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Original Article

Burden among caregivers for children with asthma: A mixed-method study in Guangzhou, China

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ARTICLE INFO

Article history:

Received 4 June 2015

Received in revised form

2 September 2015

Accepted 29 October 2015

Available online 10 November 2015

Keywords:

Child with asthma

Caregiver burden

Qualitative study

Quantitative study

ABSTRACT

Objective: Research suggests that caregivers of children with asthma experience a substantial amount of stress, though no comprehensive study examines this problem. Here we both quantitatively and qualitatively examined the burden on caregivers of children with asthma. **Methods:** Surveys were administered to 138 caregivers of asthmatic children by convenience sampling. The Zarit Caregiver Burden Interview (ZBI) was used to assess the degree of caregiver burden. In addition, 13 qualitative semi-structured interviews were carried out via purposive sampling and were used to explore the perception of caregivers. SPSS and content analysis were used to analyze quantitative and qualitative data, respectively.

Results: We found that caregiver burden (mean = 31.56 ± 14.19) ranged from 24% with no or mild burden, 52% with mild to moderate burden, 22% with moderate to severe burden and 2% with very severe burden. Caregiver burden was also assessed as 5 different dimensions. Self-criticism ranked most burdensome (2.09 ± 1.05), followed by sacrifice (1.57 ± 0.94), embarrassment/anger (1.30 ± 0.80), dependency (1.21 ± 0.77), and lastly, loss of control (1.20 ± 0.84). The highest individually scored item on the ZBI was “fear of the future of the relative” (mean = 3.04). Interviews of caregiver burden were summarized into three main themes, namely: 1) life is too chaotic; 2) negative emotions; and 3) gaps in the medical support system. **Conclusions:** These findings expand our understanding about the burden caregivers of children with asthma face, and may help to propose targeted strategies to help caregivers adapt to their roles, and maintain and promote the health of themselves and their families.

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1. Introduction

Asthma has become the most serious respiratory disease worldwide, and its prevalence continues to rise [1]. The

condition adversely affects children both physically and mentally. The first global report from the International Study of Asthma and Allergies in Childhood (ISAAC) reported in 2013 that the current prevalence of asthma in 13–14-year-olds was 14.1%, and 11.7% in 6–7-year-olds [2]. A 2010 study in the

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Peer review under responsibility of Chinese Nursing Association.

<http://dx.doi.org/10.1016/j.ijnss.2015.10.004>2352-0132/Copyright © 2015, Chinese Nursing Association. Production and hosting by Elsevier (Singapore) Pte Ltd. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

United States estimated that seven million children aged 0–17 years had asthma, corresponding to a prevalence of 9.5% [3]. The National Cooperative Group on Childhood Asthma in China organized a nationwide, cross-sectional survey conducted in 43 cities in China between 2009 and 2010. The study showed that the prevalence of childhood asthma (aged 0–14 years) was 2.32%, with a cumulative incidence of 3.02%. These figures were 50.6% and 52.8% higher, respectively, compared to 10 years ago [4]. In Guangzhou, China the prevalence of self-reported asthmatic children has reached 6.6% [5]. Due to the continuously rising prevalence of childhood asthma, diseases associated with asthma are also increasing [6]. The impact of asthma is reported to limit children's activities even more seriously than epilepsy [7].

Recent developments in medical care have changed the treatment of asthma from hospitalization to ambulatory treatment. Consequently, family care has become the most important part of treatment. Nearly all treatment responsibilities have fallen onto parents, while their physical, mental, and social lives are seriously affected. Family caregivers need to also deal with the heavy economic burden created by the recurrent attacks of asthma and routine treatment for a long term. Due to long-term, challenging, and costly care work, family caregivers suffer from a relatively heavy burden [9–13]. Studies indicate that mothers of asthmatic children have a higher level of anxiety and depression than those without children with chronic diseases [8]. High levels of caregiver burden can also have considerable adverse effects on patients [7,14,15]. Previous studies found that caregivers' stress and depression could predict increases in children's inflammatory profiles over time [16], decrease adherence to asthma medications, and increase visits to the emergency department [10,14]. A more thorough examination of burden among caregivers of children with asthma is therefore warranted.

Most studies focusing on the burden on caregivers of children with asthma have been nearly all quantitative in nature [10–12,17], and are unlikely to adequately communicate caregivers' inner thoughts and feelings. The difficulty arises because human emotions are hard to examine [18]. Further, quantitative studies rely solely on scales where average changes are reported, and do not identify individual differences [19]. Qualitative studies can be applied to supplement the limitations of quantitative studies, and vice versa [18]. By combining these two types of studies, researchers can rule out alternative explanations for their findings and pose questions that would not be tested by one approach alone [20]. The complementary approach builds a richer picture and a more coherent conclusion [19]. Here we carried out a quantitative investigation with surveys, complemented with qualitative interviews in order to more thoroughly examine burden among caregivers of pediatric asthma patients.

2. Material and methods

2.1. Participants

All participants were recruited from the pediatric clinics of the top three hospitals in Guangzhou, China, from August 2014 to

January 2015. A convenience sampling strategy was used to select participants. We then used purposive sampling to recruit a subset of caregivers who looked anxious or who frequently consulted about the disease. These individuals were invited for in-depth individual interviews. Although purposive sampling may be subjective and can lead bias results, it is the most efficient way to extract the subjects who can provide the largest amount of information concerning the subject at hand.

Interviews ended when the data met the criterion of saturation. Inclusion criteria included: 1) caregivers of patients who were not over 14 years old and had a clinical diagnosis of asthma; 2) caregivers could clearly express their inner thoughts and experiences; and 3) signed informed consent forms. Exclusion criteria included: 1) caregivers concurrently served as a caregiver for another family member; 2) caregivers had psychological or physical disorders that affected their ability to communicate; and 3) caregivers had extreme trauma in the past three months.

2.2. Data collection

2.2.1. Questionnaires

The questionnaire for the qualitative part consisted of a demographic sheet and a written Zarit Caregiver Burden Interview (ZBI). Demographic information was collected for both caregivers and asthmatic children. The ZBI was developed by S.H. Zarit in 1980, and has subsequently been translated into several different versions and used widely worldwide [21]. We utilized the Chinese version of the ZBI translated by Wang et al. [22] in 2006, where they demonstrated a high internal consistency (Cronbach's α 0.87), validity, and reliability [23]. The Chinese ZBI consists of 22 items and has been divided into five main factors, which were adopted for Chinese caregivers, including Sacrifice, Loss of control, Embarrassment/Anger, Self-criticism, and Dependency [23]. Higher scores indicate heavier caregiver burden. Although the ZBI scale was developed to measure burden among caregivers of people with dementia, it has also been used in patients with heart failure [24], stroke [25], cancer [26], and pediatric asthma [13].

2.2.2. Interviews

In a subset of questionnaire participants, a semi-structured interview was also conducted. Two trained researchers performed the interview in a private setting, and lasted for 30–45 minutes. The entire interview was video recorded. Facial expression, tone, and body movement were noted to help researchers more thoroughly understand their feelings. Participants were encouraged to express their deep feelings as much as possible without any leading questions. All interviews were guided by a semi-structured interview guide, which was based on literature reviews and team discussion. All interviews began with the following questions: "What was your feeling when the doctor told you that your child had asthma?", "What concerns you the most when you care for your asthmatic child, and how?", "Can you tell me the biggest challenge you face when caring for your asthmatic child?", "What sort of support do you feel you need from the medical system?". Responses were used to further probe

their experiences. For example, “You responded that a relative depends on you. Can you tell me more about that?”

2.3. Data analysis

Quantitative data were analyzed using SPSS version 19 (SPSS Inc., Chicago, IL, USA). Descriptive statistics were used to assess caregivers' demographic information and mean ZBI scores were calculated. Qualitative data were analyzed by content analysis [27]. Responses were transcribed and thoroughly read several times. The meaningful content of caregivers' feelings of burden on caring for an asthmatic child was then extracted. Information was condensed into meaningful units, and then coded. All researchers involved in this study met to discuss which units should go together and how each unit should be named. Major and minor concepts were formulated by discussion amongst the researchers. Four caregivers were randomly selected to confirm the evaluation of the results. During the analyzing process, two researchers were appointed to independently analyze the same data. If major discrepancies materialized, a third researcher mediated the final decision.

2.4. Ethical considerations

The current study was approved by the hospital ethics committee. Names were replaced with unidentifiable codes. All participants signed informed consent and could terminate participation in the study at any time.

3. Results

3.1. Questionnaires

A total of 147 caregivers of children with asthma participated in the quantitative survey, though 9 were excluded for incomplete data, leaving 138 participants. A complete overview of demographic data is found in Table 1. The mean age of patients was 6.17 ± 3.13 years old, with 72.5% of them boys. The average course of the disease was 2.4 ± 2.26 years. The mean age of caregivers was 35.71 ± 6.29 years and 92% of the caregivers were mothers. Half of the caregivers had an education level of college or above, and 80.4% of patients paid medical bills out-of-pocket.

The total ZBI score ranged from 2 to 69 and averaged 31.56 ± 14.19 . Severity of burden ranged from 24% (35 cases) with no or mild burden, 52% (70 cases) with mild to moderate burden, 22% (30 cases) with moderate to severe burden, and 2% (3 cases) with severe to extreme burden (Table 2). Of the five ZBI dimensions, the mean scores for Self-criticism (2.09 ± 1.05) ranked highest, followed by Sacrifice (1.57 ± 0.94), Embarrassment/Anger (1.30 ± 0.80), and Dependency (1.21 ± 0.77), while Loss of control (1.20 ± 0.84) ranked lowest (Table 3). Among the individual items on the ZBI, the highest score was for “fear of the future of the relative” (mean = 3.04). The top five ranked individual items are shown in Table 3.

3.2. Interviews

A total of 13 interviews were conducted (12 mothers, 1 father, and 1 grandfather) and responses were coded from A to M. Of these participants, 9 of 13 experienced at least moderate caregiver burden. Three major themes and corresponding sub-themes were extracted in the analysis process (Table 4). All themes and sub-themes roughly corresponded to the ZBI dimensions, with the exception of “Sleep rhythm has been disrupted” and “Poor access to medical care services”.

3.2.1. Theme 1: life is too chaotic

Families with more than one asthmatic child pushed family members to use their extra time and energy to manage the disease. They sacrificed their work and/or social time, or even gave up their jobs in order to care for their children. The subthemes below describe these experiences in detail.

3.2.1.1. Takes up all of my time. Daily treatment of childhood asthma occurs under the direction of caregivers. Nearly all interviewees stated that looking after their asthmatic child had become the most important part of their daily life. One participant stated, “I gave up my job since he had asthma. Every day, my only job is to take good care of him, which includes ensuring he takes his medicine, cleaning the house to decrease dust mites, and urging him exercise. It causes me to become exhausted. Another said, “My wife and I check on him every morning when we get up. If he coughs, we worry that his asthma will keep him home from school.”

Since asthmatic attacks can occur suddenly and children may not be prepared to deal with them, many parents were afraid of leaving their children alone. As a result, their daily work was disrupted and allowed them no free time. The ZBI measured these factors in items 2 and 7. One parent claimed, “No matter where I go, I never left him alone even for a minute.”

3.2.1.2. Disrupts my sleep pattern. Asthma attacks typically occur at night, especially in childhood asthma. Previous research found 39% of 8000 asthma patients experienced asthma attacks nearly every night, 64% at least three nights per week, and 74% at least one night per week [28]. Almost every interviewee had trouble being woken up and/or with sleeplessness. One interviewee said, “I have to go to his room several times every night and listen to his lungs with a stethoscope.” Another participant stated, “Nighttime is a nightmare for me. I have a hard time falling asleep. When he coughs, I carry him on my back until he sleeps, sometimes the whole night.”

3.2.1.3. Declining health status. Since childhood asthma is a chronic disease requiring long-term treatment, a substantial amount of time, energy, and money are spent. On top of that, many experience a considerable amount of psychological pressure, especially working mothers or others unable to seek help from others. These physical and psychological difficulties take a toll on their health. Item number 10 in the ZBI inquires about this issue. An interviewee described, “My health deteriorated year after year. Migraines and stomach problems progressed. The doctor told me to take medication for my depression.” Another parent explained, “My body is in much

Table 1 – Demographic summary statistics of children and caregivers.

Characteristics	Questionnaire participants (n = 138)		Interview participants (n = 13)	
	n (%)	Mean (standard deviation)	n (%)	Mean (standard deviation)
Child's age		6.17 (3.13)		6.72 (2.84)
Child is a boy	100 (72.5)		11 (84.6)	
Course of disease		2.40 (2.26)		4.69 (2.72)
Caregiver's age		35.71 (6.29)		40.08 (11.46)
Caregiver is a mother	127 (92)		11 (84.6)	
is a father	9 (6.5)		1 (7.7)	
is a grandparent	2 (1.1)		1 (7.7)	
Caregiver's education level				
< High school	33 (24.0)		6 (46.2)	
High school graduate or equivalent	36 (26.1)		3 (23.1)	
College/university graduate	69 (50.0)		4 (30.8)	
Family monthly income				
<1000	8 (5.8)		0	
1000–3000	38 (27.5)		5 (38.5)	
3000–5000	30 (21.7)		4 (30.8)	
>5000	62 (44.9)		4 (30.8)	
Provider payments				
Out-of-pocket	111 (80.4)		13 (100)	
Health insurance	17 (12.3)		0	
Government insurance	10 (7.2)		0	

Table 2 – Degree of caregiver burden.

Degree	Percentage (Number)
None to mild	25% (35)
Mild to moderate	51% (70)
Moderate to severe	22% (30)
Very severe	2% (3)

poorer condition than before. Every day I feel dread. I have lost 30 kg since he developed [asthma]. How terrible it is!"

3.2.1.4. Impact on relationships with others. Negative effect on the relationships between caregivers and others were caused by multiple factors. First, caring for the patients reduced caregivers' social time. Second, since caregivers were overloaded with responsibilities, they more easily lost their patience. Third, as with many other parent-child disagreements, the generation gap caused opposing views on how to

deal with the condition. One parent described, "Since he developed this disease, the relationship between [my mother-in-law and I] has deteriorated. We quarrel nearly every day about asthma, about Western medicine versus Chinese medicine, and about which kinds of food are best for him."

3.2.1.5. Heavy economic burden. It was estimated that \$3300 are spent on each asthma patient per year from 2002 to 2007 in United States [6]. In Guangzhou, China, the cost of an asthmatic family was estimated to be 6111.84 RMB per year [29]. These large medical expenses were due to a number of reasons. The main problem is that treatment is long-term. The problem is exacerbated when parents are forced to give up their jobs to become fulltime caregivers. Moreover, the majority of caregivers must pay out-of-pocket. Item 15 in the ZBI looked into the economic burden of the families. An interviewee explained, "I have two asthmatic children. I have to spend two or three thousand RMB on long-distance fares, drugs, and examination fees every month, which is equal to

Table 3 – Scores of the 5 ZBI dimensions and ranking of the top five items in the ZBI.

Item Number	Dimension/Item	Mean score ± SD
3, 7, 8, 10, 11, 12, 13, 14	Sacrifice	1.57 ± 0.94
15, 16, 17, 19	Loss of control	1.20 ± 0.84
4, 5, 6, 9	Embarrassment/Anger	1.30 ± 0.80
20, 21	Self-criticism	2.09 ± 1.05
1, 2, 18	Dependency	1.21 ± 0.77
1–22	Total	31.56 ± 14.19
7	Are you afraid of what the future holds for your relative?	3.04 ± 1.35
21	Do you feel you could do a better job in caring for your relative?	3 ± 1.28
3	Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	2.85 ± 0.99
8	Do you feel your relative is dependent on you	2.69 ± 1.03
17	Do you feel that you have lost control of your life since your relative's illness?	2.46 ± 1.66

Table 4 – Themes and subthemes of burden among caregivers of asthmatic children and the corresponding dimensions and items in the ZBI.

Themes	Sub-themes	Dimensions	Items
1. Life is too chaotic	A. Takes up all of my time	Sacrifice, Loss of control, and Dependency	2, 3, 11
	A. Disrupts my sleep pattern	n/a	n/a
	A. Declining health status	Sacrifice	10
	A. Impact on relationships with others	Sacrifice	6, 12
	A. Relatively heavy economical burden	Loss of control	15
2. Negative emotions	A. Self-accusation and guilty	Embarrassment/Anger, Self-criticism	20, 21
	A. Uncertainty about illness	Sacrifice, Embarrassment/Anger	7, 9
	A. Irritability and Anger	Loss of control, Embarrassment/Anger	5
3. Gaps in medical support system	A. Poor access to medical care services	n/a	n/a
	A. Poor knowledge of caring for an asthmatic child	Loss of control, Self-criticism	19

my monthly salary. Sometimes I have to borrow money from my relatives, friends, or anyone else who can help us.” Another explained, “I haven't gone back home for several years in order to save money for this disease. I do not have enough money.” Finally, another described her situation, “[My child] developed desensitization over four years ago. The desensitization cost alone is over 100,000 RMB. On top of that, we must pay for the drugs. We really struggle [financially].”

3.2.2. Theme 2: negative emotions

3.2.2.1. Self-accusation and guilt. Caregivers scored the highest in the ZBI dimension of self-criticism (2.09 ± 1.05), and we found similar results in interviews. Nearly two-thirds of interviewees experienced self-accusation and guilt. Interviewees attributed the bad feelings to genetic predisposition, fear of improper care, failure to get a diagnosis earlier, and poor adherence to inhaled corticosteroids (ICS). One parent explained, “It was all my fault. He wheezed when he was a baby, and I took him to a small clinic to save money and out of convenience. I always thought it was just a cold. I never took him to a better hospital.” Another interviewee said, “I shouldn't have stopped the medication, but there is no use in regretting it now. He is 11 years old. Doctors said that if he still can't adequately control when he reaches 12, then the chance of it developing into adult asthma will be much greater. I feel so guilty. It is very painful to think about.” A study examining adherence to treatment, measured by electronic logging devices, showed that the median adherence rates of the total number of doses prescribed vary between 30% and 70% [30]. Poor adherence to ICS severely compromises the effectiveness of medication and leads to disease progression, complications, more emergency department visits, and more frequent hospitalizations [31].

3.2.2.2. Uncertainty about illness. Due to a lack of knowledge and worry about the disease prognosis, most of the interviewees had some extent of uncertainty about the illness. The ZBI item, “Are you worried about the future of your child?” scored the highest (3 ± 1.35), in agreement with the thought that uncertainty about the illness caused an increase in caregiver burden. One parent described it, “I worry about his future day and night. Now he is 12 years old, and I am afraid that he might have to use the medication the rest of his life.”

3.2.2.3. Irritability and anger. Since asthma is a chronic disease and may be difficult to control, some caregivers lose their patience, manifesting itself as irritability and anger. The dimension of “Loss of control” scored 1.23 ± 0.78 . An interviewee explained, “His disease makes me lose my temper easily. I became very angry when he wouldn't exercise or when he would eat junk food. I smacked him or broke dishes, which made me a little comfortable.” Another parent said, “It is common to shout at him and beat him when he coughs. I become very irritable. Why others' children are healthy and mine has such a terrible disease [seems unfair].”

3.2.3. Theme 3: gaps in medical support system

3.2.3.1. Poor access to medical care services. Asthma can become an intractable disease and can be difficult to diagnosis. Access to adequate medical treatment in China can be a problem. Quite a few caregivers in this study traveled long distance to visit a trusted doctor at a respectable hospital. One caregiver said, “It is too difficult to see a doctor. Our family, including my parents-in-law, has to wait in a queue all night just to see a doctor. There are so many patients, you can't even image.”

3.2.3.2. Poor knowledge of caring for an asthmatic child. Most families are not familiar with asthma until someone they know is diagnosed. Major misunderstandings even persist when a patient is diagnosed and is trying to manage the disease. Such circumstances lead to the delay of treatment, unsatisfied treatment effects, or even life-threatening situations. Item 19 in the ZBI addresses this problem. Many caregivers complained that they didn't know where to get additional help. For example, one interviewee described, “I remember one night when my baby was coughing severely and then wheezed. We heard some sounds and saw his face turning blue, but we didn't know what to do. We were helpless and started to cry.”

Asthma can be effectively controlled with long-term standardized treatment [32]. Dosage reduction and discontinuation need to be strictly evaluated by doctors for every individual case [33]. Improper use of medications can result in relapse of the illness, difficulty in controlling it, and increased direct and indirect costs [34]. One parent told us, “Yesterday evening, he was severely coughing. I asked him to bear it instead of taking medication, so that he could still come to the appointment today. You know, it is not so easy

for him to stop the medications for these examinations for two weeks. If he took medication, all our efforts would have been undercut.” Another parent described, “Last week the specialist stopped prescribing medication. I didn't know what to do because my child used the [inhaler] all the time.”

Some interviewees were skeptical of the side effects of inhalers. They wondered whether the children had addiction, toxic effects, or negative effects on growth and development. As a result, discontinuation of drugs was very common. “I have checked on the Internet, and found that glucocorticoids inhibit growth and development. It makes me weary since she is so small. I limit its use for only asthma attacks,” one parent described. Another stated, “My friend said that if [my child] takes so much medication every day, [my child] will die from it eventually. I was so scared to hear this that I discontinued use of the inhaler.

4. Discussion

Both the quantitative and qualitative methods used in this study demonstrated a relatively heavy burden on caregivers of children with asthma. The results call attention to the need to deal with caregivers' challenges, for which some general solutions are discussed below.

4.1. Enhance caregivers' positive experience to lighten their burden

In some of our interviews, caregivers also described some positive experience in their caregiving experiences. These included affirmation brought on by personal growth, learning how to deal with challenges, the satisfaction they received from bringing pleasure and comfort to their patients, closer relationships with their patients, and realizing the fulfillment of self-worth. Hsiao et al. [35] previously reported that positive experiences can also be found during caring, alongside burden. Another study found that positive experiences can significantly ease the burden [36]. Our interviews also probed this idea. One participant said, “I can manage it now. You know, I can see progress. I'm so happy. It gives me such a sense of relief”. Medical workers should try to highlight caregivers' positive experiences to try and deflect focus from their burden.

4.2. Build an effective social support system

Previous studies show that family and social support systems can reduce burden [37]. Our interviews indicate that most of the caregivers can acquire some understanding and support from their families, but little from community workers, professionals, or people with similar experiences. In Guangzhou, China, few community health centers consider childhood asthma as a type of disease. Community organizations should establish asthma support groups and asthmatic clubs, carry out seminars, and send out informational booklets. These approaches would facilitate communication between those who have similar experiences and connect them with professional support.

The Global Initiative for Asthma (GINA) [1] underlined the importance of health education and self-management, and considered them as the key factors influencing treatment effects and family and medical system burden. In a study by Min et al. [38], 48 parents of children with asthma underwent one year of intervention of self-management. They showed that self-management can ease parents' psychological pressure. A viable approach for community hospitals is to implement case management, which is a prevalent model for managing childhood asthma. The approach involves asthma symptom management, asthma education, care coordination/referrals, and home environmental assessment/intervention [39]. A previous study sought to decrease caregivers' stress through case management [40]. The Chinese Asthma Alliance is a national asthma prevention and control organization that provides a platform for communication between professors, spreading public knowledge about asthma control [41]. Unfortunately, its website and WeChat are seldom known to the public. Governments, hospitals, and community organizations should promote the application of these platforms.

4.3. Limitations

A number of study limitations should be considered. For the quantitative survey, 138 participants in a small number of hospitals are unlikely to be representative for all asthmatic caregivers in Guangzhou, China. Additional studies with a larger sample size and multiple settings may produce more comprehensive findings. Also, since childhood asthma is affected by seasons, a relatively short research period may exclude some patients that are simply in the stable phase during the study period. For the qualitative interviews, the use of purposive sampling may have resulted in selection bias.

5. Conclusion

This mixed-methods study, combining quantitative and qualitative methods, provides us with a more comprehensive picture of burden among caregivers of children with asthma. We find that caring for an asthmatic child negatively affects the physical, psychological, social, and financial well-being of caregivers. More than 76% of the caregivers studied here experienced at least mild burden. Our surveys revealed that “self-criticism” and “fear of the future of the relative” were the most impactful aspects on burden. Interviews with these caregivers show that a chaotic life, negative emotions, and gaps in the medical support system also contribute to caregiver burden. These findings suggest that Chinese health workers should provide relevant supportive care to ease the burden on caregivers. Future studies should further examine how to treat children's asthma, while also reducing caregiver burden.

Author contributions

Miaolan Guo and Jinlan Guo conceptualized and designed the study, analyzed and interpreted the data, drafted the initial manuscript, and approved the final manuscript as submitted.

Litao Wen and Liting Zeng acquired and interpreted the data, drafted the initial manuscript, and approved the final manuscript as submitted. Guozhen Gao analyzed data, revised the manuscript critically for important intellectual information, and approved the final manuscript as submitted.

Conflict of interest

None.

Funding

Funding was provided for this manuscript: We receive the fund of Science and technology department of Guangdong province, NO. 2014A020212366.

Acknowledgments

The authors would like to thank the staff of the pediatric clinics and all caregivers who participated in the current study.

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