JBI
BEST PRACTICE
Evidence-based information sheets for health professionals

Experience of parents and carers in managing asthma in children

Recommendations*

- In the absence of a diagnosis, communicating a clear pathway to attaining a diagnosis and an immediate treatment plan for current management should occur. **(Grade A)**
- Education should be provided to parents and carers at first hospitalization or GP presentation for the condition and include information on the chronic nature of the condition, symptoms, assessing severity, triggers, medications and ongoing management. **(Grade A)**
- Health care professionals should assist parents and carers to identify support networks including specialist respiratory nurses, asthma clinics or asthma foundations for ongoing support and to access asthma education programs to develop knowledge and skills. **(Grade A)**
- Schools and educational settings should provide supportive environments including asthma friendly school policies ensuring students have quick access to asthma medications. Staff training is essential to increase staff knowledge in asthma management, including how to minimize triggers in the school environment and asthma first aid to treat an asthma exacerbation. **(Grade A)**

**Please refer to: JBI's Grades of Recommendation*

Information Source

This Best Practice Information Sheet is a summary of evidence derived from a systematic review published in 2019 in the JBI Database of Systematic Reviews and Implementation Reports.[1]

Background

Asthma is a chronic inflammatory disease affecting the airways of approximately 14% of the world's children. The causes of asthma are not well known but it is associated with genetic, lifestyle and environmental factors. Symptoms of asthma include episodes of wheezing, breathlessness and chest tightness.

Diagnosis of asthma in children can be particularly difficult. Spirometry is often used to test lung function and assist with a diagnosis of asthma, however spirometry can be difficult for children under five to master. Therefore, in this age group, a recurrent wheeze, cough, family history of asthma and allergies and a clinical response to inhaled bronchodilator or preventer is often considered a diagnosis of asthma.

Parents and carers are often the primary persons responsible for caring for their child and managing their asthma. This poses a significant burden on health systems and society, with an estimated AUD 1.2 billion dollars annually related to the direct costs of asthma, including loss of productivity in the workplace, particularly with pediatric asthma.1 While managing asthma relates to the medical management of the condition, caring for a child with asthma extends beyond this and relates to the family, social and emotional impacts of the condition. Caring for a child with asthma is challenging for families, particular in the pre-diagnosis stage with parents reporting feelings of fear and uncertainty.

The findings of the review provide a comprehensive understanding of the experiences and challenges faced by parents and carers in caring for their child with asthma as well as providing an evidence- base to inform services, support and programs ensuring parents and carers needs are met.

Objectives

The purpose of this BPIS is to present the best available evidence on the lived experience of parents and carers in caring for a child aged 0-18 years with asthma, wheeze or bronchiolitis. Diagnosing asthma in children under the age of five is difficult as they are often unable to adequately perform lung function tests, therefore wheeze and bronchiolitis was also included.

Phenomena of interest

The phenomena of interest is focused on the parents and carers experience of caring of their children with asthma, wheeze or bronchiolitis in any setting, including the home, community and primary healthcare. Barriers and enablers that hinder and support the provision of asthma care were also considered.

Quality of the research

A total of 77 qualitative studies, including grounded theory, phenomenology and qualitative descriptive studies were included, representing 1655 individual participant experiences. Mothers dominated the participants group (n=1078) followed by 127 fathers, 44 others including grandparents, aunts or carers and 406 were unspecified and described as families or parents. The methodological quality of the included studies was assessed independently by two reviewers using the standardized critical appraisal instruments for qualitative research in JBI SUMARI; all studies were deemed to be of high methodological quality.

Findings

Using the process of meta-aggregation a total of 1161 findings were extracted from the included studies. Similar findings were grouped to produce 41 categories with categories further aggregated to produce seven synthesized findings. Twelve countries were represented in the review, the majority from United States of Americas, Canada and United Kingdom. The majority of the studies were conducted in the home or community setting followed by the hospital setting. A description of each of the synthesized findings are presented below.

Synthesized finding 1: Negotiating the meaning of having a child with asthma

Parents and carers experience a range of emotions when their child is suffering with symptomatic asthma including fear, anxiety, uncertainty, panic, denial and guilt. Parents constantly felt on guard and fearful their child may die; these feelings can be exacerbated by the unpredictable nature of asthma.

"Scary because I feel like OK, there is nothing else I can do. It is out of my hands when it comes to breathing. You [are] scared for them because you know asthma can kill."

"Asthma is changing and the child's condition isn't always the same either. And with asthma, that's another thing, it's so unpredictable and there are so many factors that can cause an attack. It's a very frustrating disease because you just do not know and what might be a trigger to one child isn't for another."

Synthesized finding 2: Impact on Family Life

Family life and activities are often disrupted and limited when caring for a child with asthma; parents and carers often long for a normal life. Mothers, who may often be the primary caregiver, juggle multiple roles including work, household activities and the demands of asthma management. The labor intensiveness of asthma impacts on time available for other family members.

"That affects us, the fact that it's very difficult for me and my husband to get time together. Which sounds very selfish but it's also quite important. I do not really get any time to myself because I'm either in work or looking after them. It's even silly things like we can't organize to go out because you can bet your bottom dollar that would be the night that one or the other of them would decide they're going to be poorly. I think we went out last weekend. That is the first time we've been out in nearly a year because we've arranged to go out and then one or the other of them has got poorly and it just hasn't happened. If there's any doubt in my mind, I won't leave them."

Synthesized finding 3: The process of getting a diagnosis and learning about asthma

Often there are lengthy delays in a child being diagnosed with asthma with parents often feeling a sense of relief once a diagnosis has been provided. Once armed with the diagnosis parents and carers focus on learning as much as they can about the condition.

"I've learned from talking to other people who have asthma and who have children with asthma...Things that have caused triggers for them you are now aware of and you watch for in your own child. Things that are beneficial for their children you may also try with your child."

Synthesized finding 4: Relationships with health care professionals and the emergency department experience

Parents and carers express varying levels of satisfaction when seeking health professional care. Parents and carers report difficulty in communicating to health professionals. Parents and carers at times feel they are not being listened to and language differences further contributes to lack of access to culturally appropriate information. Parents and carers also express a lack of trust in the knowledge and care being provided by their health professional.

"You have to struggle to get help from someone and you have to be strong and communicate well."

Synthesized finding 5: Medication beliefs, concerns and management strategies

Parents and carers express concern over the side effects of asthma medications, particularly the preventer medications containing corticosteroids. While some understand the importance of regular inhaled corticosteroids others choose not to or have difficulty adhering to the regime.

"They were meant to be supposedly on the daily medications....then they'd go through a time where they were symptom-free...you're meant to carry on and we get carried away with life and the asthma inhalers have fallen under beds."

Synthesized finding 6: With time, parents became more comfortable managing their child's asthma

With time, parents and carers become more comfortable and more confident in caring for and managing their child's asthma. Parents and carers learn to accept their everyday life, establish routines, plan ahead with activities and encourage children to self-manage.

"It's easier now, it's second nature. It was hard to learn it, the what to do and how to do it but once I've learnt it, it's just do what you have to do not, it's not that panic situation any more.... You have to control asthma, you can't cure it, you have to maintain and control it. I control it by not giving him foods that are going to set off an allergic reaction, by not having animals, and by trying to keep the dust bunnies down."

Synthesized finding 7: The need for support

The need for support is paramount. Parents and carers, but in particular mothers, often feel isolated when managing the burden of asthma. Many rely on family, health professionals and other networks for support. Barriers to asthma management include difficulty accessing health professional care when required and a lack of education provided by the health professionals. Parents and carers also expressed the need to be supported in the school / childcare environment.

"We need support groups....I really don't have anybody else to go [to] other than my doctor."

"I am absolutely not confident about the school to take care of my child when he has asthma attacks. I forced him to absent himself from school for a week...even though he become better."

Conclusions

Parents and carers play a key role in caring for and managing their child's asthma and the findings from this review highlight the emotional and physiological pressures parents and carers face. Education is required to build knowledge, confidence and skill in managing asthma and to understand and recognize symptoms, avoid triggers and administer appropriate medication. Parents and carers expect health professionals to provide high quality, culturally appropriate care to their child while considering their opinions and concerns. A partnerships approach between parents and carers and healthcare providers, where individual needs are emphasized and not just the disease, is imperative to achieving this.

Implications for practice

The findings from this review provide a deeper understanding of parents and carers experience and the stages parents and carers undergo as they negotiate the meaning of having a child with asthma. These findings should be used to inform and improve services, supports and programs to ensure parents and carers receive high quality care from knowledgeable and informed health professionals, to ensure they receive the support they need from schools and educational settings, as well as the education and support they need to be confident in their own skills and abilities to care of their child with asthma.

EXPERIENCE OF PARENTS AND CARERS IN MANAGING ASTHMA IN CHILDREN

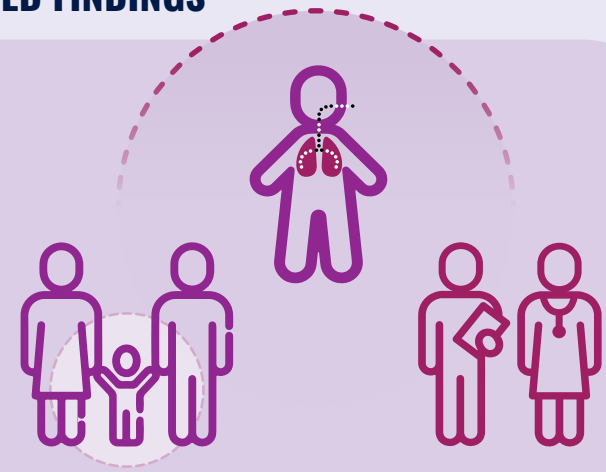
POPULATION
Parents and carers who care for a child aged 0-18 years with asthma, wheeze or bronchiolitis

PHENOMENA OF INTEREST
Experience of caring for their child with asthma, wheeze or bronchiolitis

CONTEXT
Any setting, including the home, community and primary healthcare

SYNTHESIZED FINDINGS

- The process of getting a diagnosis and learning about asthma
- Negotiating the meaning of having a child with asthma
- Medication beliefs, concerns and management strategies
- Impact on family Life
- With time, parents became more comfortable managing their child's asthma



The need for support

Relationships with health care professionals and the emergency department experience

RECOMMENDATIONS FOR PRACTICE

COMMUNICATE A CLEAR PATHWAY TO DIAGNOSIS AND MANAGEMENT

In the absence of a diagnosis, communicating a clear pathway to attaining a diagnosis and an immediate treatment plan for current management should occur.

(Grade A)

PROVIDE PATIENT EDUCATION

Education should be provided to parents and carers at first hospitalization or GP presentation for the condition and include information on the chronic nature of the condition, symptoms, assessing severity, triggers, medications and ongoing management.

(Grade A)

IDENTIFY SUPPORT NETWORKS TO DEVELOP KNOWLEDGE AND SKILL

Schools and educational settings should provide supportive environments including asthma friendly school policies ensuring students have quick access to asthma medications. Staff training is essential to increase staff knowledge in asthma management, including how to minimize triggers in the school environment and asthma first aid to treat an asthma exacerbation.

(Grade A)

References

1. Fawcett R, Porritt K, Stern C and Carso-Chahhoud. Experiences of parents and carers in managing asthma in children: a qualitative systematic review. JBI Database System Rev Implement Rep. 2019; 17(5):793-984.

Authors

Kylie Porritt[1]

[1] JBI, The University of Adelaide, South Australia, Australia.

Acknowledgments

This Best Practice Information Sheet was developed in collaboration with the JBI. This Best Practice Information Sheet has been reviewed by nominees of JBI and the review author.

How to cite this Best Practice Information Sheet:
Porritt K. [Best Practice Information Sheets] Experience of parents and carers in managing asthma in children. JBI EBP Database. 2019 [updated 2022]; 21(5):1-5.

JBI, Faculty of Health and Medical Sciences, The University of Adelaide SA 5006, AUSTRALIA

Email: jbi@adelaide.edu.au | https://jbi.global