Parents' views of self-management for children with moderate to severe persistent asthma

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Abstract

Objectives: Children with moderate to severe persistent asthma, including those with asthma attacks more than once daily, asthma symptoms at night more than once a week, or asthma attacks that affect activities and sleep, may have irregular and recurrent symptoms until adolescence. Such symptoms may affect quality of life and even cause death. This study explored the self-management experiences of children with asthma in Hualien City, Taiwan, based on the views expressed by their parents.

Materials and methods: This study used a qualitative inquiry of 15 parents of children with asthma, in order to understand the children's self-management experiences.

Results: The findings from this study, as derived from content analysis, showed the following six domains of self-management: (1) knowledge of asthma; (2) use of asthma medications; (3) issues related to physical exercise; (4) self-care in daily life; (5) prevention and handling of asthmatic episodes; and (6) other issues related to asthma.

Conclusion: The results of the study can help health professionals understand the self-management experiences of families who have a child with persistent asthma, which in turn could provide appropriate guidelines and valuable information for development of self-management programs for children with asthma.

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how to deal with their disease [6,7]. This study focused on families of children with moderate to severe persistent asthma in Hualien, and used the qualitative research method to understand experiences with disease self-management from the perspectives of parents. This information can be used as a reference when developing self-management programs for children with moderate to severe persistent asthma in Hualien.

2. Materials and methods

2.1. Research design

This study used qualitative inquiry as the research design to conduct semi-structured in-depth interviews. The purpose of this study was to understand the self-management experiences of families of children with moderate to severe asthma in Hualien. This qualitative study focused on individuals' personal feelings and descriptions of life and experiences. Based on interviews with the participants, the researcher could understand and explain their personal perceptions of social facts [8].

2.2. Research scope

The study site was the outpatient clinic of the Division of Pediatric Allergy and Immunology at a medical center in Hualien. The participants were parents with children aged 8–12 years, with moderate to severe persistent asthma. Purposive sampling was used in this study. The inclusion criteria were as follows: children diagnosed with moderate to severe persistent asthma by Global Initiative for Asthma guidelines [9] for at least 6 months and their parents with no physical and psychological disabilities who could speak Chinese or Taiwanese.

2.3. Research tools

The research tools included a basic information form and the semi-structured interview guidelines. This study was conducted with face-to-face in-depth interviews and the content was recorded. The interviews lasted for approximately 30–60 minutes. The interview guidelines included six directions: (1) What is the current asthma condition in the children? What are the parents' opinions on asthma? What are the parents' opinions on their current medical context? What are the parents' opinions on well-controlled asthma? (2) What is the self-care situation of children with asthma at home and in school and society? (3) What kind of self-care ability (knowledge, skills, environment, drug use, learning, interpersonal relationships, social interaction, prevention of onset, and handling of onset) do parents expect their children to develop for asthma? (4) How do parents usually assist their children in developing self-care ability for asthma? What kind of stress or difficulties do they encounter? (5) What is the parents' ultimate objective in developing their children's self-care ability for asthma? (6) Based on the questions above, would you like to give any supplementary information or share anything?

2.4. Research procedures

Prior to when this study was conducted, the researcher applied to the Research Ethics Committee of the hospital to review this research project. This study was initiated upon review and approval of the research project. Prior to the formal study was initiated, a pilot study was done with parents of children with moderate to severe asthma (8–12 years old) meeting inclusion criteria identical to those of the study. This was done to test whether the interview guidelines could help obtain information on self-management experiences, whether the inclusion criteria were adequate, and the maturity of the interviewer's interview skills. Formal enrollment was initiated upon confirmation of the interview guidelines. A specialist at the Division of Pediatric Allergy and Immunology referred individuals who met the inclusion criteria to the researcher. The researcher explained the research purpose and methods. After the individuals agreed to be interviewed and completed an informed consent form, the interviews were conducted in the outpatient clinic.

2.5. Research data analysis

Content analysis was used to process and analyze the qualitative data. This study used induction to analyze data. The recorded interview content was converted into transcripts without any modification (addition or deletion of words). The researcher then scrutinized the overall text to identify meaningful sentences and classify them into different categories with specific themes [10,11].

2.6. Research rigor

This study used the rigidity standards proposed by Lincoln and Guba [12] to control research quality, including truth value, fittingness, auditability, and neutrality. The researcher has abundant experience caring for children with asthma and conducting qualitative studies and has been exposed to children with asthma and their parents for a long time. Two qualitative researchers with identical backgrounds in peer debriefing were invited to increase the truth value of this study, as well as to assist in exploring the hidden meanings of this study. These three researchers jointly controlled the consistency and stability of data, to ensure authentic reflection of meanings and characteristics of life experiences. During data collection and analysis, the researcher also used a reflection log, where various data were documented to establish the reliability of the study. All tapes and texts of interviews with participants, analysis records, and the reflection log were preserved as references for future inspection for other researchers to inspect this study and compare it with their own conclusions, based on identical information, to determine the research value [12–14].

3. Results

This study enrolled a total of 15 parents of children with moderate to severe persistent asthma. Their personal characteristics are shown in the Table 1. This study used content analysis to analyze data. After the analysis, there were no new themes and the data analysis reached saturation. Therefore, the collection of data was terminated. This study summarized the self-management experiences of families with children with moderate to severe persistent asthma in Hualien, and included six themes: (1) knowledge of asthma; (2) other issues related to asthma; (3) use of asthma medications; (4) issues related to physical exercise; (5) self-care in daily life; and (6) prevention and handling of asthmatic episodes.

3.1. Theme 1: knowledge of asthma

Mothers did not understand what asthma is and hoped that their children could understand how it takes place, how it develops, the symptoms, and whether it can be cured. The theme of knowledge of asthma included five subthemes: (1) differences and correlations among asthma, colds, and allergic rhinitis; (2) why asthma occurs; (3) classification of the severity of asthma; (4) common allergens of asthma; and (5) prognosis.
3.1. Differences and correlations among asthma, colds, and allergic rhinitis

Mothers and children had no idea what asthma is, and thought that it is just like a cold or allergic rhinitis. They only know that there is a “wheeze” sound when children experience an asthmatic episode.

Case 15: The mother indicated that her child usually experienced nasal congestion, a runny nose, and sneezing, and thus could not concentrate in class. Recently, her child started coughing and experiencing symptoms similar to those of cold. She said, “The doctor diagnosed her with asthma. I only know that she has allergic rhinitis. I really don’t know what caused her allergy.”

3.2. Why does asthma occur?

Children could exercise normally when they did not have an asthmatic episode. Parents had no idea why their children had asthma.

Case 14: The mother indicated that her child usually experienced an acute asthmatic episode and was healthy when there was no asthma attack. Therefore, she wondered why her child had asthma, because he had won a marathon, could exercise normally, and could even swim.

3.3. Classification of severity of asthma

Mothers suggested that severe asthma should be a situation where their children could not breathe at all. Therefore, they did not understand how severe their children’s asthma was.

Case 6: This mother suggested that her child suffered from mild asthma because he has never told her that he could not breathe at all. The mother suggested that the asthma of her child was an allergic reaction instead of real asthma, because her child did not experience severe symptoms. She said, “The doctor told me that he has asthma. To my knowledge, patients with asthma die and cannot breathe at all if they do not take ‘medicines’.”

3.4. Common allergens of asthma

Mothers were unaware of the allergens of asthma and suggested that their children should understand which allergens lead to asthmatic episodes.

Case 5: The mother indicated that she had no idea which allergens lead to asthmatic episodes, and suggested that her child should know them.

3.1.5. Prognosis of asthma

Children usually controlled their asthma by taking medication. The mothers worried whether their children’s asthma could be cured and whether they had to continually take medication.

Case 4: The mother originally thought that her child’s asthma was cured because she had not experienced an asthmatic episode for a while. The doctor had told her previously that if her child could develop good health, her immune system should be strong enough to prevent asthmatic episodes when she grows older.

3.2. Theme 2: other issues related to asthma

Mothers suggested that the symptoms of asthmatic episodes in children were similar to those of colds and allergic rhinitis. Therefore, it was hard to differentiate between them, which tended to delay treatment for asthma. They hoped that their children could understand the differences in the symptoms of these three conditions. They also wanted to understand why smoking and sandstorms could lead to asthmatic episodes, as well as obtain information on improving immunity to reduce asthma attacks. Other issues related to asthma included two subthemes: (1) allergen specific immunotherapy (ASIT)-related information; and (2) asthma-related alternative treatment information.

3.2.1. ASIT-related information

Mothers hoped that ASIT could reduce asthma attacks in their children.

Case 4: The mother had heard that ASIT could help cure or prevent asthma episodes. She hoped that her child could be cured after receiving ASIT. The mother suggested that it was really a burden to take care of a child with asthma.

3.2.2. Asthma-related alternative treatment information

Long-term medication is required to control asthma. Mothers were concerned this could physically damage their children or prevent them from growing tall. They hoped that their children’s allergic reactions could be improved and asthma attacks reduced with alternative treatment.

Case 15: The mother indicated that she would like to let her child try Chinese medicines, because the child’s condition had not improved after taking Western medicines for a long time. The mother thought that her child had not grown much in height or gained weight. She hoped that taking Chinese medicines could help her child become better.

3.3. Theme 3: use of asthma medicines

Mothers usually instructed children in the importance of taking medicines, as well as when to take them, in order to make children learn to quickly take the medications and determine when to use inhaled medications. Moreover, they hoped that their children could develop the habit of taking medicines regularly. However, mothers also worried that long-term medication use could affect the physical health of their children. However, children had to take medicines to alleviate the symptoms of asthma. Therefore, the mothers tended to feel conflicted. The theme of use of asthma medicines included four subthemes: (1) purpose and side effects of oral asthma medicines; (2) the timing of and correct way to use inhaled asthma medicines; (3) taking asthma medicines quickly and regularly; and (4) side effects of long-term asthma medication.
3.3.1. Purpose and side effects of oral asthma medicines
When children stopped feeling uncomfortable or experienced asthma attacks, mothers worried that they took too many medicines and experienced side effects. Mothers spontaneously discontinued medication, but the children started to feel uncomfortable again.

Case 4: The mother said, “Sometimes, it is difficult for me to observe whether she is experiencing any asthma attacks. Therefore, I will not ask her to take asthma medicines when she is fine because I am not sure whether the side effects of the medicines will affect her growth.”

3.3.2. Timing of and correct way to use inhaled asthma drugs
Mothers asked children to take medicines to school. They hoped that children could take the medicines quickly and correctly when they felt uncomfortable.

Case 7: The mother said, “I think that my child knows exactly when she feels uncomfortable because she has had frequent asthma attacks since she was very young. I told her to use the inhaled medications and oral medicines prescribed by the doctor if she feels uncomfortable. At present, it is useless to ask her to take the spray and oral medicines with her to school because she forgets to use them.”

3.3.3. Taking asthma medicines quickly and regularly
Children usually did not take medicines regularly unless their parents reminded or assisted them. Parents hoped to cultivate their children’s habit of taking medicines regularly.

Case 3: The father hoped that his child could take medicines regularly or use inhaled medications when feeling uncomfortable, because tolerating the discomfort only worsened the symptoms. The father indicated that his child had been hospitalized frequently when the disease was not as stable as it is now. His child still had to use inhaled medications in the Emergency Room (ER).

3.3.4. Side effects of long-term asthma medication
Parents were afraid that long-term medication would affect the growth or renal function of their children.

Case 13: The mother indicated that she experienced a sense of powerlessness. She wondered why her child had to take medicines for a long time, because long-term medication has an adverse effect on renal function and medicine has been progressively developed. She felt that asking her child to take medicine harmed him.

3.4. Theme 4: issues related to physical exercise
Mothers reminded their children not to exercise strenuously, such as running. Some children complained about why they could not exercise, whereas others refused to exercise. Parents hoped that their children fully understood the guidelines on asthma-related physical exercise. The theme of issues related to physical exercise included four subthemes: (1) the definition of exercise-induced asthma and its causes; (2) types of exercise suitable for children with asthma; (3) guidelines on exercise in asthma patients; and (4) handling asthmatic episodes during exercise.

3.4.1. Definition of exercise-induced asthma and its causes
Parents suggested that every child breathes hard after strenuous exercise. They did not understand what exercise-induced asthma is and its causes. However, they reminded their children to avoid strenuous exercise.

Case 15: The mother said, “I tell my child not to run too much at school because she breathes hard and coughs after running. The doctor said that exercise can induce asthmatic episodes. However, not every child gasps for air after exercising, I don’t know the causes well. So I do not dare to let my child run a lot.”

3.4.2. Types of exercise suitable for children with asthma
Mothers understood that their children could not exercise strenuously. However, they did not understand which sports children with asthma could participate in.

Case 14: The mother said, “I do not let my child participate in strenuous exercise at school. However, I still let him participate in school activities, such as running and swimming. The coach of the track and field team wants to recruit him because he won first place in a marathon.” The mother had no idea whether to let her child join the track and field team.

3.4.3. Guidelines on exercise in asthma patients
When participating in activities, children sometimes felt uncomfortable owing to asthma attacks. Parents did not understand what to look for when their children exercised.

Case 9: The mother indicated that she intended to enhance her child’s pulmonary function in the past year to prevent asthma attacks. However, her child started to gasp for air after swimming less than 20 minutes. Therefore, the mother wondered whether swimming was suitable for her child.

3.4.4. Handling asthma episodes during exercise
When children experienced an asthmatic episode during exercise, parents let them stop exercising to rest. However, they did not understand other handling methods.

Case 7: The mother said, “There is a playground near our home. My child can ride a bike there. Sometimes, he likes to go outdoors to play. He will come home soon. However, after staying at home for 1–2 hours, he would like to play ball outside or go running. Because he does not usually exercise much, he gasps for air. When he does this, I ask him to stop exercising and rest at home.”

3.5. Theme 5: self-care in daily life
Mothers thought that they could not be with their children all the time. Therefore, they hoped that their children could develop self-care abilities to strengthen self-protection, avoid allergens, and control the environment. The theme of self-care in daily life included four subthemes: (1) physical care information in daily life for asthma patients; (2) control of the environment to avoid allergens; (3) emotional management to prevent asthma attacks; and (4) anti-mite product-related information.

3.5.1. Physical care information in daily life for asthma patients
Mothers wanted more guidelines on daily life issues for children with allergies.

Case 1: The mother hoped that her child could clean his room frequently and rinse his mouth with salt water when he had an uncomfortable feeling in his throat, to alleviate swelling and prevent transmission to others. Moreover, she also hoped that her child could wear a mask frequently, not eat ice cream in the summer, and quickly drink warm water when he feels cold.

3.5.2. Control of the environment to avoid allergens
Mothers paid attention to cleaning and dehumidifying the environment because their children had asthma. However, they did not know any other strategies to avoid allergens.

Case 13: The mother said, “When it rains, I turn on the air cleaner and dehumidifier for him. Usually, there is nothing much different I can do, except that I have to irregularly clean and dry quilts in the sun. I have no idea what else to pay attention to.”

3.5.3. Emotional management to prevent asthma attacks
Parents usually taught their children to control their emotions to prevent asthma attacks. They wanted to know
how to help the children learn how to control their temperament.

Case 13: The mother told her child not to get angry or laugh loudly; otherwise he may gasp for air because he suffers from asthma.

3.5.4. Anti-mite product-related information

Mothers purchased or intended to purchase anti-mite products because their children had asthma. However, they had no idea what the effects were.

Case 12: The mother said, “I don’t know why my child has asthma. I only know that he is allergic to mites because he had a blood test. I heard that there are some anti-mite products. I have no idea what their effects are.”

3.6. Theme 6: prevention and handling of asthmatic episodes

Sometimes, children did not tell their parents when they felt uncomfortable during asthmatic episodes. The reason may be that they did not understand their asthma. Parents could only take children to the hospital when asthmatic episodes could not be controlled by medication or inhaled medications. However, they had no idea when to take the children to the hospital. The theme of prevention and handling of asthmatic episodes included four sub-themes: (1) symptoms of asthmatic episodes; (2) maintaining calm behavior to avoid panic and actively seek assistance during asthmatic episodes; (3) timing for admitting children to the ER during an asthmatic episode; and (4) methods of preventing asthmatic attacks.

3.6.1. Symptoms of asthmatic episodes

Mothers observed children’s symptoms of asthmatic episodes. However, they could not do this when they were not with their children. Therefore, they hoped that their children knew the symptoms of asthmatic episodes.

Case 2: The mother hoped that her child could know when he had an asthmatic episode and immediately tell his parents, because sometimes they did not know their child was having an episode. Moreover, parents are not with the child all the time. By the time they find their child is experiencing an asthmatic episode, the child is gasping badly and has cyanotic lips and dark circles under the eyes.

3.6.2. Maintaining calm behavior to avoid panic and actively seek assistance during an asthmatic episode

Parents hoped that their children would not panic when they experienced asthma attacks at school, would know how to handle them, and would actively seek assistance from parents, teachers, and classmates. If parents did not know how to deal with asthmatic episodes, they usually took their children directly to the hospital.

Case 11: The mother suggested that her child should be able to take care of himself (e.g., drink more water, sit down quietly, and not exercise strenuously) or quickly tell school teachers, classmates, and daycare teachers when he feels uncomfortable at school.

3.6.3. Timing for admitting children to the ER during an asthmatic episode

When asthma worsened, mothers took their children to the hospital. However, parents had no idea when to take their children directly back to the emergency room after they returned home and the symptoms had not improved.

Case 8: The mother said, “I don’t know how to prevent asthma attacks. Last week, the doctor told me that he did not experience an asthma attack. However, in the afternoon when we returned home, I found that he had another asthma attack when he was sleeping. His condition was better at night. I really had no idea what to do because he had just seen the doctor.”

3.6.4. Methods of preventing asthma attacks

Mothers and children did not know how to prevent asthma attacks, because the symptoms were similar to those of colds and their children did not gasp. Therefore, they did not pay particular attention to them.

Case 1: When the child experienced an asthma attack, the mother did not know how to teach her child how to handle it or prevent it. The mother said, “My child does not understand what asthma is. He does not know that his discomfort is caused by asthma. He usually does not gasp and he only experiences it when he catches a cold. I can tell that he completely does not understand what asthma is. However, sometimes, he coughs without gasping when he catches a cold. Therefore, I have no idea what to do.”

4. Discussion

Hafetz and Miller [15] conducted a quantitative study to investigate the disease management of 18 children and adolescents aged 8–19 years, with chronic diseases (diabetes, asthma, and cystic fibrosis), from the perspectives of adolescents and parents to summarize several themes, monitoring-surveillance, monitoring-control through restrictions and observation, parental sense of duty and purpose, balance of control and youth autonomy, youth irritation with parental solicitation, and youth acknowledgement of parental role. Similarly, this study explored the disease management experiences of Asian parents of children with moderate to severe asthma, and found that parents also helped children control asthma through supervision, constraint, and observation. They perceived that it was their responsibility and obligation to assist children in controlling asthma. In Case 15, for example, the mother said, “I usually teach my child to avoid places where there are mites. Sometimes, I look around at school, especially in gym class. Children like to jump over the box horse and then lay directly on the floor. When I see my child lying on the floor, I yell at her. At the end of the school day when students tidy up the school, I remind her to wear a mask. I constantly remind her of every detail until she pays attention.”

However, in balancing parents’ assistance in the control of the disease with children’s autonomy, Western parents hope that their children and adolescents with chronic diseases can be free of their supervision to avoid becoming dependent on them and to become independent and autonomous in controlling the disease. Those results and the results of this study show differences between Asian and Western cultures. Although some studies indicated that children as young as 8 years of age are able to learn self-management of asthma and participate in health decision-making, some Asian parents feel that this age is too young to learn these guidelines and tend to protect their children more. Moreover, the disease is usually controlled under parents’ supervision. Fifty-three percent of parents indicated that they were relieved to have their children participate in the management and decision-making of asthma until they are at least 10 years of age. The mother in Case 5 said, “It is impossible for a young child to take care of himself. Although he has asthma, he does not have to pay particular attention to anything or do anything at home, at school or when he plays outside.” The mother in Case 14 said, “I completely protect my child because I still worry about him. Maybe I will let him take care of himself when he is in grade 4, 5, or 6. I still worry about him because he is naughty and very energetic now.”

Tzeng and Gau [16] showed that after parents knew what asthma was, and how to control the symptoms at home or in school from nurses, they could help their sick children learn how to self-manage their disease, even if the children were as young as
11 years of age. In Western countries, coping skill training programs for children with chronic type 1 diabetes have proven effective in both disease or glucose control and illness adaptation, even in young children. However, in Taiwan, there is a little evidence-based research related to children with type 1 diabetes and there are currently no intervention studies applying coping skill training programs for children. This may be related to cultural differences and needs to be explored further [17].

Results from a qualitative study by Laster et al [18], which focused on children and adolescents (aged 8–17 years) and their parents, showed that barriers to self-management in dealing with their disease included children’s health beliefs, parental health beliefs, lack of school support, insurance payments, and the effectiveness of communication with healthcare providers. Further study should explore barriers to self-management for ill children and their parents in Taiwan. Results from the research could be used for future intervention studies.

The researcher has been exposed to children with asthma and their parents at the study site in Hualien for 3–4 years, and found that parents are usually perplexed by the differences among asthma, allergic rhinitis, and colds. They have no idea which of these three conditions is affecting their children, which further affects the proper control of asthma. Therefore, this study authentically reflects the actual clinical status of the self-management experiences of families of children of moderate to severe asthma in Hualien. To understand parents’ need for information on desensitization and asthma-related adjunct therapy, the researcher conducted a quantitative study with Cheng et al [19] to investigate mothers’ experiences in assisting children with asthma in grades 1–3 in adapting to school. One of the themes was improving the child’s physical condition. The theme included three subthemes: (1) concern about long-term harmful effects; (2) attempts to improve the child’s physical condition using alternative treatment; and (3) undertaking allergy-reduction treatment. The results were similar to those in this study. Mothers worried that taking too many medications routinely could harm their children. They attempted other methods to improve the children’s physical condition and reduce asthma attacks, as well as reduce the amount of drugs taken. The results are also consistent with those in a qualitative study by Barton et al [20] of Australian parents’ experiences in caring for children with asthma.

The research results of this study can be used as a reference for health education instruction for families of children with moderate to severe persistent asthma in Hualien. The following suggestions are proposed based on the research results and lecture review [21]. Children’s health beliefs and self-management ability are significantly affected by their parents’ health beliefs. Therefore, during health education, medical and nursing personnel are advised to first clarify health beliefs with parents, in addition to developing a partner relationship between parents and main supporting caregivers, which would be beneficial to the development of the self-management ability of children with asthma. Theoretically, children aged ≥ 8 years old can learn disease self-care, but in an Asian culture, training in disease management may be more suitable for children aged ≥ 10 years old and they may be more motivated as well. Children aged 8 years and 9 years are still dependent on parents’ care and supervision. Therefore, during clinical care for children with asthma, it is necessary to take into account their ages and differences in needs for health education to provide them with individualized instruction.

Results from the literature show that the repeated, irregular asthma episodes are usually caused by misunderstandings about asthma and feelings of frustration due to ineffective treatment [4]. The distribution and accessibility of medical resources in Hualien are insufficient compared with western Taiwan [3]. Therefore, it is very important to teach families who have children with moderate to severe asthma how to deal with their disease and symptoms in self-management programs. This could also increase their ability to manage their disease, prevent asthma attacks, reduce medical fees, and decrease the rates of hospital admission and death due to asthma.

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