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# Development and Psychometric Testing of a Chinese Version of the Caregiver Burden Scale for Parents of Children With Allergies

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## Key words:

Instrument development;  
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Children with  
allergies (CWA);  
Parents;  
Children

**Background** No specific instrument has thus far been developed for measuring the caregiver burden perceived by parents of children with allergies (CWA).

**Objectives:** To determine the psychometric properties of the Caregiver Burden Index (CBI).

**Methods:** A mixed-methods design was adopted to evaluate the psychometric properties of the scale.

**Results:** The content validity index was 0.89, and the internal consistency was high with a coefficient alpha of 0.98. Three factors were extracted after exploratory factor analysis.

**Conclusion:** The study findings suggest that the CBI has sufficient reliability and validity to evaluate the caregiver burden of parents of CWA.

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THE PREVALENCE OF allergic disorders is increasing worldwide, and this increase is mostly in the young population (Bråbäck, Hjern, & Rasmussen, 2004; Hansen, Rappoport, Vestbo, & Lange, 2000; Pawankar, Canonica, Holgate, & Lockey, 2011). The economic burden brought on by allergic diseases is significant and includes the direct cost of medication or insurance reimbursement and the indirect cost from days missed from school/work or loss of productivity (Meltzer et al., 2009; Nathan, 2007). There are many different types of allergic disorders that affect multiple organs, and their prevalence is ranked high among chronic diseases in the pediatric population (American College of Allergy, 2010; Weinberg, 2011). Asthma is one of the most well-known allergic diseases and is responsible for nearly

\$56 billion in medical expenses in the US (Bahadori et al., 2009; Barnett & Nurmagambetov, 2011). Moreover, over the 5-year period of 2000–2005, the cost of treating allergic rhinitis nearly doubled from \$6.1 billion to \$11.2 billion in the US (Soni & Medical Expenditure Panel, 2008). In Taiwan, it is reported that atopic dermatitis, asthma, and allergic rhinitis are the most common allergies, and 61.2% of children affected by atopic dermatitis also has asthma or allergic rhinitis (Hwang et al., 2010).

Caring for chronically ill children has a significant impact on families. The burden of caring for a chronically-ill child is associated with health deterioration in caregivers and parents leading to adverse health outcomes such as emotional strain and depression (Beach, Schulz, Yee, & Jackson, 2000; Montgomery, Borgatta, & Borgatta, 2000; Nijboer, Triemstra, Tempelaar, Sanderman, & van den Bos, 1999). Allergic diseases are composed of a variety of dysfunctions presenting a miscellany of symptoms that have a multi-faceted impact

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on many dimensions of family life (Meltzer, 2001; Weinberg, 2011). Children with allergies may suffer from issues related to schooling, sleep quality, physical limitations, symptom control and behavioral or developmental problems (Bursch, Schwankovsky, Gilbert, & Zeiger, 1999; Hung & Gau, 2004; Hung, Huang, Lin, & Gau, 2008; Juniper et al., 1996a; Kickhefer & Ratcliffe, 1996). Parents may also have trouble maintaining normal family functions and parental-child communication or interaction, resulting in a compromised quality of life (Everhart, Fiese, & Smyth, 2008; Juniper et al., 1996b; Meltzer, 2001). Although, several instruments have been developed to measure the burden or impact encountered by the parents caring for chronically-ill children (Messer, Angold, Costello, & Burns, 1996; Stein & Riessman, 1980; Streisand, Braniecki, Tercyak, & Kazak, 2001), no specific instrument has been designed to measure the caregiver burden of parents providing health care to children with allergies.

## Background

Caregiver burden was first conceptualized in the 1960s and is defined as a subjective perception of the emotional or physical consequences resulting from providing direct care to a sick family member (Ankri, Andrieu, Beaufile, Grand, & Henrard, 2005; Beinart, Weinman, Wade, & Brady, 2012; George & Gwyther, 1986; Hoening & Hamilton, 1966; Hunt, 2003; Zarit, Reever, & Bach-Peterson, 1980). Caregiver burden is associated with health deterioration of caregivers and also has a great impact on the quality and quantity of the healthcare received by the care recipients (Deeken, Taylor, Mangan, Yabroff, & Ingham, 2003). Parents who have to simultaneously play a role as a caregiver to meet the children's health demands and take the responsibility of parenting may experience increased stress leading to worsened quality of life. Both parents and children may suffer resulting psychological distress (Crespo, Carona, Silva, Canavarro, & Dattilio, 2011; Fiese, Winter, Anbar, Howell, & Poltrock, 2008). Although the term "caregiver burden" is widely recognized among geriatric scholars, pediatricians often use other terms to describe the impact of childhood illness on parents and family. "Parenting stress" is one of those parallel concepts and was formulated into the parenting stress model (PSM) by Abidin et al. The Parenting Stress Index (PSI) has been translated into several different languages including Chinese and applied in pediatric studies worldwide including Taiwan (Abidin, 2014; Yeh, Chen, Li, & Chuang, 2001). Even though this scale was originally designed to measure parenting stress in ordinary situations (i.e., stress incurred from daily life events concerned with raising a child without any health concerns), it was applied in many pediatric studies to measure the parenting stress perceived by parents caring for children with chronic conditions (Abidin, 2014). However, fulfilling both the parental and caregiver roles and providing disease-specific caregiving to a child with a chronic illness was recognized to introduce

additional stress and burden to parents (Manor-Binyamini, 2012; Raina et al., 2004). To address this concern, Streisand et al. (2001) developed a pediatric-specific parenting stress scale to evaluate the contributions of illness-specific stressors to the overall parenting stress level (Streisand et al., 2001).

Extensive efforts have been made by researchers to develop instruments to measure the impact of childhood illness on parents and family, for example, the Impact on Family Scale (Stein & Riessman, 1980), the Child and Adolescent Impact Assessment (CABA) or the Caregiver Strain Questionnaire (CGSQ) (Brannan, Heflinger, & Bickman, 1997; Messer et al., 1996). Although these tools are applicable to parents or families caring for children with a variety of chronic childhood illnesses, none were specifically designed for parents of children with allergies (CWA). The prevalence of allergic disorders has increased dramatically over the past two decades, and they are now one of the most common chronic pediatric conditions (Isolauri, Huurre, Salminen, & Impivaara, 2004; Pawankar et al., 2011). The increase is attributed mostly to young children (Weinberg, 2011). In addition, the nature of allergic disorders, including a variety of aggregated allergic symptoms, different comorbidities, and an unpredictable course of disease progression, causes a multi-dimensional and pervasive interruption of daily life that poses a unique and demanding challenge to parents and families (Streisand & Tercyak, 2004). Also, when compared with other generic instruments, disease-specific instruments have been reported to be more suitable for capturing the in-depth experience perceived by parents with regard to providing disease-specific care for their children (Patrick & Deyo, 1989; Streisand & Tercyak, 2004; Streisand et al., 2001). Therefore, in this study we developed a scale named the "Caregiver Burden Index" (CBI), originally written in Chinese and based on a sample of Taiwanese parents to explore the caregiver burden perceived by parents caring for children affected by allergic disorders. In this study, "allergic disorders" refers to different combinations of or the singular presence of the three allergic disorders (asthma, allergic rhinitis, and atopic dermatitis) reported to be most common in the Taiwan pediatric population (Hwang et al., 2010).

## Methods

### Aim

The purpose of this study was to develop and test the psychometric properties of an index named the Caregiver Burden Index (CBI), which measures the burden on parents taking care of CWA.

### Design

This was a mixed-methods study that adopted a sequential, quantitative dominant (qual → QUAN)

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