



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

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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, Hjerm, & Rasmussen, 2004; Hansen, Rappeport, 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, Beaufrils, Grand, & Henrard, 2005; Beinart, Weinman, Wade, & Brady, 2012; George & Gwyther, 1986; Hoenig & 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, Canavaro, & 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)

exploratory design and an instrumental development model (Creswell & Plano Clark, 2007). During phase 1, qualitative and quantitative data were collected and integrated from three different sources: (1) a literature review and in-depth interviews with mothers of CWA (qualitative data); (2) feedback and suggestions made by a panel of experts regarding the content of the CBI scale (qualitative and quantitative data); and (3) a focus group discussion with parents of CWA (qualitative perspective). The consecutive second phase was a field test of the finalized version of the CBI by conducting a cross-sectional study in a larger sample.

Phase 1: Development of the CBI

Critical Literature Review and In-Depth Interviews

As illustrated in Figure 1, three different tasks were encompassed within the first phase of the study that lasted for 2 years. First, the authors conducted in-depth interviews with mothers living in Taiwan caring for CWA and conducted a critical review of relevant literature both in English and Chinese. A convenience sample of seven Taiwanese mothers was recruited. The mean age of these mothers was 41.3 years old, and they all had an educational

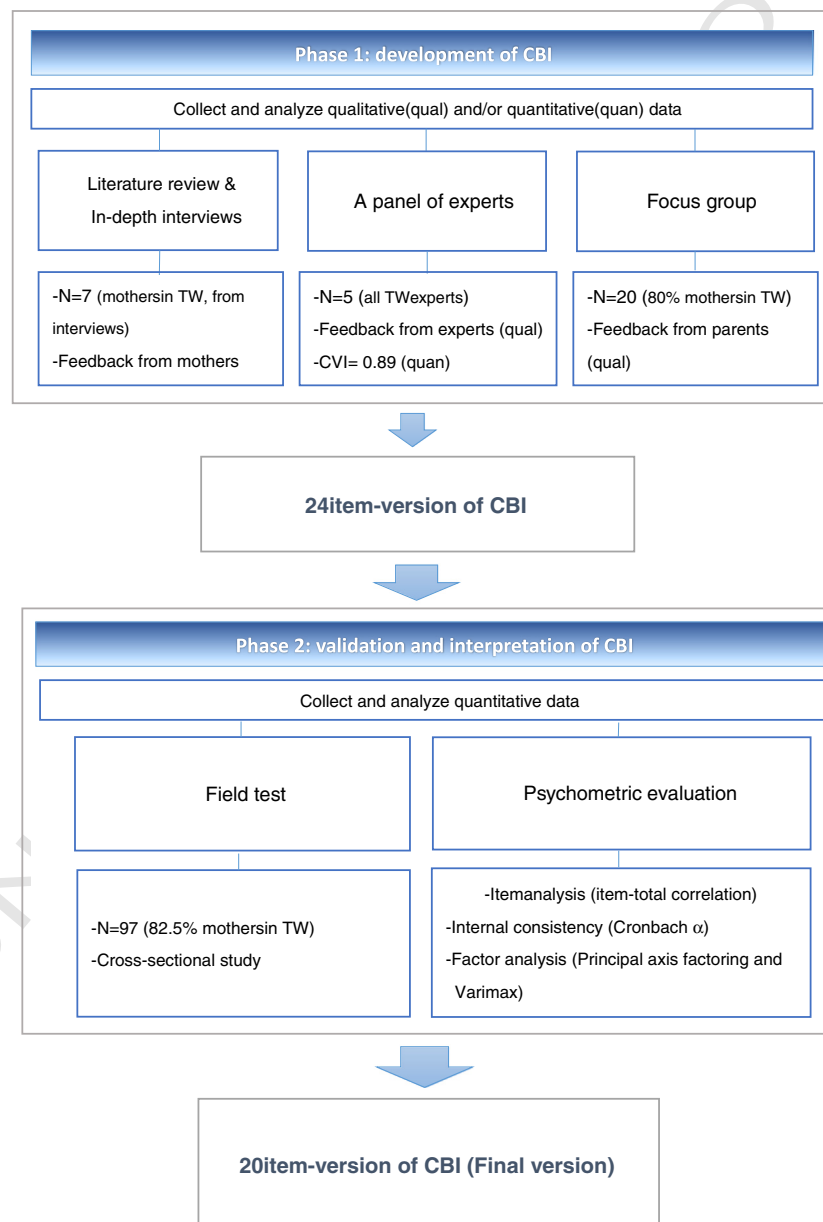


Figure 1 Diagram of the CBI development process.

level of 2-year college/4-year university. In-depth interviews were conducted by the authors using a previously established interview guide. Mothers were encouraged to elaborate on any concerns related to taking care of their CWA. The narrative content of the interviews was then transcribed and analyzed to produce major themes. During the same time period, a critical literature review was conducted to retrieve relevant articles from Pubmed, CINAHL, MEDLINE, and the Airiti Library (Chinese). Inspired by the qualitative work of Lin (2007) and the translation of Abidin's parenting stress model (PSM) by Zan (1995), we decided to adopt the PSM as a framework to guide the process of merging the findings from the in-depth interviews and the literature (Abidin, 1990). While searching for studies conducted in the Taiwanese population, we found that parenting stress is a widely recognized notion in Taiwan and that the Chinese version of the Parenting Stress Index (PSI) has been psychometrically tested and applied to many studies in Taiwan (Wu, 2008; Yeh et al., 2001). Finally, caregiver burden was categorized into three major categories: "constraints on personal and family life", "psychological distress", and "physical health complaints". Thirty items were included in this preliminary version of the CBI. This categorization mainly emphasized the parents' domain of the parenting stress model since the CBI scale was designed to measure the burden perceived by parents or caregivers in providing healthcare to their CWA.

Review of the Content of the CBI by a Panel of Experts

Next, a panel of experts was formed to examine the content validity of the CBI scale. These experts were all pediatric professionals with more than 10 years of clinical or academic working experience in a hospital or a medical college setting in Taiwan. One of the reviewers was an academic nursing professor majoring in pediatric care, two were pediatric immunologists, one was a pediatric nurse practitioner, and another was a pediatric clinical nurse who was also the mother of a child with an allergic disease. Each expert was asked to review the relevancy, clarity, and appropriateness of each item and rate them according to a four-point scale (1 = not relevant, 2 = somewhat relevant, 3 = quite relevant, 4 = highly relevant). The Content Validity Index (CVI) of the scale was then calculated as 0.89, which was higher than 0.80, the CVI value recommended for developing a new instrument (Davis, 1992). The researchers also collected the suggestions or comments made by the experts to revise the scale by rephrasing, retaining, adding or deleting items encompassed within the CBI. After summarizing the qualitative and quantitative feedback from the experts, six items were excluded due to redundancy. Finally, a 24 item-version of the CBI scale was formulated.

Focus Group Meeting

The researchers then conducted a focus group meeting with twenty parents of CWA to review the content of the CBI scale revised according to the expert opinions. The parents

were recruited from a pediatric immunological outpatient department in a university hospital by convenience sampling. The majority of the caregivers recruited were mothers (80%) aged between 35–58 years old, and 85% had an education level of 2-year college/4-year university or graduate school. The authors asked parents if the scale reflected their worries and burdens in caring for CWA. The items included in the CBI scale were all written in Chinese. The parents in this focus group reported that this scale was easy to read and echoed their everyday concerns while providing care to their CWA. No revision was suggested by the participating parents except one description regarding the allergic status of the affected children. At first, we phrased some items with "I feel... because I have to take care of my child with allergies or asthma..." to give a more detailed description of the allergic status of the child. However, some parents considered the term "asthma" already covered by the concept "allergies" and suggested that the word "asthma" be deleted. The researchers agreed with this and accepted the modification.

After collecting and analyzing both the qualitative and quantitative data generated from phase 1, the first version of the CBI scale, which comprised of 24 items concerning the caring experience perceived by parents of CWA, was finalized. This version was to be further tested in phase 2 with a larger sample in a field test. The scale was designed on a five-point Likert-type scale. Each item represents one statement describing the subjective perception of the caregiver regarding caring for his or her child during the previous 2 weeks (5 = extremely serious; 4 = serious; 3 = ordinary; 2 = little; 1 = not at all). Items included statements such as "I feel tired because I am taking care of my child with allergies" and "I lose my temper more often because I am taking care of my child with allergies". The higher the score, the more burden the caregiver perceived while taking care of the CWA.

Phase 2: Validation and Interpretation of the CBI Scale

This phase was primarily composed of two parts, conducting a field test and a psychometric evaluation of the collected data. During the field test, a cross-sectional survey was conducted in a medical center in northern Taiwan between September 2006 and July 2008. Item analysis was performed by computing the corrected item-to-total correlations which needed to be above 0.30 to be considered sufficiently related (Ferketich, 1991). Reliability was also evaluated by calculating the coefficient of Cronbach's alpha for the CBI scale. A value of at least 0.80 indicates adequate internal consistency for a well-developed instrument (Portney & Watkins, 2000). We used exploratory factor analysis (EFA) to extract factors by the principal axis factoring estimation method with varimax rotation. Factors were extracted if they fulfilled the following criteria: (a) eigenvalues > 1; (b) the variance explained by each factor exceeded 5% (Hair, 1998). Item

reduction was performed using the following criteria: (a) factor loading for items of at least > 0.50 ; (b) each factor loaded by at least two or three items.

Sample

During the process of the field test, systematic random sampling was adopted in a pediatric immunological outpatient center in a university hospital in Taiwan to recruit parents who cared for school-age CWA. Allergic diseases in this study refer to different combinations of or the singular presence of the three allergic disorders (asthma, allergic rhinitis, and atopic dermatitis). The original number of recruits was 120, which was in accordance with the ideal 5-to-1 ratio (five individuals per scale item) for conducting exploratory factor analysis (Gorsuch, 1983). However, the final sample consisted of 97 caregivers, with a response rate of 80.83%, who were able to complete the questionnaires needed for further data analysis.

Data Analysis

All the data were entered and analyzed using SPSS Statistics software version 16.0 (SPSS, Chicago, IL, USA) for Windows. Descriptive analyses, including means and standard deviations, were performed to describe the item responses and the characteristics of participants recruited for the study.

Ethical Considerations

The study was approved by the research ethics committee of the research medical center (IRB approval No: 9561706066). Parents of children with asthma were given an informed consent form and oral explanation of the study and were given a chance to clarify questions before they decided to participate in the study. All the data were anonymous. The caregivers of CWA were assured that they could decline participation in the study process without harm to their medical rights.

Results

Participant Demographics

The valid sample in the field test consisted of 97 caregivers aged 29 to 53 years old. Most caregivers were mothers (82.5%), whose mean age was 39.9 years ($SD = 5.0$) with a range of 29.8 to 52.7 years. More participants reported that they were mainly caring for a boy (63.2%) than a girl (36.8%) with allergies. The mean age of the children was 9.2 years ($SD = 1.6$), ranging from 6.2 to 12.5 years. Most of the children had been diagnosed with atopic dermatitis (72.1%)

combined with other allergic diseases including allergic rhinitis (50%) or asthma (35.3%). About 75% of caregivers had completed university or graduate level of education. Less than 25% of caregivers' highest level of education was senior or junior high school. Most caregivers were married (92.7%) and reported a family history of allergies (83.8%) (Table 1).

Psychometric Evaluation of CBI Scale

Item Analysis

The corrected item-total correlations of the 20 items ranged from 0.71 to 0.89 and were all above the cut-off point of 0.30. There was only a slight improvement in Cronbach's alpha if any item was deleted; therefore, all 20 items were kept in this scale for the adequate homogeneity between each item to the overall scale (Table 2).

Internal Consistency

Cronbach's alpha was calculated to examine the internal consistency of the CBI scale. The coefficient alpha for the total 20-item CBI scale was 0.98. The coefficient alpha was 0.96 for the "constraints on personal and family life" subscale; 0.95 for the "psychological distress" subscale; and 0.91 for the "physical health complaints" subscale (Table 3). The correlations between subscales are significant with a Pearson's coefficient of $r = 0.86$ ($p < 0.01$) between "constraints on personal and family life" and "psychological distress"; $r = 0.79$ ($p < 0.01$) between "constraints on personal and family life" and "physical health complaints"; and $r = 0.77$ ($p < 0.01$) between "psychological distress" and "physical health complaints".

Factor Analysis

Before conducting factor analysis, the Kaiser-Meyer-Olkin (KMO) value and Bartlett's test of sphericity were computed to assess the adequacy of sampling. Both were above the acceptable values, suggesting that the sample was adequate for further factor analysis (KMO: $0.94 > 0.80$; the Bartlett's test of sphericity: $\chi^2 = 2704.43$, d.f. = 276, $p < 0.00$) (Kaiser, 1974). Three factors with eigenvalue > 1 were extracted successfully. However, four items were eliminated during this process due to their low factor loadings (< 0.50). The items eliminated were: "I feel a loss of freedom because I have to closely watch my child with allergies", "I am worried about the change in the condition of my child with allergies", "I cannot take good care of other family members due to my child with allergies" and "I feel economical strain since the medical expenses for the child with allergies are large". Therefore, a total of 20 items made up the final version of the CBI. The first factor "constraints on personal and family life" consisting of 7 items accounted for 28.26% of the variance. The second factor "psychological distress" encompassing 9 items was able to explain 26.66% of the variance. The third factor "physical health complaints" 391

Table 1 Sample characteristics.

Variable	<i>n</i> (%)	Mean (SD)	Minimum	Maximum
Age of the caregivers (in years, <i>n</i> = 97)		39.9 (5.0)	29.8	52.7
Education level of caregivers (<i>n</i> = 97)				
Junior high school	2 (2.1)			
Senior high school	22 (22.7)			
2-year college or 4-year university	60 (61.9)			
Graduate school	13 (13.4)			
Marital status of caregivers (<i>n</i> = 96)				
Unmarried	2 (2.1)			
Married	89 (92.7)			
Divorce	5 (5.2)			
Gender of children (<i>n</i> = 68)				
Girls	25 (36.8)			
Boys	43 (63.2)			
Age of children (in years)		9.2 (1.6)	6.2	12.5
Type of allergies of children(<i>n</i> = 68)				
Allergic rhinitis (AR)	34 (50.0)			
Atopic dermatitis (AD)	49 (72.1)			
Asthma (AS)	24 (35.3)			
AR & AS	8 (11.8)			
AS & AD	3 (4.4)			
AR & AD	7 (10.3)			
AR, AD, & AS	11 (16.2)			
Family allergy history (<i>n</i> = 68)				
Yes	57 (83.8)			
No	11 (16.2)			

accounted for 20.63% of the variance and was composed of 4 items. In summary, the three extracted factors accounted for a cumulative variance of 75.55% (Table 4). The total score range of the CBI was from 20 to 100, whereas the scores for

the subscales are as follows: “constraints on personal and family life” ranged from 7 to 35; “psychological distress” ranged from 9 to 45; and “physical health complaints” ranged from 4 to 19.

Table 2 CBI item means, SD, corrected item-total correlations, and Cronbach’s alpha if deleted.

Brief descriptions of items	Mean (SD)	Corrected item-total correlation	Alpha if item deleted
Sleep and rest deprivation (B1)	2.50 (1.07)	0.719	0.975
Physical fatigue (B2)	2.45 (1.07)	0.781	0.975
Loss of appetite (B3)	1.70 (0.91)	0.711	0.975
Poor physical condition (B4)	1.89 (1.05)	0.779	0.975
Interfering the personal life schedule (B5)	2.22 (1.04)	0.838	0.974
Sense of physical stress (B6)	2.58 (1.16)	0.854	0.974
Sense of psychological tension (B7)	2.57 (1.20)	0.878	0.974
Feeling depressed of caring for the allergic child (B8)	2.35 (1.14)	0.857	0.974
Feeling helpless and frustrated for taking caring of the allergic child (B9)	2.52 (1.23)	0.824	0.974
Feeling of less competence to resume the long-term care responsibility (B10)	1.90 (1.13)	0.722	0.975
Sense of over-dependent by the children (B11)	2.13 (1.19)	0.864	0.974
Losing temper more often while caring for the allergic child (B12)	2.49 (1.10)	0.804	0.974
Having quarrels with family members (B13)	1.90 (1.07)	0.709	0.975
Unable to manage on the daily life events successfully (B14)	1.97 (1.00)	0.834	0.974
Loss of personalized or private time (B15)	2.20 (1.15)	0.889	0.974
Limited connection to families and relatives (B16)	1.94 (1.17)	0.887	0.974
Limited opportunities to participate community or religious activities (B17)	1.76 (1.10)	0.848	0.974
Limited chances to have the leisure time (B18)	2.07 (1.14)	0.778	0.975
Interfering the daily-life of whole family (B19)	1.92 (1.08)	0.853	0.974
Loss of chance to work and earn money (B20)	1.67 (1.13)	0.744	0.975

Table 3 Statistics and Cronbach's alpha of CBI subscales.

Subscale	N of item	Cronbach's alpha	Mean	SD
Constraints on personal and family life	7	0.960	2.01	0.99
Psychological distress	9	0.953	2.23	0.98
Physical health complaints	4	0.908	2.14	0.91
Total scale	20	0.976	2.14	0.90

Discussion

This study reports the development and psychometric testing of a scale designated the CBI to measure the burden on parents taking care of their CWA. The findings provide evidence supporting the adequate internal consistency of the CBI scale which had a Cronbach's alpha of 0.98 (Portney & Watkins, 2000). The final CBI scale consisted of 20 items and takes only 5–10 minutes to complete. Three factors, “constraints on personal and family life”, “psychological distress”, and “physical health complaints” were revealed after conducting factor analysis, and they accounted for a cumulative variance of 75.55%. This suggests that these extracted factors are able to capture the essence of the phenomenon (DeVellis, 2003). Moreover, supportive evidence can be found among contemporary research that these three factors are reasonable for articulating the caregiving burden of parents caring for CWA.

The first identified factor was “constraints on personal and family life” which explained most of the variance (28.26%) compared with the other two subscales (Table 4). The simultaneous fulfillment of roles as parent and caregiver and compliance with daily medical regimens consumes considerable time and energy that may keep parents of CWA from working full-time, having personal time, contacting with other family members, or engaging in community activities (Laforest et al., 2004; Marklund, Ahlstedt, & Nordstrom, 2006; NIH, 2007; Streisand & Tercyak, 2004). Moreover, the complexity and unexpected nature of allergic diseases may sometimes frighten parents so that they are reluctant or afraid to share their caregiving loads with others. This may increase the caregiving burden and the possibility of social isolation (Coffey, 2006; Ratcliffe, Harrigan, Haley, Tse, & Olson, 2002; Rehm, 2013; Yawn, 2003). In addition, economic burden is greater among caretakers who spend more time in caring for a child than working and among those who must deal with accumulating medical bills (Laforest et al., 2004; Major, 2003; Ratcliffe et al., 2002; Yawn, 2003).

Childhood allergic diseases may also bring up significant and pervasive interruptions and restrictions in normal daily life for all family members (Cohen, Noone, Muñoz-Furlong, & Sicherer, 2004; Fiese, 2008; Yawn, 2003). Family resources including time, space, or money need to be redistributed to accommodate the healthcare needs of CWA (Major, 2003). Household surroundings need to be rearranged to avoid possible allergens, and a simple symptom such as coughing at

Table 4 Factor matrix of burden in caregivers of children with allergic diseases.

Descriptions of items	Constraints on personal & family life	Psychological distress	Physical health complaints
Interfering the personal life schedule (B5)	.536	.416	.520
Unable to manage on the daily life events successfully (B14)	.728	.344	.372
Loss of personalized or private time (B15)	.731	.433	.368
Limited connection to families and relatives (B16)	.738	.455	.341
Limited opportunities to participate community or religious activities (B17)	.732	.388	.351
Limited chances to have the leisure time (B18)	.757	.327	.276
Interfering the daily-life of whole family (B19)	.754	.381	.353
Sense of physical stress (B6)	.386	.657	.449
Sense of psychological tension (B7)	.392	.631	.524
Feeling depressed of caring for the allergic child (B8)	.379	.667	.356
Feeling helpless and frustrated of caring for the allergic child (B9)	.333	.741	.433
Feeling of less competence to resume the long-term care responsibility (B10)	.267	.739	.439
Sense of over-dependent by the children (B11)	.568	.616	.314
Losing temper more often while caring for the allergic child (B12)	.378	.595	.247
Having quarrels with family members (B13)	.379	.674	.148
Loss of chance to work and earn money (B20)	.518	.544	.185
Sleep and rest deprivation (B1)	.283	.280	.779
Physical fatigue (B2)	.300	.332	.828
Loss of appetite (B3)	.366	.361	.534
Poor physical condition (B4)	.520	.265	.604
Eigen value	5.65	5.33	4.13
Explained variance (%)	28.26	26.66	20.63
Cumulative variance (%)	28.26	54.92	75.55

night may not only affect sleep quality but also the quality of life of the whole family (Fiese, 2008).

The second factor identified in the CBI scale was “psychological distress” with 9 items (Table 4). This subscale was reported to have the highest mean score among the subscales (Table 3). According to the study findings presented by Townsend et al. (1991), emotional disturbance had been recognized as the primary source of burden compared with other factors among parents providing care to their CWA. Findings from previous studies also indicate that parents of CWA may suffer from depression, anxiety, a sense of helplessness and being overwhelmed, or exhaustion (Coffey, 2006; Fiese et al., 2008; Shalowitz et al., 2006; Townsend et al., 1991; Yawn, 2003). When compared with mothers of healthy children, a significant higher percentage of mothers who raised children with atopic eczema reported that they feel tired and distressed while taking care of their children (Daud, Garralda, & David, 1993). Although this factor mainly conveys the idea of psychological strain, some items such as B12, B13 and B20 (Table 2) seem to imply that there are some other subcategories embedded within the concept of emotional distress. To put it more clearly, items B12 and B13 may be linked to the notion of “family conflicts” and B20 to the notion of “financial difficulties”, both of which have been found in other corresponding studies (Coffey, 2006; Juniper et al., 1996b; Townsend et al., 1991).

The third factor “physical health complaints” encompasses the health deterioration encountered by parents caring for CWA. Parents of chronically ill children are more prone to experience physical somatic complaints including headaches, ulcers, insomnia, and loss of appetite (Mescon & Honig, 1995). Previous study findings also revealed that parents of CWA are at greater risk of suffering from somatic complaints such as fatigue or sleep deprivation when compared with other parents of healthy children (Chamlin, Frieden, Williams, & Chren, 2004; Gau et al., 2010). Another study found that although parents of children with asthma reported less stress due to parenting, they assigned a higher score to the parental health dimension compared to parents of children with chronic conditions other than asthma (Chiou & Hsieh, 2008). We also found evidence of physical stress during our in-depth interviews. For example one mother said: “I feel tired all day since I can barely fall asleep at night..I have to keep my eyes open the whole night to watch my kid. I am so afraid that she might suddenly not catch her breath.”

Although the CBI is a disease-specific scale intended to specifically measure the burden experienced by caregivers or parents of children suffering from allergic disorders, the content of the final CBI seemed to include some generic items that may also be applicable to other chronic conditions. The reasons for this may be that, first, in order to incorporate three different allergic disorders (asthma, allergic rhinitis, and atopic dermatitis), the content of the CBI scale needed to be modified and some disease-specific terms needed to be

“sacrificed”. For instance, parents usually complain of not getting enough rest or sleep at night because they are caring for their CWA. We therefore formulated an item to assess this concern on our scale (“I did not get enough sleep and/or rest because I was taking care of my child with allergies”). But the reason that parents of children with asthma do not get sufficient sleep at night (e.g., an asthma attack) may not be the same as the reason caregivers of children with atopic dermatitis (e.g., serious itching and scratching) or allergic rhinitis (e.g., difficult breathing because of a stuffy nose) do not get sufficient sleep. However, it did not seem to be practical or necessary to separate this item into three different parts to delineate different allergic conditions, since they all represent a general concern faced by parents of CWA.

Second, to establish more convincing evidence supporting the construct validity for this scale, some disease-specific items were deleted during the factor analysis process. Those items were—“I feel a loss of freedom because I have to closely watch my child with allergies” and “I am worried about the change in the condition of my child with allergies”. Parents of CWA have to pay close attention to their children and constantly worry about any incidental changes in their child’s condition (Yawn, 2003). Although these two dropped items reflected a characteristic aspect of concerns experienced by parents regarding providing care for their CWA, they were not incorporated into the final version (20 items) due to low factor loading (<0.50).

Third, the main purpose of this scale was to explore the overall caregiver or parental burden experienced by parents of CWA. However, parents of CWA also encounter stressful life events such as moving to a new residence, changing schools, job loss, or family conflicts that are similar to those encountered by parents of children without allergic disorders or any other health concerns. Therefore, it is not surprising to see that some generic items seemingly applicable to other populations with or without any health concerns (e.g., interference with personal life schedule or unable to manage daily life events successfully) are included in the scale.

In summary, to our knowledge this is the first instrument specifically designed to measure the caregiver burden experienced by parents of CWA. Though this scale was developed based on a sample of parents living in Taiwan, the three factors extracted from this scale may suggest that parents from different countries experience similar concerns while caring for their CWA (Chamlin et al., 2004; Townsend et al., 1991). The three factors extracted from this scale points out the underlying constructs of caregiver burden perceived by parents of CWA in Taiwan. Compared with other disease-specific instruments designed for only a single type of allergic disease, this scale is more practical targeting combinations of different allergic disorders, especially since the comorbidity of several allergic conditions is not uncommon (Baiardini et al., 2003; Zheng, Yu, Oh, & Zhu, 2011).

Study Limitations and Suggestions for Future Research

Several limitations need to be addressed before this scale can be readily applied in future investigations. With the limited sample size recruited in the field test, the generalizability of the findings of this study may be compromised. Although we intended to incorporate both fathers and mothers (either one) of children with asthma and/or allergic rhinitis and/or atopic dermatitis who had varying levels of education into the study, the majority of the caregivers included were mothers that had an education level of 2-year college/4-year university or higher (Table 1). This homogeneity may limit the generalizability of this study. However, the strategy of random sampling adopted during the field test may improve the representativeness and generalizability of this study. Although mothers are presumed to be the primary caregivers in traditional Chinese societies, evidence suggests that fathers are taking more responsibilities as primary caregivers of children (Wu, 2008). Future studies with a larger sample including more parents, especially fathers, are highly recommended to further consolidate the psychometric properties of the CBI scale. In addition, the reading level of the scale needs to be further evaluated by a more diverse sample as a significant portion of the participants in this study were highly educated.

Another limitation that may be considered is the application of this scale to other cultural populations. This instrument was mainly developed based on the parenting or caregiving experiences shared by a group of Taiwanese parents. Parents from different cultural backgrounds may convey different concerns while providing care for their CWA. For instance, one item mentioned in the final CBI version is “loss of appetite”; however, parents from different countries or cultures may suffer from different stress-induced psychological or physical consequences such as eating behavior change or weight gain, rather than loss of appetite when threatened by an increasing burden from taking care of a chronically ill child (Smith, Baum, & Wing, 2005). Not only language translations, but also other modifications may be needed to make this scale more suitable for other cultural groups. In addition, we found from the meeting of the focus group that parents tend to avoid the term “asthma” and are reluctant to admit that their children have been diagnosed with asthma. This may be a unique attribute presented by Taiwanese parents of CWA, and future investigations may be needed to further explore this phenomenon.

Future studies should include surveys on a larger scale and the concurrent application of the index with other established instruments including the Parenting Stress Index (PSI) and health-related quality of life (HRQL) measures to test and establish the psychometric properties and validity of the CBI scale. By conducting more large-scale studies in the future, researchers will benefit from a larger sample including a wider spectrum of allergic diseases and conduct test–retest analysis to improve predictive and convergent validity. Also, comparisons among different subgroups (e.g., asthma vs. atopic dermatitis;

Chinese vs. Japanese caregivers; fathers vs. mothers and so on) can be achieved by incorporating a more heterogeneous sample.

Conclusion

This paper reports a preliminary attempt to construct an allergy-specific CBI to explore the caregiving burden experienced by parents of CWA. The study findings provide evidence suggesting that this scale has sufficient internal consistency with three separate dimensions underlying the caregiver burden. As one of the most prevalent childhood chronic diseases, allergic disorders impact a great number of children and parents. As parents are assumed to undertake most caregiving responsibilities, the caregiver burden resulting from providing healthcare to CWA needs more in-depth and specialized evaluation to help parents and families cope with the caregiving demands brought on by their children in their daily life. It is hoped that the use of this specific instrument, which measures caregiver burden as perceived by this group of parents, clinical nurses, and healthcare providers, can provide more understanding about the level of burden confronted by parents and therefore lead to more focused and effective interventions.

Relevance to Clinical Practice

To our knowledge, this is the first scale developed specifically to measure the caregiving burden perceived by parents taking care of CWA. By applying this disease-specific instrument measuring the impact perceived by parents while caretaking their CWA, nurses and healthcare providers can better understand the difficulties and challenges faced by these parents so that more effective interventions can be developed and provided targeting their needs.

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