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When Control Exacerbates Distress: A Qualitative Study Exploring the Experiences of Hong Kong Chinese Parents in Caring for a Child with Asthma

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Abstract: Many parents have difficulty managing childhood asthma. In Hong Kong (HK), while medication is the primary form of treatment, traditional Chinese medicine is another favored option. In addition, HK follows a dual-track healthcare system, which may pose unique experiences for Chinese parents in childhood asthma management. This qualitative descriptive study aimed to explore the experiences of HK Chinese parents in caring for their children with asthma. Methods: Fourteen HK Chinese mothers of children (aged 3-10) suffering from asthma were purposively sampled to participate in individual, semi-structured interviews. A realist approach following conventional content analysis was used to interpret the interviews. Results: The mothers expressed feelings of uncertainty, fear of asthma crises, and searching for ways to cope. These feelings triggered various strategies to control their child's asthma. As long as the child's asthma symptoms recurred, the mothers' distress continued. Their distress was sometimes exacerbated by self-doubt and worries about whether they would receive adequate support from their family and healthcare professionals. Conclusion: Helping parents to understand their limits may help them be more open to varied aspects of their caregiving experiences, and thus to cope better. Psychological interventions together traditional educational training may help to alleviate parents' psychological difficulties.

Keywords: Parents; children; asthma; qualitative research; psychological distress; psychological adjustment

1. Introduction

Asthma is the most common chronic respiratory disease affecting over 235 million people worldwide [1]. The International Study of Asthma and Allergies in Childhood (ISACC), involving approximately 1.2 million schoolchildren worldwide, reported a global prevalence of asthma of 11.7% for children aged 6-7 years, and 14.1% for children aged 13-14 years, respectively [2]. Globally, as countries industrialize and more people adopt Western lifestyles, the prevalence of childhood asthma has grown by approximately 50% each decade. In China, the growth is even more pronounced [3], particularly in Hong Kong (HK), whereby the highest rate of prevalence occurs in children (10.2%); higher than that of other urban cities such as Beijing (6.3%) and Guangzhou (6.9%) [4].

Parents are the crucial caregivers and primarily responsible for managing their young child's asthma, which is challenging. During the pre-diagnostic phase, the unpredictably of asthma is characterized of its life-threatening nature and triggers distress in parents [5]. Further, parents typically report feelings of uncertainty and powerlessness at this stage [6]. Hence, in attempts to control their child's symptoms, they engage in a variety of asthma management activities, including complying with medical treatments [7], monitoring their children's symptoms, and coordinating

family routines to avoid environmental triggers [8]. This creates daily routines that may be complex and are burdensome [8-10].

Generally, when compared with parents of healthy children, parents of children with asthma experience a greater level of stress [11], anxiety, and depressive symptoms [12]. This is likely because even though some parents learn to strategically gain access to the healthcare system and confirm their children's diagnoses [6, 13], many still report ongoing fear and anxiety that their child's asthma may become life-threatening [14-16].

Asthma is regarded as effectively treatable when parents and their children are educated about the disease management and have access to high-quality healthcare services [1]. In HK, the healthcare system runs on a dual-track basis. Children who have been diagnosed with asthma receive asthma-related healthcare services on a fee-for-service basis in private clinics and hospitals, and/or on a subsidized basis in general outpatient clinics and public hospitals run by the HK Hospital Authority [17]. Very often parents need to decide which of the abovementioned healthcare services to choose when their child has an acute asthma attack or needs follow-up care.

Following the best evidence from the Global Initiative for Asthma, the primary treatment of childhood asthma is medication, including inhaled corticosteroids and short-acting bronchodilators [1]. Meanwhile, in HK, traditional Chinese medicine is another option for which the local population favors. In particular, traditional Chinese medicine is perceived to enable "curing the root of the problem" though slow to demonstrate outcomes, and Western medicine is "more powerful but sometimes too powerful with significant side effects" [18]. Hence, within these social structures of a dual-track healthcare system, and how HK Chinese parents perceive the problem, they may have unique experiences in caring for their children with asthma. Moreover, given the limited understanding of the state of asthma management among families in the Asia-Pacific region, the aim of the present study was to explore the experiences of HK Chinese parents in caring for a child with asthma.

2. Methods

Authors chose a qualitative descriptive design, deemed appropriate for exploring the experiences of individuals situated in a particular context that have received little attention in the literature [19]. A realist paradigm was employed in order to reveal social representations of truth, apart from what may be actual (including empirical), within the narratives of individuals' inner experiences [20]. A realist approach explores how individuals experience events as they occur, in the ways they occur; that is, what social structures (e.g., cultural, familial, and institutional) trigger actions [20].

The study took place at one Ambulatory Care Centre (ACC) under the Department of Pediatric and Adolescent Medicine in a public hospital in Hong Kong. The ACC is a specialist outpatient clinic where children aged 18 years or below who have been diagnosed with chronic respiratory diseases, such as asthma, allergic rhinitis, pneumonia and obstructive sleep apnea, can access medical consultation services provided by pediatricians, and receive education from an Advanced Practice Nurse. This setting was suitable because in the past six months, the majority of children with asthma, whom were under the care of the ACC, attended the emergency department at least once due to an asthma attack.

To achieve a purposive sample, inclusion criteria were parents living in HK who had children aged three to 12 years, and possessed a physician's diagnosis of asthma (International Classification Diseases – 10 codes J45, J46) as documented in their electronic medical records. In addition, the parents had to be: (a) between 18 and 65 years old, (b) fathers or mothers who designated themselves as primarily responsible for the daily care of their child with asthma, (c) living together with the

index child, (d) able to communicate in Cantonese, and (e) Hong Kong permanent residents. Exclusion criteria included parents of a child with asthma, whom had a mental and/or congenital problem. Purposive sampling was adopted to capture of wide range of experiences, to obtain rich information from parents engaged in childhood asthma management, and to gain in-depth understanding of the phenomenon.

2.2. Data collection

Participants were invited to complete a short survey to indicate their socio-demographic characteristics, personal and family history of asthma, and their children's clinical characteristics. Next, data were collected through individual face-to-face interviews in Cantonese. A semi-structured interview guide containing the following open-ended questions was used: (a) "I wish you would share your experiences in taking care of a child with asthma. What experiences do you think are most worthy of sharing? Which were the most memorable to you? And how did you feel at the time?" (b) "As a parent of a child with asthma, what do you do to take care of your child? (c) "What are the most challenging situations you have faced when taking care of a child with asthma?" (d) "What are the issues of most concern to you when taking care of a child with asthma?" This interview guide was designed by the research team and refined after a pilot test involving two parents of children with asthma. Prompts were used where necessary to encourage more detailed responses, such as, "Can you describe this in a bit more detail?" and "Please tell me more about…"

Interviews were conducted by the lead author who is a registered nurse with experience in pediatric care and had no affiliation to any of the participants prior to the study. Interviews were held in a private room of the ACC at a time convenient to the participants, and audio-recorded with the participants' permission. Field notes were taken to capture non-verbal cues within 24 hours of the interview. Each interview lasted between 45 to 75 minutes. Data collection continued until the research team determined that data saturation had been reached after 14 interviews.

2.3. Ethical considerations

Before the commencement of the study, ethical approval for this study was granted by the New Territories West Cluster Clinical Research Ethics Committee (reference number: NTWC/CREC/15042) and by the Human Subjects Ethics Application Review System of the Hong Kong Polytechnic University (reference number: HSEARS20150109001). The parents were reassured that their participation would not affect the healthcare services that their children received. Informed written consent was obtained from all participants. Childcare services were offered at the request of the parents, so that they could focus on providing interviews. In addition, the parents were informed verbally about the study aim and future publication in the scientific literature. All information was treated confidentially.

2.4. Data management and analysis

The interviews were recorded and transcribed verbatim in Chinese by two trained student assistants. The lead author further checked the transcripts against the audio-taped data for accuracy. Conventional content analysis was used to detect the manifest and latent meanings from the data [21, 22]. In this process, the audio recordings and transcripts were read several times to obtain a general understanding of the parents' experiences. Next, different segments of the text were fractured into meaning units and assigned a code. Codes were chosen to retain the core meaning of the participants' experiences. The codes were then grouped into patterns and labeled under subcategories. The subcategories were grouped into main categories representative of a process of the participants' experiences over time.

Interpretation followed ideas of metaphorical extraction, which means that the codes, subcategories, and categories drew from the direct meaning of the extracted text (denotation) and,

more importantly, from the contextual relationship between the text and the context of the whole interview (connotation) [23]. A further comparison of one part of a participant's story was made with parts of the stories of other participants, and each interview with all interviews as a whole [23]. Data analysis software was not adopted. Identified codes with core meaning of the participants' experiences were extracted from the transcripts to an excel file for subsequent levels of analysis.

Rigor was achieved through a process of reflexivity and documentation of all analytic decisions in an audit trail. The lead author (Y.Y.C.) is a registered nurse in HK, who sought the help of the research team (all authors) to examine her role and question possible bias throughout analysis of the data. Notably, all team members were nurses with clinical expertise in child and adolescent health. The lead author (Y.Y.C.) and one of the co-authors (Y.W.M.) are bilingual in English and Chinese. For credibility, initial codes from the first three interviews were translated from Chinese to English and independently coded by the lead author (Y.Y.C.) and an experienced qualitative researcher who is a native speaker of English (D.L.). The translation was carried out by a bilingual professional and was double-checked by the lead author (Y.Y.C.) and another qualitative researcher (Y.W.M.). To ensure plausibility, this co-author (Y.W.M.), together with the lead author (Y.Y.C.), independently scrutinized the codes and sub-categorizations from all of the translated transcripts. Regular meetings of the entire research team (Y.Y.C., D.L, and Y.W.M) helped to resolve any differences in coding and to refine the analysis to determine the final categories. Last, transferability was attained by comparing the key findings with existing literature about parents of children with asthma and other similar chronic illnesses. Further, raw excerpts of the data, which exemplify the interpretations, will allow readers to assess how results may be transferable to their contexts.

3. Results

Despite attempts to recruit fathers, a total of 14 parents were (only) mothers, whom participated. All of the participants identified themselves as their child's primary caregiver. During the interview period, one mother withdrew from the study due to health problems related to her pregnancy. Among the participants (age range = 30-54 years), two were working mothers and the rest were housewives. Nearly half of the mothers (number of participants (n) = 6) had a personal history of asthma. Four mothers reported that the child's father (n = 3) or the child's older brother and sister (n = 1) also had asthma. The children (age range = 3-10 years) were diagnosed with asthma at the preschool age (range = 6 months-5 years). As of the interview period, eight of the children suffered from asthma symptoms at least one day per week (see Table 1).

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186 Table 1. The characteristics of the parents interviewed and their children

Parent's information				Child's information			
Participant	Relationship with the child	History of asthma	Other family members' history of asthma	Gender, age	Age of asthma diagnosis	Current use of ICS for at least 6 months	Average number of days with asthma symptoms per week in the past 30 days
01	Mother	No	Child's elder brother and sister	Male, 4	2	No	No symptoms
02	Mother	No	Father	Male, 6	5	Yes	1 day with symptoms
03	Mother	No	No	Male, 10	4	Yes	1 day with symptoms
04	Mother	No	No	Female, 5	2	Yes	5 days and 5 nights with symptoms, 5 days requiring reliever therapy
05	Mother	Yes	No	Female, 4	3	No	No symptoms
06	Mother	Yes	Father	Female, 3	2	Yes	2 days with symptoms, 2 days requiring reliever therapy
07	Mother	Yes	No	Female, 6	2	Yes	No symptoms
08	Mother	No	No	Female, 8	2	Yes	No symptoms
09	Mother	Yes	No	Male, 5	2	Yes	No symptoms
10	Mother	No	Father	Male, 4	1	Yes	4 days and 4 nights with symptoms, 4 days requiring reliever therapy
11	Mother	No	No	Male, 7	1	Yes	2 days with symptoms, 2 days requiring reliever therapy
12	Mother	Yes	No	Male, 9	3	Yes	1 day with symptoms , 1 day requiring reliever therapy
13	Mother	No	No	Male, 3	3	Yes	No symptoms
14	Mother	Yes	No	Male, 8	3	Yes	2 nights with symptoms, 2

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	nights requiring reliever therapy

Note. ICS = inhaled corticosteroid.

Reliever therapy refers to the inhaled short-acting bronchodilators for a quick relief of the child's asthma symptoms.

In this study, the parents' experiences (all mothers) reflected a psycho-social process of five categories: (1) uncertainty and fear in controlling asthma when asthma was diagnosed; (2) the reoccurrence of the asthma, leading to a search for ways to endure the condition; (3) working through the challenges of controlling asthma; (4) ongoing emotional distress as the asthma continues; and (5) learning to manage asthma better after accumulating experience. Note that symbols and numbers represent different participants (M = mother's interview number, child's sex and age).

*3.1. **Category one:** Uncertainty and fear in controlling asthma when asthma was diagnosed*

Participants began to describe the occurrence of asthma attacks when their child was of preschool age (two to three years old), as something that "just happened all of a sudden". The high-pitched wheezes, which they described as "he he" sounds, together with other flu-like symptoms, recurred with no recognizable patterns. The participants' uncertainty further intensified when the doctor's diagnosis was not asthma, as some parents suspected, but "flu" or "bronchial hypersensitivity." Without a definite diagnosis, the participants found it difficult to make sense of what was happening to their child:

> *The doctor said that he [the son] didn't have asthma, but bronchial hypersensitivity, and just delayed the diagnosis.… Then, was the so-called 'bronchial hypersensitivity' that my child previously had just in fact the same as asthma? I really don't know. (M2, son aged 6)*

When children began struggling to breathe, and had difficulty speaking, participants realized that this scenario was a medical emergency. They perceived that their child's life was in danger:

> *She just wheezed so seriously, and her rib cage was just dented in, just like, losing her breath and saying 'hah mommy, hah mommy…' when you were holding her. I was definitely in great fear … when we [she and the child's father] arrived at the hospital. I did not dare to release my arms. (M6, daughter aged 3)*

*3.2. **Category two:** The reoccurrence of the asthma, leading to a search for ways to endure the condition*

Subcategory 1. Enduring suffering during acute asthma attacks

All participants reported that their child visited the emergency department due to an asthma attack, at least once, during the past six months. Five children required hospitalization for three to five days. According to the hospital's policy, only one parent, preferably mothers, was allowed to stay with the child during hospital admissions. Some of the participants witnessed the efforts of clinicians to control asthma, such as by administering bronchodilators via aero-chambers or nebulizers, or by using oral suctioning to clear the airway. They reported feelings of being "heartbroken" and "helpless" when witnessing their child's struggles. One participant became emotional when she described the scenario:

> *I was staying outside the curtain and watching how the doctors used the suction tubes to suck the phlegm out and he was shouting 'Mommy! Mommy! Help me! Help me!' He was crying so intensely; I was sitting in a chair and just could not stop crying myself. The tears, it was … I indeed felt too heartbroken, it's a kind of feeling of being stabbed by a knife…. I felt that I was useless, helpless too. (M11, son aged 7)*

Many participants described the experience of staying overnight in hospital wards without adequate facilities for rest as "the toughest experience… to endure". A few participants perceived that the treatment offered in the hospital, for example inhalation therapy, was something that they

could have done themselves at home. As such, they reported reluctance to go to the hospital again unless they perceived that their child "was on the verge of death."

Subcategory 2. Enduring suffering whenever asthma recurs

Given that a child's asthma attacks could recur unpredictably, the suffering that the participants endured continued. In general, when participants suspected something "different" about the sound of their child's breathing, they took a series of prompt actions, such as close monitoring of their child's breathing, giving symptom-relieving medications, and taking him/her to a nearby clinic for immediate medical advice or to a hospital to prevent life-threatening consequences. Their child's repeated coughing and wheezing prompted some participants to remain awake all night, to monitor their child's breathing and to administer the inhaler in a timely manner. One participant said that she had not been able to sleep well for years due to her son's asthma:

In these three years, when I hear [my child] cough, I will get up at once. I am afraid that he'll have [an attack] again. The last time [he had an attack], I simply watched my child suffering, and with great fear. He just kept on struggling and crying, so that's why I have to take care of him for the whole night, and that's why I cannot sleep well now. Yes, I sleep badly, until now during the night I'll be in great fear… (M10, son aged four)

Subcategory 3. Distress from searching for the reasons for their child's asthma

Searching for the reason why their child suffered from asthma was important, especially for participants with no family history of asthma. Some of the participants did this by comparing their child with his/her siblings, or reflecting on whether they had paid enough attention to their child's early development. For one participant, the lack of an explanation for their child's asthma was the source of great distress:

I was in great psychological distress; [I] wanted to just cry and cry, because why did I give birth to a child to have this [disease]? (M13, son aged 3)

3.3. Category three: *Working through the challenges of controlling asthma*

Many of the participants gave detailed accounts of what they had done to control the asthma, which was very burdensome.

Subcategory 1. Staying alert and preventing asthma attacks

All participants could list several asthma triggers: second-hand smoke, burning incense, fluffy toys, dust, perfume, cold air, and cold food and drinks. Some of them monitored these triggers, and others firmly prevented their children from coming into contact with them. Furthermore, many of the participants believed that the "blue inhaler" was a life-saving bronchodilator that had to be administered regularly overnight to prevent nocturnal asthma attacks. A few of them were very vigilant using the "blue inhaler." One participant shared her strategy:

I won't offer the blue inhaler frequently at one go. First [I'd] try one puff; if he's okay then I'd stop. If he's not that okay, then I'd offer him another puff. I mean I try to avoid giving too much medication to my child. Then, after one to two minutes, I'd ask him whether he felt easier to breathe... (M14, son aged 8)

Subcategory 2. Keep trying different ways to get control of a child's asthma

A few of the participants explored different kinds of complementary and alternative dietary therapies, such as "boiled crocodile meat soup" (M6, M7, M9, and M14); "boiled gecko soup" (M7); "boiled fritillary bulbs" (M7, M14), and moxibustion therapy (M14) (a non-invasive procedure that involves burning herbal materials on or above the skin at accu-points to alleviate symptoms). All of these soups or herbs were considered effective over the long term at strengthening a child's health to improve his/her asthma. As one participant stated:

> *It's just like doing homework – you've got to do it every single day; otherwise you can't see the effect on him [the child]. (M11, son aged 7)*

Subcategory 3. Working through frustration due to the unpredictability of asthma

Despite the strenuous efforts made by participants to control their child's asthma, many expressed disappointment when asthma recurred after participants had come to believe that it had "disappeared" (remission of symptoms after a year). Repeated hospital admissions led the participants to lose confidence and to feel powerless. One participant stated:

> *In the last year I was thinking it should be alright. But then, all of a sudden, it [the asthma] came again… not less than a week later, [she] wheezed and was admitted again. Then, [she] had the oral steroids again… (M4, daughter aged 5)*

Another participant reflected that she had "overlooked" the recurrence of asthma:

> *Asthma is something that I can't control. Why, when he [her child] got an attack, did it come all over again? (M3, son aged 10)*

Subcategory 4. Conflicts with others surrounding daily asthma care

A few of the participants described their concerns as misunderstood by others. This was particularly common, as their children appeared mostly asymptomatic. They often heard others say: "There's no need to be that nervous" or "It's only a cough."

Misunderstandings were more worrisome when they involved family members. For instance, some of the participants would be questioned by their spouse for hastily seeking medical advice for their child's flu-like symptoms. Some fathers, who were smokers, might not comply with instructions to keep their child away from tobacco smoke. Further, extended family members were expected to comply with house rules to avoid potential asthma triggers, such as avoiding fried snacks or cold drinks. When these rules were broken, conflict ensued. One participant expressed her resentment:

> *I told them [the extended family members], please don't let him [her child] have any junk food or soft drinks, okay? But sometimes they just let my child drink and say something like, "Come on, wouldn't it be too harsh for a kid to not enjoy cold drinks?" But I said, "It'll be even harsher for me if you attempt to let the child try it once! (M9, son aged 5)*

Subcategory 5. Searching for the best possible healthcare service suitable for the family

When a child suffered from an acute asthma attack, most of the participants immediately sought medical help from the emergency department of a public hospital. However, they stated that this did not guarantee that their child would receive immediate treatment. As one participant recalled:

When the triage nurses spot that your child's oxygen saturation is fine, they obviously won't act fast. (M8, daughter aged 8)

On the other hand, some of the participants appreciated the efficiency and comprehensiveness of the medical investigations provided by private hospitals but were deterred by the cost. One participant stated:

If it's financially affordable, I'd rather choose a private hospital for my child. (M6, daughter aged 3)

In addition, finding a pediatric respiratory specialist in HK was challenging. One participant recalled that it was "by luck" that she met a private practitioner who immediately offered inhalation therapy to her child. She further emphasized:

In fact it is really difficult for the parents. First, I didn't know where I should find [the specialist]; second, who is a good one? (M12, son aged 9)

Deciding on what was "best" was further complicated by differences in the treatment strategies offered by the public and private sectors. For instance, one participant reported inconsistencies in the method of delivering inhaled bronchodilators between the private clinic (via nebulizers, which she had been taught to use) and the public hospital (via aero-chambers). She said that a nurse working in a clinic of a public hospital once told her the following:

As you didn't really know how to use it [aero-chamber], this led to the fact that he [the child] couldn't take in all the medication powder.' But that was not the case. (M10, son aged 4)

3.4. Category four: Ongoing distress as the asthma continues

Situations that generated ongoing distress were not at the forefront of participants' thoughts but became prominent as their stories unfolded.

Subcategory 1. Worries about the effects on their child's learning and development

Most of the participants expressed worry and concern about the potential negative impact of asthma on their child's learning and development. Specifically, their child's frequent absence from school was felt to threaten their child's academic performance and social interactions with peers. Furthermore, many participants were worried about the potential detrimental side effects of the chronic use of inhaled corticosteroids on their child's development. These include appetite loss, facial puffiness, and impaired growth (M1, M7, M9, M10, M12). In addition, a few participants (M10, M11, M13) questioned whether their child would develop resistance to antibiotics.

Subcategory 2. Helplessness when losing the fight against asthma

Another concern that was worth noting was the participants' strong desire to not only control, but to "just get rid of it [the asthma]," given that the asthma symptoms had recurred throughout the years. Those participants believed that they possessed the gene for asthma, and perceived asthma as "something that you must carry for the rest of your life, carrying over to their child's next generation." One participant stated:

If you had this disease, you dare not to try to have your own family, right? (M5, daughter aged 4)

Some of the participants described a few critical moments when they encountered feelings of helplessness and a sense of "being trapped," or feeling as if "everything was just simply offensive to me." That moment occurred when the child kept wheezing despite attempts to prevent it, and when

the child was too small to voice his/her complaints. One participant projected her anger onto her child in the following way:

> *Sometimes [I] would project my negative emotions directly to him [the child] and say, 'Oh! You see, other children are good at all sort of things, but why did this [the asthma] happen to you? (M3, son aged 10)*

Subcategory 3. Despair related to insufficient support

Of the 14 participants, two recounted feelings of hopelessness and overwhelming distress when living with a child suffering from asthma. Both mothers became emotional and occasionally had to pause during the interview. One of them, who found it difficult to ask for support from others, described her feelings of despair in the following way:

> *You seem to have no energy every day, but deep in your heart you wish to share everything with others. But you don't know who you can talk to, as once you share you don't know how others would regard you. (M7, daughter aged 6)*

The lack of spousal support triggered another participant to contemplate suicide. She recalled:

> *From the beginning till now, his dad wasn't involved in anything about the care. [He] simply blamed me for not doing well enough. When she [the child] was two to three years old, she just cried for the entire night.… No matter what you did, it just failed. I was not sure what she needed! Every night was the same, and then you ... you definitely had the feeling that [you] wanted to jump from [a] height with the child. (M4, daughter aged 5)*

3.5. Category five: Learning to manage the asthma better after accumulating experience

Subcategory 1. Asthma care becomes easier when the asthma improves

Stressful experiences of childhood asthma care was emphasized by most participants. However, some of the participants, whom had at least two years of experience caring for a child with asthma, shared positive experiences. These participants became familiar with the nature of the asthma and learned how to differentiate its symptoms from other illnesses. They shared such thoughts as, "I have full confidence now" and "asthma is not a big deal to me." In this regard, their emotional distress and the challenges that they faced in caregiving were mitigated by newly formed positive perceptions that came from learning to manage asthma.

Subcategory 2. Building support with others

Multiple sources of support within the hospital, including patient support groups and follow-ups by specialist nurses, were highly valued by the majority of participants. When the responsibility for asthma management was eventually shared with their partners, they expressed relief and were less vigilant about monitoring their children. In addition, peer support helped the participants to ventilate their emotions and concerns. One participant expressed her appreciation of this mutual support:

> *I felt glad that I have a friend whose son has asthma, as we're all in the same boat. We chat a lot, and we share [our thoughts and feelings] with each other. It's a very good way, as we are all up against the [same] difficulty. (M12, son age 6)*

Subcategory 3. Learning to live a normal life

As the children grew older, their asthma symptoms became less severe. The participants described caring for a child with asthma as being "exactly the same as caring for other ordinary children." One participant with a 10-year-old son remarked:

> *You need to take a long time to understand ... but once you accept the fact that the child has asthma, face it with an open mind and accept it, you'll feel much happier. (M3, son aged 10)*

4. Discussion

To the best of our knowledge, this is one of a few qualitative studies to reveal the unique experiences of HK Chinese mothers in caring for a child with asthma, revealing that they experience significant psychological distress and managing their children's asthma in many different ways. Consistent with the findings of other studies [16, 24], the parents of children with asthma in this study expressed feelings of uncertainty and fear when seeking emergency care services, and worried extensively about the recurrence of the asthma attacks. They also worried about the impacts of asthma on their child's learning and future development [25], the side effects of medications [26], and the risk of drug dependence [26].

In this study, the parents stated that a lack of support from their partners exacerbated their distress, which is line with the findings in other studies on HK Chinese families rearing children with chronic and behavioral health problems, such as eczema [27], autism [28], and attention deficit hyperactivity disorder [29]. Moreover, as reported elsewhere, the parents in this study mentioned that conflicts with family members arose over the management of the asthma, such as when family members held different perceptions of how to handle the asthma symptoms, and when there were disagreements over the asthma management routines at home [30, 31].

However, in contrast with the findings of other studies, the distress of the HK Chinese mothers in this study was not necessarily resolved with emergency medical care for their child's asthma attacks [5], nor from being involved in treatment decisions [32]. Rather, some participants reported being heartbroken and continued to express some degree of helplessness and self-blame for long periods of time. This process was marked by a tendency to negatively evaluate their role as parents, the asthma prognosis, the adequacy of family support, and the adequacy of the healthcare system as a whole. In particular, participants' perceptions of guilt appeared more pronounced than that of parents of children with asthma in other studies, who similarly perceived an inability to safeguard their child's health [6, 33, 34]. Authors posit that Hong Kong parents may define the problem of asthma differently, and choose multiple behavioral options, due in part, to implicit cultural beliefs that their work may "cure" asthma one day.

In the present study, the participants applied various strategies to control asthma, such as searching for the root causes of the asthma; avoiding environmental triggers of the asthma; using a "trial-and-error" approach to finding the most appropriate healthcare service, similar to the "doctor shopping" found in many countries [35]; and maintaining heightened vigilance of their child's health condition. While these control strategies worked in the short term, the participants often could not fulfill their desire to control asthma permanently due to its unpredictability and recurrence, and perhaps, persistent beliefs that they ought to be able to control or "cure it." Hence, this desire may have exacerbated their psychological distress and created overwhelming crises, which led a few participants to report a sense of extreme despair with suicidal ideations early on in the process of adapting to their child's asthma.

In fact, the parents in the interviews might had gone through the process of excessively evaluating unwanted emotional experiences and making deliberate efforts to control or escape experiences, which could lead to greater dysfunction (e.g., managing childhood asthma ineffectively) and increased distress. Indeed, self-blame can be regarded as a maladaptive emotional

control strategy that allows individuals to avoid difficult thoughts and feelings when a stressful event occurs [36].

This study has several limitations. The diversity of the sample of participants was limited as the recruitment was conducted in only one study hospital and no fathers were recruited in this study. Further, the mothers who were interviewed had been recruited in an ACC of one public hospital in HK, so that their child had at least one experience of being treated by emergency care services due to a life-threatening asthma attack. Hence, the caregiving experience reported by the mothers in this study may not be transferable to other parents of children with less severe asthma.

Despite these limitations, this study adds an empathetic and detailed understanding of the experiences of HK Chinese parents who are caring for a child with asthma. In particular, this study has implications for clinical practice, revealing that healthcare providers should demonstrate more empathy and attention to parents with young asthmatic children. Structured asthma education programs that offer adequate information on asthma treatment and skills training, in addition to the management of symptoms, might be helpful to parents [37, 38]. More importantly, this study indicates a pressing need for psychological support. Psychological interventions that place a major emphasis on developing acceptance and mindfulness, such as Acceptance and Commitment Therapy [39] and mindfulness-based therapies [40], may be able to support parents. More mixed-method investigations are warranted to understand the accounts of parents, as well as measurements of their psychological processes, when managing their child's asthma.

5. Conclusions

In summary, this study highlights the substantial psychological distress experienced by HK Chinese parents in caring for their children suffered from asthma. Such distress was prominent when encountering an asthma crisis or when asthma symptoms recurred; further exacerbating their desire to take control over the asthma. Considering parents' desire to achieve a cure of their children's asthma, and the unpredictability of asthmatic crises, helping parents to understand their limits of control may support them to better copes. The findings of this study suggest that addressing parents' psycho-social needs may facilitate them to better manage their children's asthma conditions.

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