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ORIGINAL RESEARCH

Understanding Caregiver Burden in Severe Pediatric Asthma - A Qualitative Study

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Objective: This study aimed to clarify the emotional and practical burden on primary caregivers of children with severe asthma and identify the support needs of those caring for individuals with severe asthma.

Methods: A phenomenological research approach in qualitative research was used. Semi-structured interviews with caregivers of children with asthma waiting in the outpatient clinic of Shanghai Children's Hospital were conducted from January to August 2024 through purposive sampling. The researcher transcribed audio-recorded interview data verbatim into text and thematically analyzed the data using the Colaizzi 7-step analysis method and then obtained the final results.

Results: There were a total of 12 participants. Through these 12 in-depth one-on-one interviews, all necessary study data were obtained. The study identified the following four main burdens for caregivers of children with severe asthma: 1) Multiple barriers to the care-giving process. (Incomplete knowledge of disease management; lack of competence in care as well as poor child compliance making care more difficult; lack of support for asthma in schools). 2) Excessive consumption of time and energy. (Disturbed sleep rhythms and lack of physical energy). 3) Family dysfunction. (Conflicts among family members; disruption of normal life; increased financial burden). 4) Negative emotions. (fear; nervousness, worry).

Conclusion: This study focuses on caregivers of children with severe asthma who face multiple stressors. Caregivers are critical to disease management: healthcare professionals and the community should provide support; family members should share tasks; and children's poor self-management skills place a burden on caregivers, and professionals should teach children to better care for themselves. These findings have important implications for healthcare providers to develop targeted support programs and improve overall care for children with severe asthma.

Keywords: severe asthma, caregiver burden, qualitative research

Introduction

Asthma is a kind of heterogeneous disease usually characterized by chronic airway inflammation. It is the most common chronic disease in children and a major contributor to the high prevalence of chronic disease in children, as measured by school absences, emergency department visits, and hospitalizations.[1] The majority of children with asthma are able to control their condition with standard therapy, but it is estimated to be difficult for 5–10% of children with severe asthma.[2]

Severe asthma is that uncontrolled despite adherence with optimized high-dose ICS-LABA therapy and treatment of contributory factors, or that worsens when high-dose treatment is decreased.[3] Severe asthma represents only a minority of asthma patients, but a significant portion of the asthma disease burden comes from this group of patients.[4] Patients with severe asthma and their families bear a significant financial burden,[5–7] not only in the terms of medical care and medications, but also in terms of loss of income and career choices.

Patients with severe asthma have significantly higher rates of emergency department visits, hospital admissions and intensive care unit admissions due to asthma over their lifetime.[8] Their rates of emergency department visits and hospitalizations are 15 to 20 times higher than those of children with mild to moderate asthma, accounting for 50% of

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annual healthcare costs. What's more, the estimated cost for patients with acute exacerbations is 3.5 times higher than those for patients with well-controlled asthma.[9]

The anti-IgE therapy, namely omalizumab, found its main clinical utility and recommendation to treat severe asthma. However, pre-treament IgE levels limited the use of omalizumab in some patients and the cost of the therapy is still relevant.[10] Patients with severe asthma also experience a heavy burden of symptoms, exacerbations and medication side-effects.[11] Frequent shortness of breath, wheezing, chest tightness, and coughing can interfere with daily life, sleep, and physical activity, and patients often experience frightening or unpredictable deterioration.

Severe asthma often interferes with family, social and work life, limits career and vacation choices, and affects emotional and mental health. Patients with severe asthma often feel alone and misunderstood, as their experience is so different from that of most people with asthma.[12,13]

Caregiver burden refers to the negative physiological, psychological, and economic stimuli and pressures experienced by caregivers during the care-giving process.[14] It may have an impact on the child's condition and even prognosis, as well as on the child's own emotions, behavior and personality formation.[15] Negative emotions among caregivers of children with asthma have been shown to be associated with increased frequency of medical consultations and prolonged duration of symptoms.[16]

In addition, these emotions are associated with decreased treatment adherence, escalating cognitive-behavioral problems, and impaired ability to self-manage the disease. On the one hand, frequent, prolonged and poorly controlled severe asthma exacerbations in childhood can lead to increased psychological distress for caregivers.[17] On the other hand, the specificity of asthma and a weak social support system can cause carers to face a number of challenges in caring for their child, such as insufficient knowledge and care giving skills, which can directly reduce the quality of care and control of the child's condition and lead to a range of psychological, social and physical health problems.[18]

For example, Lauren Kelada[19] reported that "Schools were identified as a source of difficulty for asthma management; a common issue was that school policies often required inhalers to be kept under lock and key" and "Parents reported being unsure when their child's symptoms warranted a visit to the doctor or hospital".

Nurses and other health professionals are ideally placed to help educate parents about how to recognize worsening asthma symptoms. Although current research has gained a certain understanding of the treatment and management of severe asthma in children,[3,18] there are still some deficiencies in researches on the experiences of caregivers. For example, there is relatively little research on the needs and challenges of caregivers in different cultural backgrounds.

This study aims to gain a deeper understanding of the life experiences of primary caregivers of children with severe asthma through qualitative surveys. Qualitative methodology is indicated for this type of research as it provides a level of contextualization and immersion in the individual's life experience that facilitates understanding.[20] The objective of this study was to delineate the emotional and practical burden that caring for a child with severe asthma places on the primary caregiver, and to identify the support requirements of those who care for individuals with severe asthma in order to ensure that health professionals and policymakers are aware of and responsive to these needs.

Methods Design

This research is a phenomenological study, which is a kind of qualitative study. In the field of nursing, it is mainly applied to explore subjective perceptions or life experiences, such as values and worldviews, in relation to health and illness, and often used to conduct research on topics that seek to determine the nature of the experiences or phenomena of the research participants.[20]

In this study, it was used to describe the emotional and practical burden of patient with severe asthma and to analyze the care-giving experiences of caregivers of children with severe asthma through in-depth, semi-structured interviews.

Participants

Semi-structured interviews with families of children with asthma awaiting outpatient treatment at Shanghai Children's Hospital between January 2024 and August 2024 were conducted using a purposive sampling method. The sample size was determined based on the criteria that the respondents' information was repeated and no new themes were extracted when the information was analyzed.

Inclusion Criteria

1. Participants were children between the ages of 6 and 12 years whose symptoms met the diagnostic criteria for severe asthma as outlined in the Global Asthma Initiative.[1]
2. The children suffered ill for at least 6 months, and their caregivers were able to express their thoughts and inner experiences clearly and fluently.
3. Caregivers must meet the additional criteria of voluntary participation in the study.

Exclusion Criteria

1. Individuals with speech and communication disorders or mental disorders;
2. The caregiver of child and their family members suffer from serious chronic diseases;
3. Child and caregivers who participated in another clinical trial within the past 3 months.

Data Collection

This study used a qualitative phenomenological approach to conduct in-depth semi-structured interviews with children's caregivers. The interview outline was revised and produced based on the literature review study and after repeated discussions among the subject group.

Prior to the main study, interviews were conducted with caregivers and the interview guidelines were developed as follows: ① How do you view your child's illness? ② How does your child's illness affect your family, life and work? ③ What is your biggest concern about your child's illness? ④ What are the difficulties in caring for your child? ⑤In what ways would you like a health professional to help you? ⑥ Is there anything else you want to tell me?

The location of interview was chosen to be in the outpatient education room. The environment was quiet and undisturbed during the interview. The interviewer asked questions based on the outline, listened carefully without giving hints, and encouraged the interviewee to express his/her true feelings and experiences. The interview lasted 30–45 minutes, and the entire interview was recorded.

Non-verbal expressions were similarly transcribed, such as facial expressions, tone of voice, and body movements. All interview data collection from January through August 2024 was completed, and data review and validation was completed in September 2024.

Statistical Methods

Within 24 hours of the interviews, researcher Wu and Zhang listened to the audio recordings repeatedly, transcribed the recordings word by word into text, and organized them into textual materials. When transcribing the text, researchers did not delete or change the content of the recordings, and also did not miss the recording of non-verbal information.

The data was analyzed using the Colaizzi 7-step method of analysis.[21] This involved rereading the interview material, identifying meaningful statements, coding, clustering themes, defining and describing themes, generating theme prototypes and returning for validation (Figure 1).

To ensure the accuracy of the information, the interviewer returned the transcribed text to the respondents for validation to confirm its correctness, and then to analyze and extract it.

To reduce bias, researchers Wu and Zhang separately analyzed, coded and extracted themes from the transcribed textual data, and then team members discussed the consistency between the extracted themes and data, as well as the differences and connections between the themes and between themes and sub-themes, to form the final results.

Ethical Considerations

This study was conducted in accordance with the Declaration of Helsinki. The study was approved by the Ethics Committee of Shanghai Children's Hospital Affiliated to Shanghai JiaoTong University. The approval number was 2024R004- F02. All participants gave written informed consent. The participants' informed consent included the publication of anonymous responses/direct quotes.

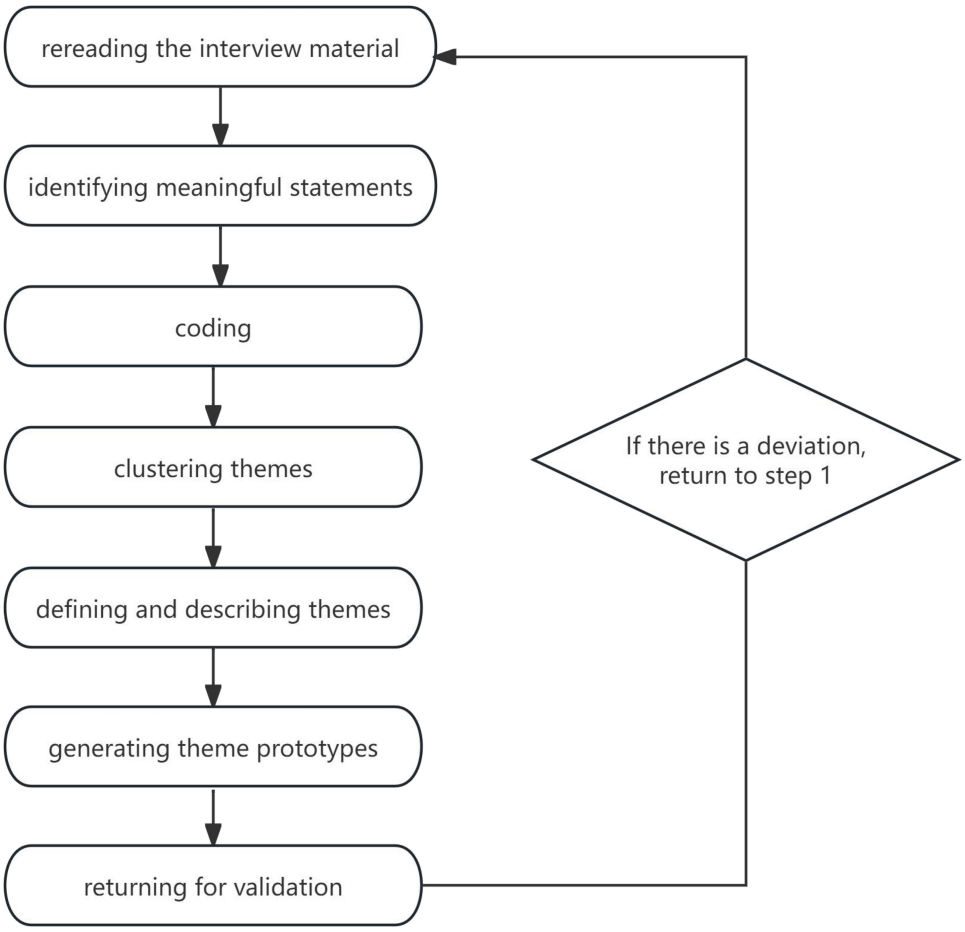

Figure 1 Colaizzi 7-step analysis procedure.

Results

In this interview, it was found that when the number of interviewees reached 10, no new themes were presented, and no new information appeared after continuing to interview 2 cases. It was considered that the interview data was saturated and the interview was stopped.

Finally, a total of 12 participants were included in this study. The mean age of the participants was 42.5 ± 10.2 years, of which three were male and nine female. The mean age of the children was 9.9 ± 2.4 years and the duration of the disease was 4.1 ± 2.8 years. The average number of asthma attacks per year was 5.1 ± 1.4. The mean annual cost of the disease was RMB 32000 ± 11000 Yuan (Table 1).

Four themes described the main results: "Multiple barriers to the care-giving process", "Excessive consumption of time and energy", "Family dysfunction", "Negative emotions" (Table 2).

Theme 1: Multiple Barriers to the Care-Giving Process

Lack of Disease Management Knowledge Leads to Insufficient Care-Giving Capacity

Asthma is an unfamiliar disease to most families, and its concept, pathogenesis, and triggers are still unclear. Most caregivers' knowledge of asthma comes only from what doctors tell them at the clinic visit. Caregivers express a strong desire to engage and communicate with healthcare professionals to acquire specialized knowledge and guidance.

> Asthma is a blind spot in our knowledge and would like to know the causes of this disease, as well as the treatment options, daily care. Understand him fundamentally and then know how to cope with it. (P6, female, 33years)

Table 1 Participants' Characteristics and Patients' Demographic Characteristics

Characteristics		**n or (M ± SD; Range)**
Age (years)	Caregiver	42.5±10.2 years
	Children	9.9±2.4 years
Gender	Male	3
	Female	9
Educational level	Primary	1
	Junior high	2
	Senior high	0
	University	9
Duration of disease		4.1±2.8 years
Acute episodes per year		5.1±1.4
Sickness costs		RMB 32000±11000 Yuan

Abbreviations: M, Mean; SD, Standard deviation; RMB, Ren Min Bi.

Table 2 Themes and Sub-Themes

Theme	**Sub-Theme**
Multiple barriers to the care-giving process	Lack of disease management knowledge leads to insufficient care-giving capacity
	Poor child compliance makes care more difficult
	Lack of support for asthma in schools
Eccessive consumption of time and energy	Disrupted sleep rhythms
	Lack of physical strength
Family dysfunction	Tension among family members
	Disrupted life
	Higher financial burden
Negative emotions	Fear
	Nervousness
	Worry

Impairment in caregivers' ability to recognize asthma symptoms frequently results in delayed treatment for children. First, some caregivers believe that asthma symptoms are just wheezing, which leads to misdiagnosis and misdirection of treatment. Secondly, some caregivers perceive asthma only as a hereditary condition, causing them tend to react with denial or skepticism when informed of the diagnosis, which further delays early-stage diagnosis and timely intervention.

> Our child had been treated as a cough and finally realized that the treatment was going in the wrong direction and our child had an allergic asthma cough. Although we found out a long time ago that our child was allergic to dust mites, we overlooked it and didn't realize it would be associated with the cough. (P6, female, 33years)

> He started coughing when he had a cold. It got worse and worse, and then he wheezed. It was the first time told by a doctor that my child may have asthma. Since we don't have hereditary asthma in our family, we insisted it was caused by a cold. (P2, female, 40years)(P2, female, 40years)

Asthma is a chronic disease that requires standardized treatment and management. If caregivers have significant misconceptions about disease management, this can often lead to delayed or poor treatment, or even life-threatening conditions.

"For a while, he looked normal and we did not pay much attention to his medication. However, the next time he was examined and found to have poor lung function results." (P12, female, 33 years old)

> For a while he seemed normal and we didn't pay much attention to his drug taking, and the next time he was reviewed the lung function results were bad. (P12, female, 33years)

> When he wheezes, give him some Ventolin spray or do a nebuliser. I had asthma when I was a child. But when I wheeze, I just hang on by myself. (P1, male, 36years).

Poor Child Compliance Makes Care More Difficult

Due to their young age, children do not have enough knowledge about the disease and do not understand the importance of treatment. In addition, prolonged treatment may cause boredom in children, making them less compliant with the treatment of the disease during treatment, which undoubtedly makes it more difficult for caregivers to provide care.

> Always craving cold things, cold milk in the fridge, and cold drinks in the summer. He doesn't like to exercise and I'm trying to figure out how to get him to exercise. He loves the water and I bought him a gym membership, but when he gets in the water he lazes around, plays with the water, swims around and doesn't move a muscle. When he's out of breath he thinks a spray of nebuliser will do the trick, and he can even take two days off from school. (P10, female, 64years)

> When he was little he was very obedient and could sucked up his meds every day like the doctor asked. Then he sucked every other day, now he sucks once a week, and he doesn't listen even when reminded. Sometimes I notice that his stock of medication stays the same and I get the feeling that he's not even sucking properly. (P7, male, 42years)

> When she started the desensitization treatment, she was a little resentful because she had to come over every week to get her shots. (P4, female, 44years)

Lack of Support for Asthma in Schools

Most of the living places for school-age children with asthma are in schools, and some caregivers expressed that schools currently pay less attention to children with asthma. The lack of awareness and concern about asthma disease among most school teachers may cause caregivers to worry about their child's life at school.

> In first grade, every time after gym class he threw up, the teacher gave me feedback that it was a gastrointestinal problem. At that days, the problem became frequent. My kid had a morning exercises between classes that time, sometimes running or jumping, and he would get dizzy a lot. But after reported to his teacher too many times, the teacher did not care anymore, and the kid did not dare to report it again. When the teacher ignores him, he just forgot about it. (P2, female, 40years)

> My child is allergic to many kinds of food. I told the teachers that my child is allergic to those foods and also sent them the reports. But then the feedback I got from my child was that he still ate these foods that would be allergenic to him together with others. I can understand that teachers can not have the means to take care of all the kids, but I am still worried. (P2, female, 40years)

Children with refractory asthma have physical limitations due to their disease and may not be able to complete physical activities as well as other children, while school teachers seem to be more concerned with the child's grades and do not give these asthmatic children as much understanding and support as they should.

> Since an exercise like jumping rope leads to chest pains, I helped him ask the teacher for a leave of absence every time he jumped rope. More times than not, the teacher had a problem with it: since he hadn't been participating in jumping rope, the child didn't have a score, which would affect the overall assessment. Although I showed his lung function report to the

teacher, I felt that the teacher did not particularly understand, and that the teacher probably valued the grade more. (P2, female, 40years)

School teachers also have KPI requirements. Students can't be excused from PE classes, they must attend. And there is an attendance rate for PE classes, so he will not be given preferential treatment in this case. (P8, male, 36years)

Caregivers expect schools to establish individualized physical activity plans and assessment methods for children based on their physical condition and to ensure that children participate in physical activity in a safe manner.

The school should tailor a sport for asthmatic children, such as the 400-meter run, and I think the speed requirement can be lowered a bit and the total length can be lengthened a bit. (P8, male, 36years)

Theme 2: Excessive Consumption of Time and Energy

Caring for a child with asthma forces the caregiver to dedicate his or her extra time and energy to disease management, leading to disruptions in the caregiver's own life and the rhythms of his or her communal rhythms, and even affecting his or her physical health.

Disrupted Sleep Rhythms

Most of the children with croup-refractory wheeze presented with nocturnal episodes, which were characterized by major manifestations of coughing, chest tightness, wheezing, shortness of breath, and dyspnoea, which severely disrupted the sleep rhythm of the family. Almost all respondents had experienced insomnia and being woken up in the past week.

He coughs when he catches a cold, and asthma attacks as soon as he coughs. Sometimes he can't catch his breath in the middle of the night. Since he would call me every time he felt uncomfortable in the middle of the night, I always keep my mind on my back when I go to sleep and dare not fall asleep. As soon as he calls me, I immediately realize that he was uncomfortable (P5, female, 62years)

When she was wheezing heavily, she couldn't fall asleep at night, that is, she cannot lie flat and has to sleep with her arms. (P9, female, 38years)

Lack of Physical Strength

For most parents, caring for a sick child has become a long-term and arduous task. While spending a lot of time and energy on caring for their children, they are also under tremendous pressure and are physically and mentally exhausted, resulting in a decline in their health.

"We are getting older and older now. When he is not in good health, his mother is not by his side and his father is working. His father is also not in good health, and now that I am getting older and older, my own health is also not good. I feel tired and sometimes depressed in this regard. "(P10, female, 64 years old)

I was tired of going to work every day and I couldn't take weekends off. I had to take my child to the hospital for treatment. Feeling exhausted, I don't know when it's going to end. (P12, female, 33years)

Theme 3: Family Dysfunction

Tension Among Family Members

The complexity of severe asthma and family disagreement over treatment can cause significant psychological stress for the primary caregiver. In addition, asthma emergencies can easily lead to high mood swings and frequent arguments among family members, which can lead to a deterioration in family relationships.

His Mom is too careless to take care of him. When the child is uncomfortable, his mother thinks it's not necessary to go to the hospital, while I and the rest of family think we should go. There are many different opinions at home, which is very annoying. We all get annoyed when he feel uncomfortable (P5, female, 62years)

Whenever the child is unwell, our whole family feel frustrated and blamed each other for not taking good care of the child. (P12, female, 33years)

Disrupted Life

Children with severe asthma require carers to spend a lot of time accompanying the treatment, which makes it difficult for carers to balance family and work. They begin to complain about the interruption of their original pace of life and the decline of their social functioning.

> We came to the hospital regularly and initially received desensitization treatment. When it got to vial #4, the reaction was so bad that he had to do nebulisation after each shot. After a period of time, he started receiving omadol treatment. All my time off now is spent with him on his treatments. (P18, male, 36years)

> Every time he wheezed, his body resistance dropped and he would get diarrhea. It would take me a month to take him to the hospital and I couldn't go to work properly. (P19, female, 38years)

Higher Financial Burden

Refractory asthma is characterized by recurrent attacks and high treatment difficulty, which requires large medical and transport costs. The fact that some caregivers give up their jobs in order to take care of their children, leading to a reduction in the total family income, and the fact that the vast majority of the children's medical expenses are paid out-of-pocket, have imposed a heavy financial burden on the family.

> Tried many hospitals and sought out specialists from all over the country. Now I have to come to this hospital every month, and the cost of transportation, accommodation, and medical treatment is around 5,000 to 6,000 RMB per time. (P6, female, 33years)

> Since the diagnosis of asthma, various treatments and tests have been going on. It's a big fixed expense, and many of the treatments are out-of-pocket. (P12, female, 33years)

Theme 4: Negative Emotions

Fear

In the early stages of disease diagnosis, caregivers are fearful of the disease and hard to accept it. During the care process, the symptoms of sudden asthma attacks in children often make caregivers feel scared and overwhelmed.

> At First the doctor diagnosed the child with asthma, there was a lot of apprehension inside. I had never been exposed to it before. Then when the doctor said it was asthma, it was like the sky was falling for me. (P4, female, 44years)

> There were a few times when he fell ill and couldn't make a sound or breathe, as if he was about to lose his breath. It was too horrible. (P5, female, 62years)

Nervousness

The irregularity of asthma attacks and the lack of awareness of this disease among parents in care-giving have led some caregivers to become overly nervous and anxious. They started to restrict their child from going outside for fear of triggering an asthma attack in the external environment.

> For example, in a smoking environment, he will have a strong reaction when he smells it. When he was a child, we didn't dare to take him to the mall to play. Whenever he went to public places, he would get sick and cough. His immunity was very poor. We dare not take him to play because he looks terrible after he falls ill. (P6, female, 33years)

> Every year when the season changes, he would get sick, and I would give him anti-allergy medicine in advance. But whenever he went to school, I got particularly nervous and wonder if he would suddenly have an attack. (P9, female, 38years)

Worry

Asthma treatment requires long-term standardized medication, and severe asthma is often treated with a combination of therapeutic modalities. A third of carers expressed concern about the side effects of long-term medication, and a proportion of carers were concerned that glucocorticosteroids would affect the child's growth and development.

> Now he has to inhale medication twice a day and be desensitized, will these have side effects? he's going to be developmental soon and if he can't get better from asthma he'll carry the disease for the rest of his life. (P10, female, 64years)

> Worried about whether too much hormone inhalation would affect growth and development or early maturity. (P10, female, 40years)

Some caregivers were satisfied with the results of treatment at this stage. However, they also expressed uncertainty about how asthma will regress in the future, causing caregivers to worry about this.

> He has asthma with allergic rhinitis, and now his symptoms are a little better because of the desensitization shots, but then he is worried that if he doesn't get them in the future he will go back to his old state. (P11, female, 40years)

Children with severe asthma need to spend a lot of time in treating the disease and restoring their health because they are less fit than their peers, and most caregivers are therefore concerned that the disease will delay their child's schooling.

> When I had a runny nose and a cough for three days, I had to take time off school, worried that I wouldn't be able to keep up with the lessons. (P3, female, 42years)

> Our boy is sick more often than not, basically 2 to 3 times a month. He is either on medication or on the way to it. (P6, female, 33years)

Discussion

Diversified Health Education to Enhance Disease Management Capacity

The results of this study show that caregivers of children with severe asthma face many barriers in caring for these children.

On the one hand, caregivers lack correct knowledge about asthma symptom recognition, triggers and disease severity. This can lead to delays in diagnosis and treatment, reduced adherence to medication and treatment regimens, and an inability to effectively respond to sudden flare-ups in children, ultimately affecting disease progression and outcome.

On the other hand, poor adherence of children also increases the difficulty of care. Inadequate knowledge of the disease, lack of self-management, recurrent episodes, and long treatment time often lead to children's poor adherence.

Reduced treatment adherence can lead to decreased quality of life, absenteeism from school, limited physical activity, and increased emergency room visits, which can also increase the burden on caregivers.[22] Health knowledge and information are essential for the development of correct and appropriate health care. Health knowledge and information are the basis for developing a correct and positive attitude towards health, and a positive attitude towards health is an intrinsic motivation to change undesirable behaviors. Caregivers are eager to receive support from healthcare professionals in disease management and to gain knowledge of asthma disease management.

Therefore, the healthcare professional support system should be continuously improved to carry out diversified health education for caregivers and children to satisfy their needs for disease information, and to provide personalized health education support and skills training according to their knowledge level, so as to improve their disease management ability.

At the same time, it is also necessary to accelerate the development of information technologies such as cloud care, remote home care and other information technologies to improve the capacity of primary care services. For example, asthma education video resource was demonstrated to be an acceptable and effective way of delivering asthma education to children and adolescents.[23] This resource was viewed by caregivers as a useful adjunct to their education, enabling consistent messaging and helping structure education delivery.

To Strengthen Asthma Management in Schools and Build a Hospital-Family-School Linkage Management System

Children with refractory wheeze spend most of their day at school, so overcoming school obstacles and improving school asthma management are key to successful disease management. Children with severe asthma have frequent deterioration of the disease and require careful care coordination among family, hospital and school. The results of this study showed

that most of the school teachers have inadequate knowledge about asthma disease and lack knowledge about disease management in asthmatic children. And, parents are concerned about the management of asthma in schools.

Therefore, more attention and support for children with asthma in schools is necessary, as well as harmonization among children, families, health care providers and schools. Successful school-based asthma programs can build strong partnerships between patients, families and clinicians to improve communication and disseminate asthma action plans and medications to schools.[24]

The School-based Asthma Management Program (SAMPRO) consists of four components: 1) Establishing a circle of support around the child with asthma; 2) Facilitating bidirectional communication between clinicians and the child's family and clinicians; 3) Comprehensive asthma education for schools; 4) Assessment and remediation of environmental asthma triggers at school[25].

The school-based asthma treatment programme forms a circle of support centred around the child with asthma to achieve control of asthma symptoms and reduce morbidity.[26] It also provides some assistance to caregivers and improves their quality of life.

Emotional and Social Supported to Focus on the Physical and Mental Health Needs of Caregivers

Studies have found that parents of children with asthma experience varying degrees of anxiety and depression during the long-term care-giving process.[27] 81.52% of caregivers reported high parenting stress and psychological distress, 67.57% of caregivers experienced varying degrees of depression, and 29.00% of caregivers were diagnosed with post-traumatic stress disorder.[28] The results of this study indicate that the recurrent, persistent, and long-term medication requirements of refractory asthma force caregivers of affected children to spend more time and energy.

The results of the study are consistent with Valero's,[29] who observed a positive correlation between the number of hospitalizations for children and the stress levels of caregivers, "the higher the number of hospitalizations, the higher the levels of perceived stress in the caregiver".

And due to the lack of professional knowledge of disease management, negative emotions such as nervousness, fear and worry may arise in the caregiver during the care-giving process. Meanwhile, the burden of long-term care-giving impairs the physical health of the caregivers, breaks their daily work life, and even affects the relationship of family members. This is consistent with Yang[14] Yang's study, which suggests that healthcare professionals should enhance the self-psychological construction of carers, give them all-round emotional and social support, promote the transformation of carers' positive emotions, and improve their psychological resilience and coping ability.

Encourage family members to take turns in caring for and accompanying their children, especially with mutual understanding and support among spouses, so as to improve the quality of sleep of the primary caregiver and alleviate psychological stress.

Secondly, a healthy support system for long-term care should be established. Parent-child activities and peer exchange sessions should be organized to encourage active participation of caregivers. Through mutual communication between family members and peers, listening to each other's inner thoughts, thus establishing good family and peer relationships. Caregivers with serious emotional disturbances should be provided with timely and targeted psychological counseling. Psychotherapeutic interventions such as cognitive-behavioral therapy, acceptance and commitment therapy, family therapy, motivational interviewing, multi-systemic therapy and problem-solving therapy are used for treatment under the leadership of medical staff and with the participation of relatives and peers.

Finally, the Government should also improve the relevant policies. Most of the interviewed groups mentioned that medical expenses are not reimbursed and the financial burden is relatively heavy.

The government and society should increase social welfare support, increase the types of outpatient asthma-related medication reimbursement, and facilitate reimbursement channels in order to reduce the financial burden on carers.

Limitations

The limitations of this study are as follows:

Firstly, the sources of samples are single. The research only focuses on the caregivers of children with asthma waiting in the outpatient clinics at Shanghai Children's Hospital. This may lead to a lack of representativeness for all caregivers of children with severe asthma.

Secondly, as a qualitative study, although it can provide in-depth insights into the burdens and needs of caregivers, the results may not be universal. Qualitative research is difficult to quantify and generalize, which may limit the application of the findings in a broader context.

In the future, qualitative and quantitative mixed studies can be carried out by expanding the sample size to explore analyze its potential influencing factors.

Conclusions

This study found that caregivers of children with severe asthma face multiple stressors related to disease management, family relationships, physical and mental health, and external support, resulting in a burden of care.

Therefore, healthcare professionals and the community should support caregivers, and caregivers' family members should actively share the care-giving tasks to reduce caregivers' stress and improve their quality of life.

In addition, health care professionals should pay attention to appropriate methods of health education for children of different ages to enhance their ability to self-manage their illnesses.

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Disclosure

The authors report no conflicts of interest in this work.

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