

HOSTED BY



ELSEVIER

Available online at [www.sciencedirect.com](http://www.sciencedirect.com)

ScienceDirect

journal homepage: <http://www.elsevier.com/journals/international-journal-of-nursing-sciences/2352-0132>

## Original Article

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



Miaolan Guo <sup>a</sup>, Guozhen Gao <sup>b,\*</sup>, Jinlan Guo <sup>c</sup>, Litao Wen <sup>a</sup>, Liting Zeng <sup>a</sup>

<sup>a</sup> School of Nursing, Guangzhou Medical University, Guangzhou, China

<sup>b</sup> Department of Nursing, The First Affiliated Hospital of Guangzhou Medical University, Guangzhou, China

<sup>c</sup> School of Nursing, Guangdong Medical College, Science and Technology District, Dongguan, China

## 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 =  $31.56 \pm 14.19$ ) 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 ( $2.09 \pm 1.05$ ), followed by sacrifice ( $1.57 \pm 0.94$ ), embarrassment/anger ( $1.30 \pm 0.80$ ), dependency ( $1.21 \pm 0.77$ ), and lastly, loss of control ( $1.20 \pm 0.84$ ). 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.

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/>).

## 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

\* Corresponding author.

E-mail address: [gygz07@126.com](mailto:gygz07@126.com) (G. Gao).

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  $\alpha$  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

Download English Version:

<https://daneshyari.com/en/article/2653117>

Download Persian Version:

<https://daneshyari.com/article/2653117>

[Daneshyari.com](https://daneshyari.com)