoids (GCSs) are the drugs of choice in all forms of chronic asthma because they most effectively control its course. Many authors emphasize that the use of glucocorticoids in the treatment of asthma is met with great reluctance by many patients, especially parents of affected children, because, apart from therapeutic effects, these drugs may trigger side effects [12, 13, 22–24]. This was further confirmed by the results of our present research (44.42%). The physician should always explain to the patient and/or their caregivers the rationale for treating with GCS. Multicentre clinical trials demonstrated that GCSs used in the treatment of asthma increase the values of ventilation indexes, minimize the frequency of exacerbations and the severity of disease symptoms, and significantly improve the quality of life. Numerous years of observation of children treated with the recom-

mended doses of GCSs also prove that it is also a safe treatment [22].

Asthma is a disease with a variable course, hence it is necessary to systematically control the effectiveness of the treatment and adjust its intensity to the patient's needs. What is essential in the treatment of a chronic disease is the constant cooperation between the doctor and the patient. Education of the child and parents is an element allowing for the practical implementation of the pharmacological treatment process, disease monitoring and active adaptation of treatment to changes in the clinical course of the disease. What is assumed is the striving to create a therapeutic team consisting of a doctor, the affected child and its parents, the school nurse, teachers, psychologist and rehabilitation specialist. Education is also to ensure the highest possible level of cooperation of the affected child and its parents with the physician in charge (compliance) as no improvement in treatment outcomes is observed without training and participation of patients in this process [21, 25–29]. Assessment of compliance can be performed with use of questionnaires completed by the patient or his/her family. The new methods of compliance assessment also include monitoring with the use of electronic devices recording the time and dose of drugs [18].

As reported in the subject literature, the issue of adherence to asthma treatment recommendations in adolescents is conditioned by many factors, including not only personality, influence of the peer group, but also health education, consultation with doctor, understanding the nature of the disease and the validity of therapy, simplicity of treatment and the appropriate motivation [1, 18, 25, 26]. Methods to improve the effectiveness of treatment in adolescents, including the GINA 2019 recommendations, include the need to explain the nature of the disease in a way that is understandable and acceptable to teenagers, as well as encouraging them to take control of their disease [6]. It was also stressed that it is beneficial to develop partnership relations by, inter alia, listening to adolescents' concerns about treatment and their need for peer acceptance. What is particularly important in children and adolescents is to enable them to be active in optimal life and protect them from exposure to side effects of therapy. It is imperative, especially at this age, to provide a written asthma management

plan and carefully schedule doctor's appointments. It is also postulated to rationalize drug prices and simplify treatment regimens (less frequent dosing, combining different drugs in one form). Experts emphasize that even partial compliance with the recommendations is better than total non-compliance [1, 17, 18, 25, 26].

The subject literature estimates the incidence of non-adherence to the recommended therapy at various levels: from 30 to even 70% [1, 17, 18, 25, 26]. The results acquired as part of our own research demonstrate that the vast majority of parents (91.74%) of sick children declared strict adherence to medical recommendations throughout the treatment period. However, despite the fact that the majority of the surveyed children with asthma (77.98%) accepted and willingly took the prescribed drugs, as many as 40.37% admitted that they sometimes forget to take them.

The causes of non-compliance with the therapy include: forgetfulness, lack of time, too mild symptoms of the disease, lack of satisfactory effects of therapy or uncomfortable treatment [1, 17, 18, 25, 26]. Results of our research further confirm these data.

According to the subject literature, although there is a connection between poor socioeconomic status and adherence to treatment, it does not constitute a decisive factor [1, 17, 18, 25, 26]. The presented results of our own research are similar, as only the age of patients had a significant impact on compliance.

The subject literature describes that adherence to therapy may also be influenced by factors related to the context of the disease, i.e. the so-called condition-related factors [1, 17, 18, 25, 26]. Our research material revealed a relationship between the severity of asthma and adherence to therapy, while the influences of duration of the disease and the frequency of exacerbations were not confirmed.

In French studies assessing adherence to chronic treatment among children and adolescents with asthma, it was found to be better in the former, with 92.3% versus 77%, respectively. It was assessed that this was the cause of the increased frequency of exacerbations as 1.4% of younger children and 5% of adolescents experienced more than one asthma exacerbation per month (in our own studies this percentage was 3.67% for younger children and 7.34% for teenagers) [16]. Even during an exacerbation, 19.6% of patients in the adolescent group were off medication, waiting for the asthma attack to resolve itself. This situation was much less common in case of younger children, with only 4.7% of them not receiving medication from their parents. Similar results were obtained in our own research, where younger children complied with the therapy in 73.68% and older children only in 44.23%.

Studies conducted in Australia emphasized the need to improve care for adolescents with asthma as 58% of them did not consult a doctor regularly, only 19% had an individual peak air flow meter, and 17% had a written treatment plan [16]. This led to the overuse of short-

acting  $\beta_2$ -agonists, with 90% of adolescents using them regularly. In the authors' own research, a small percentage of children measured their PEF on their own (31.2%) and kept a self-monitoring diary (18.35%), and a large percentage (63.3%) of them used rescue inhalers.

Assessment of compliance with therapeutic recommendations by children and adolescents suffering from bronchial asthma has not been the subject of many studies in Poland so far. The phenomenon of steroid phobia among caregivers of children with asthma in Poland was studied e.g. by Czerwińska-Pawluk *et al.* [30]. The results of our own research in comparable groups (109 questionnaires) differ from the results of these authors (122 questionnaires) as they revealed that, although a greater percentage of parents express fear of using GCSs in their children (with > 44% vs. 20%), but at the same time definitely more parents declare compliance with the therapy throughout the treatment period, and not only at the onset of the disease (91.74% vs. 19%), which should be deemed an optimistic conclusion. In our own research, other reasons for non-compliance with the therapy were also observed as these were not mainly the fear of side effects of the drugs used as in Czerwińska-Pawluk *et al.* (37%), but also the resolution or reduction of asthma symptoms (approx. 89%). Nevertheless, similarly to the research of the authors quoted above, the fear connected with use of GCSs resulted from lack of knowledge about the disease and its management.

Compliance research should be continued in the future. Identification and reduction of hindering factors and improvement of compliance may have a greater impact on the health of the population than the entire progress associated with specific medical procedures.

## Conclusions

Despite the fact that majority of the children with asthma in the study accepted the prescribed therapy, they often forgot to take their drugs. Among the respondents, the main reasons for non-compliance with the therapy were: remission or alleviation of asthma symptoms, the child's reluctance to take medications every day, difficulties in using the inhaler and fear of side effects of medications used. In the group subjected to our research, compliance with the therapy increased with the severity of the disease. Compliance with doctors' orders was worse in adolescents than in younger children. Parents who knew about the benefits of treatment were more likely to follow doctors' orders.

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## Conflict of interest

The authors declare no conflict of interest.

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