

Inhaler therapy

What it means for children with asthma

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ABSTRACT

OBJECTIVE To investigate what inhaler therapy means for children with asthma and to identify problems and concerns children experience with inhalers.

DESIGN Qualitative research design.

SETTING A community-based family practice in rural Newfoundland.

PARTICIPANTS Seventeen children, aged 5 to 16, who had been diagnosed with mild or moderate asthma and were being prescribed inhaled steroids or bronchodilators.

METHOD Two in-depth interviews with each of a purposive sample of participants were analyzed by the selective or highlighting approach.

MAIN FINDINGS Common positive themes were identified: inhalers were easy to use, and medication was necessary for good quality of life. Common negative themes were simply forgetting, inconvenient and annoying, only-as-needed approach, medication does not work well anyway, and side effects.

CONCLUSION Inhaler therapy had both positive and negative meaning for children. Although inhaled medications were seen as very important for good quality of life when taken regularly, most children wanted to use them only as needed for symptom control. Children knew the importance of inhaler therapy but still complied poorly.

RÉSUMÉ

OBJECTIF Vérifier auprès des enfants asthmatiques ce qu'ils pensent de l'inhalothérapie, et identifier leurs problèmes et préoccupations concernant les inhalateurs.

TYPE D'ÉTUDE Étude qualitative.

CONTEXTE Un établissement de médecine familiale d'une région rurale de Terre-Neuve.

PARTICIPANTS Dix-sept asthmatiques légers à modérés âgés de 5 à 16 ans avec une prescription de stéroïdes ou de bronchodilatateurs en inhalation.

MÉTHODE Deux entrevues en profondeur avec chacun des participants d'un échantillon raisonné ont été analysées par l'approche de sélection ou de mise en relief.

PRINCIPALES OBSERVATIONS Les thèmes positifs communs identifiés étaient la facilité d'utilisation des inhalateurs et la nécessité de la médication pour une bonne qualité de vie. Les thèmes négatifs communs incluaient le simple oubli, l'aspect ennuyeux, agaçant ou uniquement au besoin des inhalateurs, le doute sur l'efficacité, les effets indésirables et les réponses négatives.

CONCLUSION Les enfants trouvaient que l'inhalothérapie avait des bons et des mauvais côtés. Même s'ils croyaient qu'une utilisation régulière est importante pour leur qualité de vie, la plupart préféraient s'en servir seulement au besoin, pour contrôler les symptômes. Ils connaissaient l'importance de l'inhalothérapie, mais ne s'y conformaient pas très bien.

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Cet article a fait l'objet d'une évaluation externe.

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Childhood asthma is a serious illness that imposes a substantial burden on society. In Canada, approximately 2 million adults suffer from asthma (6.4%).¹ While the death rate from asthma in Canada has slowly decreased since 1990, 500 adults and 20 children still die of it each year. Approximately 10 people die of asthma per week.²

Poor medical adherence results in unnecessary illness, disability, hospital admissions, and deaths. Rates of hospital admission for asthma in Canada increased 50% for both sexes between 1972 and 1982. The largest increases occurred among those younger than 15 years; in Newfoundland, hospital admission rates increased 64% for male and 113% for female patients.³

A large and convincing body of evidence, summarized in a meta-analysis,⁴ shows that use of oral corticosteroid medication can effectively reduce the frequency and severity of respiratory problems in chronic obstructive pulmonary disease. Evidence is equally, if not more, convincing for use of corticosteroid medication to treat asthmatic children.⁵⁻⁷

Patients' compliance with or adherence to therapy is defined as "the extent to which the patient's behavior, in terms of taking medication, following diets, or executing life-style changes, coincides with a clinical prescription."⁸ Some reasons for not taking prescribed medication have included embarrassment, lack of understanding about the role of the drugs, lack of trust in the prescribing physician, forgetfulness, and feeling better.⁹ Most studies attempting to understand the nature of medication adherence among children or adolescents with asthma have not truly assessed the meaning that

such compliance has in their and their families' lives. In other words, researchers have not attempted to hear the voices of the children and determine what it is like for them or what problems they experience in taking inhaled corticosteroids and bronchodilators to control and relieve asthma. Instead, most researchers have addressed the problem from a developmental or health-belief framework.¹⁰⁻¹³ Evidence shows that, although adolescents do not respond exactly as adults do in assuming responsibility for management of their own care,¹⁴ their stage of development is not in itself a reason for non-adherence. Indeed, adolescents' compliance rates are comparable to those of adults.¹⁵

Studies of asthma education programs have shown that they are ineffective at changing patients' behaviour.¹⁶ Before behaviour can be changed, we must know more, and it seems necessary to investigate thoughts and feelings in this area. Therefore, our qualitative study attempted to answer the question: What does inhaler therapy mean for children with asthma?

Specific objectives of the study were to examine common themes in order to understand:

- What it is like for asthmatic children to have to take inhaled corticosteroids and bronchodilators for control and relief of asthma and asthma symptoms.
- What problems and concerns children have in following prescribed inhaler therapy.

METHODS

Ethical approval for the study was obtained from the Human Investigation Committee of Memorial University of Newfoundland.

A qualitative method was employed to question and understand what the experience of taking inhaled corticosteroids and bronchodilators is like for children with asthma, from their own perspectives.¹⁷ Participants were recruited from among patients of one of the researchers, a family physician (D.H.) in a community-based practice in rural Newfoundland. Seventeen children (aged 5 to 16 years), who had mild or moderate asthma and

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Table 1. Respondents' demographic data

AGE	SEX	SERIOUSNESS OF ASTHMA AS DETERMINED BY PHYSICIAN	PRESCRIBED MEDICATIONS	NUMBER OF EMERGENCY VISITS IN PAST YEAR
5	M	Moderate	Fluticasone, Salbutamol as needed	2
6	M	Mild	Beclomethasone, Salbutamol as needed	0
8	F	Mild	Budesonide, Terbutaline as needed	0
8 1/2	F	Mild	-	0
10	F	Moderate	Fluticasone, Salbutamol as needed	1
11	M	Moderate	Fluticasone-salmeterol combination, Terbutaline as needed	1
11	M	Mild	Budesonide, Terbutaline as needed	0
12	M	Moderate	Fluticasone, Salbutamol as needed	1
12	M	Moderate	Fluticasone, Salbutamol as needed	0
13	M	Mild	Budesonide, Terbutaline as needed	0
13	M	Moderate	Fluticasone-salmeterol combination, Terbutaline as needed	2
13	M	Mild	Budesonide, Terbutaline as needed	0
13	F	Moderate	Budesonide, Terbutaline as needed	1
14	M	Mild	Fluticasone-salmeterol combination, Salbutamol as needed	0
14	F	Moderate	Budesonide, Terbutaline as needed	0
15	M	Moderate	Fluticasone-salmeterol combination, Salbutamol as needed	1
16	M	Moderate	Fluticasone-salmeterol combination, Salbutamol as needed	1

were being prescribed inhaled corticosteroids and bronchodilators (**Table 1**), were contacted by the researcher, and all agreed to be interviewed. This number of participants is generally enough to guarantee saturation and refinement,^{18,19} which was easily obtained in this study.

The only inclusion criteria were willingness to participate and ability to articulate their experience to the researcher. Dr Hewitt made the initial contact with his patients, to introduce the study. Parents of the children were contacted by telephone. Those in agreement were informed about the nature of the study, and an interview time was arranged. Before beginning the interview, a trained research assistant obtained written consent for participation and for audiotaping.

Data were collected during two interviews with each child. Participants were given the opportunity to choose any quiet setting that allowed for privacy. The second interview took place 1 to 2 weeks after the first. The purpose of the second interview was to clarify responses and to explore themes from the first interview. All interviews were audiotaped and transcribed.

The children were asked: “What does it mean for you to have to take inhaled medications for your asthma?” Other non-leading questions (**Table 2**) encouraged children to share their experience or clarify ideas. Interview data were analyzed using the selective or highlighting approach¹⁷ in which the researcher reads the text several times and highlights statements or phrases that seem particularly revealing about the phenomenon or experience. Every attempt is made to avoid conceptualization of the sentence, and to just

Table 2. Interview guide for asthmatic children

Tell me how having asthma affects your life.
What changes have you had to make in your life because of your asthma?
Do you always take your medication as you are supposed to?
If, not, why?
What does the medication make you feel like?
Tell me about an experience that stands out for you regarding taking your medications.
Why is this experience important?
How do your friends feel about you having to take medications for your asthma?
What would make taking your medications easier for you?
Is there anything else that you would like to tell me?

capture a meaning. As descriptions and themes began to emerge, we noted that certain themes recurred. These themes or appropriate phrases were lifted and captured in single statements to express the main thrust of the meaning.

Throughout the entire analysis, the researcher maintained a log. This helped ensure that the researcher's "decision trail"²⁰ could be followed. This also provided a record for purposes of data analysis, and was important as a source of credibility.¹⁷ Following preliminary identification of themes by the primary investigator in each of the interviews, the research team met for debriefing. Debriefing allowed the primary investigator to get expert judgment and direction from other members of the research team.

FINDINGS

Common themes highlighted both positive and negative aspects of taking inhaled medications for asthma control and relief. Children of all ages expressed very similar thoughts. The only differences between adolescents and younger children could be attributed to the fact that adolescents took more responsibility for their own treatment, whereas younger children were more directly supervised by their parents.

Positive aspects of inhaled medication

Inhalers are familiar and easy to use. All children said that inhalers were easy to use, and they were able to demonstrate and describe correctly how to use the devices. They also felt that taking the inhalers was just a routine part of most days, and although it was described as "not any fun," comments such as, "I just got used to it," and that it was "no big deal," were common. None of the participants could think of anything that would make using the inhalers any easier. "Sure, it's no big deal. You just do this [child demonstrates] and that's all there is to it, really. I mean, it's really not all that hard. I see a lot of kids use them."

Respondents expressed very little concern about negative reactions from their peers. One teenager said that her friends actually thought that having to use an inhaler was "cool." Another stated that asthma was a very common problem in his school, so almost everyone was familiar with the condition and the treatment. Despite the generally positive responses from peers, one of the younger children did feel embarrassed about using the inhaler and kept it hidden in her book bag while at school so that others would not see it. She said that she felt others might not understand or could possibly laugh at her.

Medication is necessary for good quality of life.

All children felt that medication for asthma control was essential to their well-being and quality of life. All described how they found most activities, especially sports, very difficult without their medications. One teen said that without medication he was unable to do many laps in gym class; with the medication, he could now perform much better. He said that the best thing about taking his inhaler was being able to run around and do normal things that he probably would not be able to do without it. Another said that when he took his puffers in gym class he usually felt well throughout the rest of the day, and this was not the case when he forgot to bring his puffer to school. Another said that not participating in gym made him feel generally unhappy: "[B]efore this puffer I hadn't been able to play sports; like when I was younger. But I can play it now, like last year I was on the basketball team up to the school and I had no trouble with it."

Sleep was less disturbed by coughing, and school was missed less often. When discussing what it was like without her inhaler, one 12-year-old girl said, "I wake up some nights. It gets pretty bad at night because I'm lying there trying to sleep, and I can just feel it there; [I've] just got to cough."

Negative aspects of inhaled medication

Despite the positive aspects of inhaler therapy for children, compliance was relatively low when

children were asymptomatic; therefore, corticosteroids used for prevention were often neglected. Themes emerged that shed some light on this phenomenon.

Simply forgetting. One of the biggest reasons children did not comply with inhaler therapy was that they simply forgot. Taking medications once or twice a day, when symptoms were absent, was a major problem for almost all. Adolescents in the study said that because they did not feel sick they would often run off to school, especially when they were in a hurry, without remembering to take their puffers. Younger children were monitored by their parents and were more likely to be reminded to take their medication. "Well, if my mom is not there and I go somewhere, like if I was up to the cabin with my grandparents, I'd forget about it sometimes, you know." "Sometimes on the weekends my friends will call for me to go out and do something, so I have to jump up in a hurry and get dressed, and I'm out of the door without my puffers."

Inconvenient and annoying. Many children thought that taking their medication was just too much of an annoyance. They felt that they had to stop whatever they were doing and take their inhalers, often interfering with things like television and doing things with friends. "Well, ah, I consider it sometimes a little bit of a pain." Another participant said that it was "kind of boring, just sitting there, waiting for it to finish. It's annoying, sitting there having to bother with it, especially when I'm busy in the morning going to school."

It was sometimes difficult to distinguish whether it was a matter of simply forgetting or an inconvenience. One girl, when asked if she always took her inhaler as she was supposed to, said: "No, because sometimes I forget. ... Because like when I'm getting ready for school, I have to try and get my breakfast and my stuff packed and my bag down by the door and get dressed and all that stuff, so I hardly have time for puffers."

Several children said that puffers were just too much of an inconvenience, "You are going around with two puffers in your pockets, a bit clumsy, I think."

Another child said that she only liked putting small things in her pockets when she was out and the worst thing was having "to take out that Aerochamber." Many participants said they would prefer to take only oral medications instead of inhaler therapy.

Interestingly, one of the adolescent boys said that the worst thing about having to take medications for asthma was "not having it on you when ya need it." This certainly represents the paradox that existed for most participants, who (although they often forgot to bring their medications with them when they went out) realized the importance of the medication when asthma symptoms flared up.

Only as needed. Many said that taking their inhaler therapy as prescribed during times when they were asymptomatic was not really necessary, and simply got in the way—especially when they were busy. Even when prompted by parents, many adolescents did not bother to take their medications because they believed that they did not really need them. Parents sometimes discouraged children from taking their medications regularly, as they were afraid of the consequence of long-term use. One girl said the worst thing about having to take medication for asthma was that you have to take it all the time, even when you were not sick.

Doesn't work much anyway. Two male adolescents stated that the inhalers were not that effective in controlling their asthma symptoms. They were taking both steroid and bronchodilator inhalers but found that steroid inhalers were a waste of time. "I found that one helps, but like this here [shows steroid] low-grade thing is not very good. ... It takes a while to kick in."

Side effects. Side effects, such as nausea and especially headaches (although common among all age groups), were not particularly bothersome and were not given as reasons for non-adherence. When asked about his headaches, one participant said, "It lasts for a few minutes, and then it was gone." Another said, "They're bad enough that I have to take Aspirin, sometimes, and then about maybe 5 to 10 minutes later I'm all better." Another

problem identified was the bad taste of the inhalers. "It tastes disgusting, like flat ginger ale." For those who experienced a bad taste, it was more of a deterrent among younger children than adolescents. One little girl said, "[S]ometimes my medications taste funny and I don't want to take them."

DISCUSSION

Although it is not the aim of qualitative research to make generalizations to the entire population of interest, results of this study do shed some light on the phenomenon of inhaler therapy for control of asthma in children. One positive theme that emerged is that none of the children had difficulty using the inhalers. All were able to correctly articulate and demonstrate use of their inhalers. This is contrary to other studies^{10,21,22} in which adolescents had not mastered the art of using the inhalers. This could be because most participants in this study had been using inhalers for more than 2 years. Further, participants recognized that inhalers improved their quality of life.

Other studies^{10,23} have found embarrassment and inconvenience associated with asthma inhalers. Contrary to some literature,¹⁰ all participants but one in this study were unembarrassed by using their inhalers in the presence of peers. Many said that several of their friends had asthma and that most were accustomed to seeing inhalers. Peer pressure and defiance of authority was not an issue, as suggested by some,²⁴ and did not come through in any of the interviews.

Both younger children and adolescents clearly comprehended the importance of inhaler therapy in treatment of asthma. They very clearly articulated how such medication had improved the quality of their lives. Despite this understanding, a paradox did exist. Non-adherence was still an important issue. A major reason participants in this study did not take their medications as prescribed was that they simply forgot, especially during times when they were free of symptoms or too busy. This was consistent with the findings of another study,¹⁰ where mornings and other busy times often resulted in forgetfulness.

A second and predominant reason for non-adherence was the only-as-needed approach. Consistent with the literature, participants did not take their medications when they were feeling well.⁸ During this time medication was seen as a bother. It seems obvious that participants had no comprehension of the importance of their corticosteroid inhalers as a preventive measure. Therefore, corticosteroids were most often not taken as prescribed because they were not believed to be any good. Other less compelling reasons for non-adherence were side effects and the bad taste of some of the medications.

Treating the issue of non-adherence among children, using a purely developmental approach, appears to limit the effectiveness of education programs. This study suggests that increasing awareness and knowledge of medication use (especially long-term use of corticosteroids) and putting medication use into daily schedules might prove effective. Most inhaled corticosteroids can be effective for most patients when used twice daily, and relatively mild persistent asthma can be controlled with once-daily dosing.²⁵

One possible limitation of the study is that all participants suffered from mild or moderate asthma. Results might have been different if participants had had severe asthma. Also, responses from those with mild asthma were not separated from those with moderate asthma. Differences might have been noticeable between the two groups. Another limitation is that several of the children were very young (ages 5, 6, and 8), limiting their ability to engage in critical reflection on the experience. These children often answered with a yes or no or with minimal discussion regardless of prompting from the trained interviewer. Their minimal responses make it difficult to determine whether their experience has been adequately captured, and if so, whether it is markedly different from adolescents'.

CONCLUSION

Inhalers had both positive and negative meanings for most of the children interviewed. Common

positive meanings were that inhalers were fairly easy to use, and even more importantly, they made their lives better when used as prescribed. Common negative feelings were related to forgetting to take the medication regularly, to failing to understand that regular medication was best, and to the irritation of minor short-term side effects. A common paradox was that, although inhaled medications are seen to improve the quality of life when taken regularly, most children want to take them only as needed for symptoms. Children know the importance of inhaler therapy, but often fail to comply with therapy, especially for medications prescribed to control the underlying problem. This study suggests that increasing awareness and knowledge of medication use, especially long-term use, and that scheduling medication daily might prove effective. ❁

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Contributors

Ms Parsons as primary investigator wrote the proposal, hired and trained the data collector, managed the budget, requisitioned supplies, was responsible for data analysis, was primary writer of the proposal, and took responsibility for the final work as a whole. Dr Worrall helped write the proposal, analyzed data, helped write the article, and gathered the literature. Mr Knight helped write the manuscript, gathered the literature, and organized the mailings. Dr Hewitt originated the idea for the study and recruited the patient sample.

Competing interests

None declared

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EDITOR'S KEY POINTS

- This qualitative study is the first to explore how children and adolescents view inhaler therapy for asthma. This is important because asthma education programs have not improved compliance with inhalers to date.
- Children found that taking inhaler treatment was easy to do, and noted that it improved their quality of life.
- Despite this finding, children often did not take treatment because they "forgot," found it inconvenient, thought it did not help much anyway (especially steroids), or believed they did not really need it when they felt well.

POINTS DE REPÈRE DU RÉDACTEUR

- Il s'agit d'une première étude qualitative sur ce que les enfants et les adolescents asthmatiques pensent de l'inhalothérapie. Cette étude est importante parce que jusqu'à présent, les programmes d'éducation pour asthmatiques n'ont pas augmenté l'utilisation des inhalateurs.
- Les enfants trouvent que les inhalateurs sont faciles à utiliser et qu'ils améliorent leur qualité de vie.
- Malgré cela, les enfants négligent souvent leur traitement parce qu'ils l'oublient, le trouvent peu commode, croient de toute façon qu'il n'est pas très utile (notamment les stéroïdes) ou pensent qu'ils n'en ont pas vraiment besoin quand ils se sentent bien.

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