

Original Research Article

Experience and perception of asthma by parents of asthmatic children

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ABSTRACT

Background: Childhood and infant asthma are a common condition with a currently increasing prevalence. Few studies have examined the parental aspects of the difficulties associated with this condition. The main objective of this study is to explore the experience and perception of asthma by parents of asthmatic children.

Methods: This was a qualitative descriptive study in semi-directed interviews with parents of asthmatic children from 01 to 30 April to 2023, conducted in three pediatric departments in Antananarivo. The survey focuses mainly on the experience, feelings and perception of asthma.

Results: Thirty parents, the majority of whom were mothers, were surveyed. Most parents defined asthma as "a chronic, serious disease that can be fatal" and some as "a condition." They mainly reported a fear of the severity of the attack and death with each exacerbation of their child's asthma. Five children were not followed by a doctor for their asthma. All parents knew the medications used for their child's asthma but not all knew their mechanism of action. Most parents said they had no reason not to follow the doctors' recommendations and prescriptions and took precautions to avoid contributing factors. However, some also used lemon and honey as a "cough suppressant," crocodile oil, traditional massage, or kept a turtle at home to cure asthma.

Conclusions: Information provided to parents regarding asthma is still insufficient, requiring increased therapeutic education to promote therapeutic adherence and better asthma control.

Keywords: Asthma, Child, Experience, Infants, Parents, Perception

INTRODUCTION

Asthma is a chronic inflammatory disease of the bronchi affecting approximately 339.4 million people worldwide, including nearly 14% of children under 15 years of age.¹ In Africa, the prevalence varies between 4% and 21.5%.²

In Madagascar, a study conducted in Mahajanga in 2013 reported a prevalence of 5.6% among children under 15 years of age.³ In recent years, a significant increase in this prevalence has been observed among children, leading to numerous cases of absenteeism and negatively impacting their quality of life. A good understanding of asthma is a key element in treatment adherence and is associated with

improved lung function and a reduction in the number of emergency room visits for severe asthma attacks.⁴

While numerous studies have described the epidemiological, clinical, and therapeutic aspects of asthma, few data focus on the parental perspective, particularly their experiences and perceptions of the disease. However, parental perception strongly influences treatment adherence and asthma control.

The objective of this study was to explore the experiences and perceptions of asthma among parents of children with asthma in Antananarivo.

METHODS

Study type

This was a qualitative grounded theory study designed to generate concepts and theories from the collected data. The study took place from 01 to 30 April 2023 in three pediatric departments in Antananarivo: The Tsaralalana Mother and Child University Hospital, the Ambohimandra Mother and Child University Hospital, and the Joseph Rassetta Befelatanana University Hospital.

Study population

The study population consisted of parents of children with asthma who had experienced at least one second asthma attack. Parents who refused to participate were excluded. Sampling was carried out progressively, as the data were analyzed, until theoretical saturation was reached that is to say the collection of new information no longer provides additional ideas, themes, or perspectives for the research.

Study variables and data collection

The variables studied were: parental characteristics (gender, education level, history of asthma) and the characteristics of children (age, residence, allergy, passive smoking).

Several areas were assessed concerning parents' experiences and perceptions of asthma, such as: description of their child's last asthma attack, their feelings during attacks, their feelings on a daily basis. They were also asked about their knowledge of the origin and definition of asthma, as well as asthma monitoring and treatment.

Data analysis

Data were collected from semi-structured interviews consisting of open-ended questions in Malagasy, conducted in outpatient clinics, pediatric emergency rooms, or during hospitalization. The interviews lasted an average of 15 minutes, with the number of interviews determined by the search for theoretical saturation. Ethical considerations included information on the purpose of the study, verbal consent, and data anonymization.

Data related to the characteristics of parents and patients were expressed in terms of numbers and percentages. Data collected on parents' experiences and perceptions of asthma were compiled and analyzed by excel software.

RESULTS

Characteristics of parents and children

During the study period, thirty parents were interviewed, with no refusals to participate, and theoretical saturation was reached at the 27th interview. The characteristics of

the parents are shown in Table 1. The median age of children with asthma was 4.3 years, ranging from 22 months to 13 years. The characteristics of the children are presented in the Table 2.

Table 1: Parental characteristics.

Parents' level of education	Number	Percentage
Father		
Primary school	0	0
Secondary school	9	30
University	21	70
Mother		
Primary school	1	3
Secondary school	6	20
University	23	77
One of the parents has or has had asthma		
Yes	5	17
No	25	83

Table 2: Characteristics of children.

Characteristics	Number	Percentage
Gender		
Male	12	40
Female	18	60
Residence		
Urban	25	83
Rural	5	17
Allergy		
Yes	10	30
No	20	70
Passive smoking		
Yes	6	20
No	24	80

Parents' experiences with asthma attacks

Parents describe their children's asthma attacks as beginning with an ENT infection, followed by breathing difficulties and wheezing. When faced with these asthma attacks, parents mainly expressed intense fear particularly of death or a sudden worsening of their child's condition by saying "I'm afraid my child's crisis will worsen", "I'm afraid of death".

Some described a state of panic and shock as a near-death experience, and said: "I can't bear to see him suffer." While others who were more experienced and had an action plan provided by their pediatrician, were calmer and more composed, saying: "I'm not worried, I know what to do according to the action plan given by the pediatrician. I'm already used to it."

Perception of asthma in everyday life

According to parents, asthma was a source of constant worry in everyday life. Feelings of guilt were frequently

reported, linked to housing conditions or the use of coal. Asthma was perceived as a serious, chronic disease, sometimes compared to diabetes, but some parents said: “*I think it's because my child was resuscitated at birth » or believed that it could be cured with age*”.

Origin and definition of asthma

Parents attributed the origin of asthma to several factors: heredity, pollution, allergies, viral infections, or neonatal events such as resuscitation at birth. The definition of the disease often remained vague, reflecting a partial understanding of asthma.

Treatments and associated practices

Most parents were familiar with medical treatments (salbutamol, oral or inhaled corticosteroids), but the mechanisms of action were sometimes poorly understood. Concerns about side effects, particularly dependence on salbutamol and growth retardation when taking corticosteroids, were frequently expressed.

The use of traditional remedies such as crocodile oil, lemon with honey (often used as a cough suppressant), and traditional massage was reported and motivated mainly by curiosity, advice from friends and family, and the hope of a cure.

Other associated preventive measures were also mentioned by some parents.

Therapeutic adherence

When parents were asked about the reasons for non-adherence to treatment, they responded that it was mainly due to forgetfulness, the cost of treatment, changes in doctors and treatment at each consultation for an asthma attack, difficulty in using inhalation devices, fear of side effects, and insufficient information. Some parents answered that: “*It depends on the doctor; if it's not the regular doctor, I hesitate.*”

DISCUSSION

This qualitative study, conducted through a survey of 30 parents of children with asthma, explored their experiences and perceptions of asthma.

The median age of the children was 4.3 years, which is consistent with the average age of children with asthma, which was 4.77 years \pm 3.3 months in a similar study conducted in Tunisia on the knowledge and perceptions of parents of children with asthma in 2022.³

According to the literature, key periods or exacerbations are common in early childhood (0–4 years), preschool and early school age (3–6 years), often linked to viral infections, and school age (6–10 years) and adolescence, sometimes linked to hormonal changes.⁵

In this study, the respondents were mainly mothers (77%) because they are usually the ones who take their children to appointments and stay by their bedside during hospitalization.

It was also found that the majority of parents have a university education. Indeed, according to numerous studies, a high level of education is linked to a better understanding of the disease, as well as easier access to and better assimilation of new information through reading and research.⁶⁻⁹ However, despite this high level of education, most parents in this series still lack a great deal of information.

Regarding parents' feelings, there are similarities and differences with the findings reported in the literature.

Parents' feelings are consistent with those observed in studies conducted in mainland France and Mayotte, highlighting the strong emotional burden associated with childhood asthma.

Fear of death and hope for recovery are central elements of the parental experience.¹⁰⁻¹²

Divergent ideas concern the perception of asthma. In a study conducted in Mayotte, as observed in our study, it is considered a very serious, potentially fatal disease, often causing fear linked to the death of someone known to the respondent following an asthma attack.¹²

In contrast, in a study conducted in the European States, asthma is perceived as a manageable disease.¹³

Our study shows a perception of seriousness, possibly influenced by personal or community experiences of asthma-related deaths.

The responses to questions about the origin of asthma found in this study are the same as those reported in the Mahoran study: parents mentioned heredity, triggers, and allergies as causes of asthma.

Parents had difficulty defining asthma and understanding the mechanisms of treatment, which highlights the importance of therapeutic education.^{13,14}

The information given to parents about the disease, treatment, and the mechanism of action of medications is insufficient, prompting them to seek other solutions.

Indeed, the use of traditional remedies found in this study and in the Mayotte study reflects a need for hope and complementary solutions in the face of a chronic disease.¹²

The strength of this study lies primarily in the fact that it is one of the first qualitative studies on the experiences and perceptions of asthma among parents of children with asthma in Madagascar. However, this study has its limitations, mainly related to the small sample size, the

recruitment in an urban hospital setting and the risk of social desirability bias or memory bias.

CONCLUSION

This study highlights a parental experience marked by fear, guilt, and a perception of the severity of their child's asthma. The information provided to parents appears insufficient, impacting treatment adherence. Strengthening therapeutic education for parents is essential to improve asthma control and the quality of life of children with asthma.

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