



Psychometric Properties of the Turkish Version of Caregiver Burden Index (CBI) for Parents of Children with Allergies



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ABSTRACT

Childhood chronic diseases have a great impact, including physiological, social and financial burdens, on parents. The concept of “caregiver burden” is gaining importance to understand the effects of allergic diseases and plan family-centered strategies.

Purpose: The purpose of this study was to examine the psychometric properties of the Caregiver Burden Index (CBI) in Turkish mothers of children with allergies.

Method: The participants of this methodological study were 213 mothers of children with allergies between 6 and 12 years. Construct validity was evaluated through factor analysis and reliability was evaluated through internal consistency and item-total correlation.

Results: In reliability analysis, the overall Cronbach's alpha value (0.85) demonstrated a high level of reliability. The corrected item-total correlation varied between 0.63 and 0.84. In exploratory factor analysis, it was detected that 3 factors structure explained 73.6% of the total variance.

Conclusion: This study indicated that the CBI is a valid and reliable tool to assess the caregiver burden of mothers of Turkish children with allergies.

Implication for Practices: The results of this study contribute to the development and implementation of evidence based models of care that address the caregiver burden needs of parents whose children have allergies.

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Introduction

Allergic diseases are among the most common diseases affecting children worldwide (World Health Organization, 2007). An allergic condition is a hypersensitivity disorder in which the immune system reacts to normally harmless materials. Food allergies, respiratory allergies, and skin allergies are the most common types of allergies in children. Allergic reactions may threaten the life due to their sudden impacts. In addition, neglect of symptoms may exacerbate the effects of the disease (Cantani, 2008; Jackson et al., 2013).

Even though providing care is a normal and routine part of a parent's life, parenting the child with a chronic disease is assessed in a different perspective (Khanna et al., 2015). Besides daily-life needs, supplying special care can affect not only parents' resources, including time, finances, and relations, but also their health (Khanna et al., 2015; Wijesinghe et al., 2015). The load, appearing as the result of providing care and experienced difficulties, is conceptualized as “caregiver burden” (Chow et al., 2013; Deeken et al., 2003; Raina et al., 2004).

Caregiver burden indeed is characterized by the experience of load; imbalance between perceived demands and resources might cause the feeling of desperation (Chou, 2000; Parham et al., 2016). Today, research on the multidimensional understanding of a patient and his family's caregiving load has gained importance in nursing literature, particularly in terms of the design and implementation of efficient caring strategies (Raina et al., 2004).

The effect of a chronic disease on caregivers is generally a remarkable issue, but it is a crucial issue for pediatric patients because disease management is always shared by the child and his parents (Majani et al., 2005; Price et al., 2002). It is highly important to assess the burden of caregivers and to provide care according to their needs in order to protect them from adverse biopsychosocial consequences. Unmet needs of caregivers and their high level of burden might hinder caregiving competencies and ongoing support system for patients (Chou et al., 2003; Deeken et al., 2003).

Parents, as primary caregivers, of pediatric diseases have to overcome a heavy psychosocial burden as well as the burden of the disease (Al-Akour & Khader, 2009; Brehaut et al., 2004). Personal difficulties and exhaustion are the most important issues in studies for parents of children with allergies (Koehler et al., 2014; Lau et al., 2014; Majani et al., 2005). The major challenges encountered by parents in managing allergic childhood diseases are divided into nine major areas: sleep issues,

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time management, lifestyle changes, treatment issues, social impacts, school and daycare, family activities, financial stresses, and personal strain (Carroll et al., 2005; Lau et al., 2014). Treatment and healthcare activities for allergic diseases involve time-consuming procedures and, therefore, markedly reduce the time a parent may spend with other family members. The lifestyle changes brought about by caregiving can reduce parents' coping skills and cause burden (Majani et al., 2005; Nagano et al., 2010).

Numerous studies have been carried out in recent years to measure the responses of pediatric caregivers. In these studies, quality of life is frequently utilized as a benchmark to evaluate caregiver burden. Although quality of life is a general benchmark; the effects of a disease on one's daily life and emotions may be determined more clearly by disease-specific instruments. Such instruments can also guide nurses in planning evidence-based practices. The purpose of this study was to investigate the psychometric properties of the Caregiver Burden Index (CBI) among Turkish parents of children with allergies. This study also increases awareness for the need to translate the questionnaire into other languages and provide opportunities for cross-cultural comparisons.

Method

Design and Setting

This hospital-based methodological study was conducted between February and April 2016 in Istanbul, Turkey. Parents of children with allergies were selected from the pediatric outpatient clinic of a public hospital.

Sample

The sample size was calculated based on a criterion of at least 10 participants for each item for exploratory factor analysis (Costello & Osborne, 2005). Because the study tool includes 20 items, and at least 200 participants needed to be included in the study. Over the three-month duration of this study, 213 mothers of 213 children were recruited. Children aged between 6 and 12 years and diagnosed having an allergy, such as food allergies, animal allergies, and respiratory allergies, with a duration of at least 6 months were included in the study. The presence of a chronic disease in addition to the allergy (e.g., epilepsy, diabetes mellitus) was an exclusion criterion.

Instruments

Demographic Information Form

A form was used to collect information on the children's age, gender, allergies, and duration of allergy, as well as the parents' age, education level, and employment status. This form consisted of 12 questions.

Caregiver Burden Index for Parents of Children With Allergies (CBI)

The questionnaire developed by Liu et al. (2015) is comprised of 20 items aiming to evaluate the perceived caring experiences of parents with children who have allergies. The questionnaire includes three subscales (i.e., constraints on personal and family life, psychological distress, and physical health complaints) and is graded using a five-point Likert type (i.e., 5 = extremely serious, 4 = serious, 3 = ordinary, 2 = little, 1 = not at all). The scores of the "physical health complaints," "psychological distress," and "constraints on personal and family life" subscales could range from 4 to 20, 9 to 45, and 7 to 35, respectively, and the total scores of the tool could range from 20 to 100. Each item of the tool refers to subjective reports provided by the caregivers within the last 2 weeks. A high score implies more difficulty experienced during caregiving.

In this study, translation and adaptation of the scale into Turkish was performed according to the principles recommended by the Report of the ISPOR Task Force for Translation and Cultural Adaptation (Wild et al., 2005). The scale was translated via the forward-and-backward translation method. The original CBI was primarily translated from English into Turkish by two linguists on an item-by-item basis. Then, it was translated back into English by two other bilinguals to check the content-suitability of the translated text to the English text. The Turkish translation of the scale was presented to 10 specialist pediatric nurses to determine its intelligibility and cultural conformity. Content validity was achieved via wording or sentence corrections made on the basis of expert suggestions.

Pilot Study

Once the translation process was completed, the clarity, comprehensibility, and legibility of the translated scale were assessed through a pilot study. Data for the pilot study were collected from 10 mothers who were not included in the study. To ensure test–retest reliability, the scale was re-applied to the participants of a pilot study 2 weeks later. The Kappa test was utilized to determine the test–retest reliability of the pilot study, and Kappa values between 0.79 and 0.87 were obtained. Furthermore, Kappa values of 0.79–0.83, 0.82–0.85, and 0.84–0.87 were respectively obtained for the subscales of psychological distress, constraints on personal and family life, and physical health complaints. The translation was put through a final review in order correct any spelling, grammar or other errors after the pilot study. Finally, the scale was approved as acceptable to gather data from the target group and apply the succeeding psychometric tests.

Ethical Considerations

This study was approved by our institution's ethics committee, and the required permissions were obtained from the hospital where the study was carried out. Each participant was informed about the purpose and privacy of the study, and willing parents signed informed consent forms after providing verbal permission. Participation was completely voluntary and all of the responses were recorded confidentially. Permits required for CBI use were obtained from Dr. Bih-Shya Gau prior to the study.

Data Analysis

Descriptive statistics were presented as percentages, frequencies, means and standard deviations. The reliability and validity of the scale were evaluated in terms of the total scale and each subscale. Total questionnaire and subscales' internal consistency reliability was examined by computing Cronbach alpha coefficient, 0.70 and above value was considered as satisfactory.

The Kappa test was used for test–retest reliability analysis, and reference values for the magnitude of agreement were taken from Landis

Table 1
Sample characteristics (N = 213).

Variable	% (n)	Mean	SD
Age of parents (years)		33.0	6.2
Education of caregivers			
Primary	44.6 (95)		
High school	33.8 (72)		
University	21.6 (46)		
Ages of children (years)		8.5	3.8
Genders of children			
Boys	55.4 (118)		
Duration of disease (years)		7.8	4.1
Presence of allergic story in the family	58.7 (125)		

Table 2
Cronbach's alpha coefficients, mean values of total scale and sub-scales.

	Cronbach's alpha	Total mean scores	SD
Physical health complaints	0.76	10.80	3.46
Psychological distress	0.80	33.91	5.95
Constraints on personal and family life	0.83	19.03	4.90
Total scale	0.85	63.73	12.73

and Koch (1977). As defined by them, ranges of Kappa values of <0.20 were applied to indicate slight agreement, 0.21–0.40 indicated fair agreement, 0.41–0.60 indicated moderate agreement, 0.61–0.80 indicated substantial agreement, and 0.81–1.00 indicated nearly perfect agreement (Landis & Koch, 1977). Construct validity, factor analysis, and principal component analysis were assessed by varimax rotation. The suitability of the sample for factor analysis was confirmed by the Kaiser-Meyer-Olkin (KMO) and Bartlett's tests. Minimum factor loading coefficient was accepted as 0.30 to keep each item in the scale (Kimberlin & Winterstein, 2008). All statistical analyses were performed using the SPSS statistical package (Version 22; IBM SPSS Statistics, Armonk, NY), and p -value < 0.05 was considered statistically significant.

Results

The mean age of the caregivers was 33.0 ± 6.2 years (range = 23–50 years) and all of them were mothers. Ninety-five of the mothers (44.6%) were primary school, 72 of them (33.8%) were high school, and 46 of them (21.6%) were university graduates; 85 of them (39.9%) had an occupation. The mean age of the children were 8.5 ± 3.8 years (range = 6–12 years), and the average length of time since disease diagnosis was 7.8 ± 4.1 years. The demographic characteristics of the participants are presented in Table 1.

Reliability

The reliability of the CBI was determined through Cronbach's alpha, corrected item-total correlation, and alpha-if-item-deleted analysis. The total-scale Cronbach's alpha coefficient was found to be 0.85. Cronbach's alpha, the mean values of items, standard deviations are shown in

Table 4
Test-retest reliability of the Caregiver Burden Index (CBI).

	Test-retest correlations	Weighted κ
Physical health complaints	0.73	0.79–0.87
Psychological distress	0.79	0.71–0.74
Constraints on personal and family life	0.80	0.81–0.83
Total scale	0.83	0.73–0.87

Table 2. The corrected total-item correlations were varied between 0.63 and 0.84 (Table 3).

Test-retest Reliability

CBI test-retest reliability was confirmed and the scale was re-applied 4 weeks after the initial study to evaluate its stability. The retest sample group consisted of 38 mothers with a mean age of 32.3 ± 4.7 years. The Kappa test was used to calculate test-retest reliability. The overall scores yielded Kappa values between 0.73 and 0.87, while the subscales of psychological distress, constraints on personal and family life, and physical health complaints yielded Kappa values of 0.71–0.74, 0.81–0.83, and 0.79–0.87 respectively. The weighted kappa value suggested for total and sub-scales which was 0.40 was exceeded. Furthermore, the test-retest correlation coefficients of the total CBI and subscale scores were well above the suggested value of 0.70 (Table 4).

Construct Validity

The normality and sphericity criteria of the scale were identified via the Kaiser-Meyer-Olkin (KMO) and Bartlett sphericity tests. Test results were satisfactory, and the sample was considered suitable for factor analysis. The KMO test yielded a value of 0.861, and the Bartlett's test yielded a value of 3118.43 ($df = 190.00$, $p = 0.000$). Factor analysis confirmed the three-factored structure of the scale. Table 5 shows the factor loadings for each item.

Discussion

The treatment and healthcare of a child with allergies can be a burden for parents with additional responsibilities and bring dramatic changes that may affect parents' lives significantly (Lau et al., 2014; Price et al., 2002). The nature of allergic diseases, including the diversity of their symptoms, various comorbidities, and unpredictable progress,

Table 3
Corrected item-total correlation and alpha if item deleted of Caregiver Burden Index.

	Item mean (SD)	Corrected item-total correlation	Cronbach's α if item deleted
I did not get enough sleep and/or rest due to caretaking my allergic child.	3.07 (1.29)	0.63	0.89
I feel tired because I am taking care of my allergic children.	3.05 (1.09)	0.65	0.91
I feel loss of appetite due to caretaking my allergic child.	1.64 (0.91)	0.72	0.88
I feel my physical condition getting poor due to caretaking my allergic child.	1.61 (0.81)	0.68	0.90
I have to adjust my personal schedule due to caretaking my allergic child.	3.04 (1.05)	0.70	0.89
I feel a sense of physical stress due to caretaking my allergic child.	2.25 (1.17)	0.73	0.93
I feel a sense of psychological tension due to caretaking my allergic child.	2.14 (1.02)	0.78	0.91
I feel depressed due to caretaking my allergic child	1.27 (0.76)	0.65	0.89
I feel helpless and frustrated due to caretaking my allergic child.	1.53 (0.91)	0.80	0.96
I feel worried that I won't be able to take care of my allergic child for a long period of time.	3.43 (1.18)	0.77	0.92
I feel that my allergic child is over-dependent.	3.00 (1.36)	0.69	0.90
I lose my temper more often because I am taking care of my allergic child.	1.62 (0.82)	0.84	0.87
I had more quarrels with other family members due to caretaking my allergic child.	1.46 (0.79)	0.82	0.94
I was unable to manage daily life events successfully due to caretaking my allergic child.	1.86 (0.85)	0.79	0.96
I had experienced a loss of personalized or private time due to caretaking my allergic child.	3.27 (1.11)	0.67	0.92
I had limited connection to families and relatives due to caretaking my allergic child.	1.72 (0.96)	0.70	0.88
I had limited opportunities to participate community or religious activities due to caretaking my allergic child.	2.35 (1.21)	0.66	0.93
I had limited chances to have the leisure time due to caretaking my allergic child.	3.16 (1.10)	0.79	0.90
The daily-life of the whole family was interrupted because of the allergic child.	1.60 (0.85)	0.83	0.89
I was unable to work and earn money due to caretaking my allergic child.	2.32 (1.60)	0.72	0.93

Table 5

Factor loadings for the 20 items in the Caregiver Burden Index (CBI).

Items	Factor 1	Factor 2	Factor 3	Name of factors
1. I did not get enough sleep and/or rest due to caretaking my allergic child.	0.78			Physical health complaints
2. I feel tired because I am taking care of my allergic children.	0.69			
3. I feel loss of appetite due to caretaking my allergic child.	0.67			
4. I feel my physical condition getting poor due to caretaking my allergic child.	0.61			
5. I have to adjust my personal schedule due to caretaking my allergic child.		0.84		
14. I was unable to manage daily life events successfully due to caretaking my allergic child.		0.81		Constraints on personal and family life
15. I had experienced a loss of personalized or private time due to caretaking my allergic child.		0.75		
16. I had limited connection to families and relatives due to caretaking my allergic child.		0.72		
17. I had limited opportunities to participate community or religious activities due to caretaking my allergic child.		0.71		
18. I had limited chances to have the leisure time due to caretaking my allergic child.		0.68		
19. The daily-life of the whole family was interrupted because of the allergic child.		0.63		Psychological distress
6. I feel a sense of physical stress due to caretaking my allergic child.			0.88	
7. I feel a sense of psychological tension due to caretaking my allergic child.			0.84	
8. I feel depressed due to caretaking my allergic child.			0.81	
9. I feel helpless and frustrated due to caretaking my allergic child.			0.78	
10. I feel worried that I won't be able to take care of my allergic child for a long period of time.			0.77	
11. I feel that my allergic child is over-dependent.			0.69	
12. I lose my temper more often because I am taking care of my allergic child.			0.67	
13. I had more quarrels with other family members due to caretaking my allergic child.			0.65	
20. I was unable to work and earn money due to caretaking my allergic child.			0.60	

can interrupts parents' daily life such as additional time needed from work for physician appointments, home-care arrangements, and time management and treatment issues can present heavy burdens to parents (Al-Akour & Khader, 2009; Carroll et al., 2005). Simultaneously, efforts to meet the child's health care needs and parental responsibilities can also increase the stress levels of a parent. Identifying specific challenges experienced by parents as caregivers of children with allergies is a key to develop effective interventions (Liu et al., 2015).

In this study, the psychometric characteristics of the CBI were examined for Turkish mothers. We utilized classical test methods to evaluate the psychometric characteristics of the questionnaire. The translation of the original text from English to Turkish and vice versa was performed by qualified linguists. The scale represented a high level of similarity with its original form following translation. Content validity, which usually depends on the decision of professionals in the absence of statistical tests to identify the presence of the desired features was used to determine the validity of the items in the scale (Kimberlin & Winterstein, 2008). In this study, the content validity of each of the items in the CBI was evaluated by pediatric nursing professionals with at least a Master's degree. The results of this evaluation indicated good content validity (86.0%).

Factor analysis and varimax rotation were used to examine the construct validity of the scale. Analysis of the results indicated that three factors similar to those in the original form could be identified from the 20 items of the translated scale. The exploratory percentages of each of these factors indicated that "constraints on personal and family life" could explain 30.0%, "physical health complaints" could explain 25.6% of the total variance, and "psychological distress" could explain 18.0%. In the original form, the first factor "constraints on personal and family life" explained 28.2% of the total variance and the second factor "psychological distress" explained 26.6%, and the third factor "physical health complaints" explained 20.6% of the total variance. "Constraints on personal and family life" factor is the most exploratory one in Turkish version as it was in its original form.

In this study, the internal consistency of the Turkish version of the CBI and its three subscales was measured by Cronbach's alpha, and values consistently >0.70 were obtained. The overall Cronbach's alpha coefficient obtained was 0.85. Liu et al. (2015) found that the Cronbach's alpha coefficient of the original form as 0.97. Factor analysis confirmed the three-factored structure of the scale, similar to that of the original form. Because total-item correlations were higher than 0.45, we did not remove any item from the original form in the translated version.

Parenting to children with health problems is highly complicated and stressful (Carroll et al., 2005; Feeley et al., 2014; Lau et al., 2014).

Since parents are primary caregivers and decision makers in the disease management of pediatric diseases, children are dependent on their parents for follow-up and additional care (Carona et al., 2014; Koehler et al., 2014). Caring for children with chronic diseases requires a combination of physical and emotional responsibilities and parenting practices (Khanna et al., 2015; Price et al., 2002). In order to evaluate and reduce the caregiver burden of parents, nursing interventions must be developed using more comprehensive data. Adaptation of the Chinese version of the CBI is a major step toward testing the validity of the form in different languages and cultures.

Limitations

The most important limitation of this study is that comparison of psychometric results is difficult because the form has not been adapted in any other language but Chinese. Wider dissemination of the tool in future studies is recommended.

Conclusion

The results of this study support the view that CBI is a reliable tool to evaluate the burden of Turkish mothers having children with allergies. Specific tools focusing on challenges experienced by caregivers may help identify their needs and promote the planning a longitudinal evaluation of an intervention that will include the use of this tool. The results of this study, focusing on burden experienced by caregivers, are going to guide the pediatric nurses to determine the needs of caregivers and to plan appropriate interventions.

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