Original Article

Evaluation of Psychometric Properties of the Caregiver Burden Inventory in Parents of Iranian Children Suffering from Cancer

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ABSTRACT

Background: The parents of children with cancer suffer from different physical and psychological health problems due to the burden of caregiving to their ill children. The Caregiver Burden Inventory (CBI) is among the most commonly used instruments for caregiver burden assessment. There is no data about its psychometric properties among the parents of children with cancer in Iran. **Objectives:** This study aimed to evaluate the psychometric properties of the caregiver burden inventory in parents of Iranian children suffering from cancer. **Methods:** This methodological study was conducted from April to September 2018 in the southwest of Iran. CBI was translated into Persian through the forward–backward method, and its face and content validity were assessed through both qualitative and quantitative methods. Then, its construct validity was assessed using exploratory and confirmatory factor analyses, and its reliability was assessed using the internal consistency and the test-retest stability assessment methods. The data for exploratory and confirmatory factor analyses were obtained from two separate samples of 125 parents. **Results:** From the 24 items, two items were deleted during content validity assessment due to their incompatibility with the Iranian culture. The impact scores, content validity ratios, and content validity indices of the remaining 22 CBI items were respectively more than 1.5, 0.46–1, and 0.80–1, and the scale-level content validity index was 0.8. Exploratory factor analysis revealed a five-factor structure for the Persian CBI which explained 64.24% of the total variance. Confirmatory factor analysis confirmed the five-factor structure. The Cronbach's alpha and the test-retest intraclass correlation coefficient of the Persian CBI were 0.907 and 0.90, respectively. **Conclusion:** The Persian CBI has acceptable psychometric properties and can be used to assess caregiver burden among the parents of children with cancer in Iran.

KEYWORDS: *Burden, Cancer, Caregiver, Children, Parents, Reliability, Validity*

INTRODUCTION

Cancer is a life-threatening disease. Its prevalence among Iranian children is around 2%.[1] Children with cancer face different challenges and experience different physical, emotional, and behavioral problems during cancer treatment.[2] These problems not only affect the afflicted children but also face their families with a wide range of challenges.[3] Stress is the main problem which affects the life of these parents.[1] Studies show that compared with the mothers of healthy children,

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mothers who care for children with cancer suffer from more acute emotional distress and have lower health status in the 1st year after cancer diagnosis.[4,5] The parents of these children experience problems such as sleep deprivation, eating disorders, and psychological distress and have inadequate time to address their own needs and the other family members.[6] They also have low levels of satisfaction with their financial status, cannot use effective coping strategies, and hence, are at risk for physical and psychological health problems[3] and need professional and social support.[1,7] Moreover, they carry a heavy caregiving burden, which negatively affects their quality of life.

Understanding the caregiving burden, also known as caregiver burden, is important for the development and the implementation of proper interventions.[3] In recent years, some studies focused on caregiver burden assessment among the parents of children with cancer[1,7] and other chronic conditions,[8] as well as the caregivers of elderly people and patients with chronic illnesses such as Alzheimer's disease and multiple sclerosis.[9-13] Some of these studies used the Caregiver Burden Inventory (CBI) for caregiver burden assessment.[11,13]

Developed by Novak and Guest in 1989, CBI has frequently been used to assess burden among the caregivers of patients with old ages, surgery, Alzheimer's disease, and multiple sclerosis.[14-18] This scale has also been validated for the caregivers of patients with chronic spinal cord injury and patients with Alzheimer's disease in Iran.[11,13] Moreover, it has been used to assess caregiver burden among nurses who provided care to medical and surgical patients.[5] Based on the results of exploratory factor analysis in a former study, the Persian version of this inventory had two main factors, which explained 64% of the total variance of caregiver burden. These two factors were physical, developmental, and time-dependent burdens as well as social and emotional burdens. That study also reported Cronbach's alpha of time-dependent (0.85), developmental (0.85), physical (0.86), social (0.73), and emotional (0.77) for the inventory.[5]

The widespread use of CBI for burden assessment among the caregivers of patients with different conditions in different areas of the world implies that it is clearer and more comprehensive than the other caregiver burden assessment tools such as the scale developed by Zarit and Robinson.[9,10] However, this scale is not available for caregiver burden assessment among the parents of children with cancer in Iran. The Persian version of CBI adapted for the caregivers of patients with Alzheimer's disease, or other conditions is not applicable to the parents of children with cancer because these children and their parents differ from patients with Alzheimer's disease and their caregivers regarding their age and physical and psychological conditions. Therefore, the adaptation of this inventory for the parents of children with cancer in Iran is necessary.

Objectives

This study aimed to Evaluation of psychometric properties of the caregiver burden inventory in parents of Iranian children suffering from cancer.

Methods

This methodological study was conducted from April to September 2018 in the southwest of Iran. The study was conducted in two main phases, namely CBI translation and CBI psychometric evaluation.

Phase I. caregiver burden inventory translation

CBI is a self-report questionnaire with a five-point Likert-type scoring scale. It consists of 24 items in five dimensions, namely, time-dependence burden, developmental burden, physical burden, social burden, and emotional burden. Items are scored 0–4, resulting in a total score of 0–96. It can be completed in 15 min. Higher CBI scores are indicative of greater perceived caregiver burden. There is no cutoff score for CBI.[2]

For CBI translation through the forward–backward method, two bilingual translators translated the inventory into Persian. Then, the two translations were compared and merged to create a single translation. Another translator was invited to back-translate the Persian CBI into English. The authors, the first two translators, and a nurse from the pediatric cancer support group compared the original CBI and the translated English CBI with each other and agreed on their conceptual similarity. Accordingly, the Persian translation of CBI was approved.

Phase II; caregiver burden inventory psychometric evaluation

The psychometric properties of CBI assessed in the present study were face validity, content validity, construct validity, and reliability.

Face validity assessment

The face validity was assessed using both qualitative and quantitative methods. Accordingly, 25 parents of children with cancer were asked to comment on the wording, grammar, relevance, and comprehensibility of each CBI item. Moreover, they rated the importance of each item using a five-point scale from 1 ("Not important at all") to 5 ("Very important"). Their rating scores were used to calculate the impact score of CBI items. Items with impact scores more than 1.5 were considered appropriate.[15]

Content validity assessment

Content validity was also assessed using both qualitative and quantitative methods. In the qualitative method, 17 experts with at least a master's degree in nursing, clinical work experience of at least 2 years, and familiarity with instrument development were invited to comment on the wording, grammar, relevance, and comprehensibility of the CBI items. They included 12 nurses with PhD degree and 5 oncology nurses from pediatric wards. In quantitative content validity assessment, the same experts assessed the items in terms of their usefulness and essentiality. Their rating scores were used to calculate the content validity ratio (CVR) of each item. CVR values more than 0.45 were considered acceptable. Then, necessary revisions were made to CBI, and it was returned to the same experts to rate the relevance, simplicity, and clarity of its items from 1 to 4 using a four-point Likert-type scale. Based on their responses, the content validity index (CVI) was calculated for each CBI item and also for the whole CBI. Items with CVI values >0.8 were considered appropriate.[19]

Construct validity assessment

Construct validity was assessed through exploratory and confirmatory factor analysis.

Exploratory factor analysis

The sample size for exploratory factor analysis was calculated using the rule of 3–10 persons per item.[19] Accordingly, 125 parents, either fathers or mothers, of children with cancer were conveniently recruited. Inclusion criteria were no affliction by physical or mental health problems, ability to read and write in Persian, agreement for participation in the study, and having a child diagnosed with cancer at least 3 months before the study with at least one course of hospitalization. Recruited parents were asked to respond to CBI items. The exclusion criterion was no answer to more than five of the CBI items. However, no one excluded from the study.

Exploratory factor analysis was conducted with varimax rotation, eigenvalues >1.0, and factor loading values >0.40. The sample was considered adequate if the Kaiser–Meyer-Olkin value was more than 0.5.[20]

Confirmatory factor analysis

A new sample of five parents per item (125 parents in total) was selected for confirmatory factor analysis.[19] Confirmatory factor analysis was conducted using the AMOS 20 software (v20, 5725-A60, Microsoft Corporation, Chicago, IL, USA). The model was considered to be fit based on the following criteria: goodness of fit index (GFI) >0.90; root mean square error of approximation (RMSEA) <0.08; Tucker-Lewis Index (TLI) >0.90; Normed Fit Index (NFI); and Comparative Fit Index (CFI) >0.90.[21]

Reliability assessment

CBI reliability was assessed using the internal consistency and the test-retest stability assessment methods. For internal consistency assessment, the data obtained from the 125 participants in exploratory factor analysis were used to calculate Cronbach's alpha. Cronbach's alpha >0.7 was interpreted as acceptable internal consistency.[22] For test-retest stability assessment, the first 60 participants in exploratory factor analysis were asked to re-complete CBI with a 2-week interval. Then, test-retest intraclass correlation coefficient (ICC) was calculated.

Ethical considerations

The Ethics Committee of Shiraz University of Medical Sciences, Shiraz, Iran, approved this study (Approval code: IR.SUMS.REC1396.S728). Participants were informed about the aim and the methods of the study and were ensured of data confidentiality and voluntary participation throughout the study. Written informed consent was obtained from all participants at the time of sample recruitment.

Data analysis

The SPSS software (version 22.0, SPSS Inc., Chicago, IL, USA) was used for data analysis. Descriptive statistics measures (such as absolute frequency, relative frequency, mean, and standard deviation) were used for data presentation. The normality of the data was tested through the Kolmogorov–Smirnov test. Then, the independent-sample *t*-test and the one-way analysis of variance were used to compare CBI scores based on participants' sociodemographic characteristics. The AMOS 20 software was used for confirmatory factor analysis.

Results

The results of face validity assessment

In face validity assessment, all 25 participating parents approved that the CBI items were simple, clear, and related to caregiver burden. Moreover, the impact scores of all items were more than 1.5 [Table 1].

The results of content validity assessment

In qualitative content validity assessment, the experts declared that the following four items were inappropriate for the Iranian culture: "I resent my care receiver," "I feel that I am missing out on life," "I feel angry about my interactions with my care receiver," and "I feel uncomfortable when I have friends over." Six experts highlighted that parents, particularly mothers, spend all their time and energy to care for their children and may sometimes get angry with themselves, not with their children. Thus, they suggested the exclusion of the items

"I resent my care receiver" and "I feel that I am missing out on life." These two items were excluded. They also suggested the revision of the items "I feel angry about my interactions with my care receiver" and "I feel uncomfortable when I have friends over" to respectively "I sometimes get angry about my care receiver's behaviors" and "I don't feel good when I communicate less with my friends due to caregiving." The CVR and the CVI values of all 22 remaining items of CBI were 0.46–1 and 0.80–1, respectively. The scale-level CVI was also 0.8 [Table 1].

The results of construct validity assessment

Participants

In total, 250 parents responded to CBI during exploratory (n = 125) and confirmatory (n = 125) factor analyses. The mean of their age was 38.87 ± 2.48 in the range of 18–53 years. Around 52% of participants were female, 93.60% were married, 40.8% held a high school diploma, and 66.66% had a monthly income of 212–318 Euros. Around 56% of their ill children were male, 61.20% had leukemia, 16.40% had lymphoma, and 22.40% had other types of cancer. Participants' CBI mean score was 69.24 ± 14.90. The highest CBI dimensional score was related to the emotional burden dimension. Participants' mean score of CBI had significant relationships with their age, marital status, monthly income, educational level, employment status, and child's type of cancer [$P < 0.05$; Table 2].

Exploratory factor analysis

The Kaiser–Meyer-Olkin value was 0.75, indicating sampling adequacy. Based on the results of factor analysis, five factors with eigenvalues more than 1 were extracted, which altogether explained 64.26% of the total variance of CBI score. These factors were time-dependent burden (five items), developmental burden (four items), physical burden (four items), social burden (five items), and emotional burden (four items). Factor loading values ranged from 0.42 to 0.70 [Table 3].

Confirmatory factor analysis

Confirmatory factor analysis confirmed the five-factor structure of the Persian CBI with the same factors identified in exploratory factor analysis. ICCs between the score of each of the five dimensions and the total score of CBI were as the following: time-dependent burden = 0.95; developmental burden = 0.92; physical burden = 0.91; social burden = 0.91; and emotional burden = 0.90. ICCs among these factors were 0.89–0.93. The Chi-square test value in confirmatory

Table 1: The impact scores, content validity ratio values, and content validity index values of the Persian Caregiver Burden Inventory items

Items	CVR	CVI	Impact score
My care receiver needs my help to perform many daily tasks	0.73	0.81	4.1
My care receiver is dependent on me	0.86	0.91	4.5
I have to watch my care receiver constantly	0.73	0.86	2.1
I have to help my care receiver with many basic functions	0.86	0.80	2.6
I do not have a minute's break from my caregiving chores	0.73	0.85	2.7
I feel that I am missing out on life	Excluded	Excluded	1.6
I wish I could escape from this situation	0.60	0.92	3.4
My social life has suffered	1	0.80	2.7
I feel emotionally drained due to caring for my care receiver	0.73	0.85	2.4
I expected that things would be different at this point in my life	0.86	0.96	3.2
I'm not getting enough sleep	0.73	0.92	2.4
My health has suffered	0.86	0.82	3.7
Caregiving has made me physically sick	0.46	0.82	3.2
I'm physically tired	0.86	1	2.6
I do not get along with other family members as well as I used to	0.86	0.84	1.8
My caregiving efforts are not appreciated by others in my family	0.73	0.90	2.3
I have had problems with my marriage	0.60	0.85	3.3
I dom to do as good a job at work as I used to	0.86	0.89	2.2
I feel resentful of other relatives who could but do not help	0.60	0.80	3.3
I feel embarrassed over my care receiver's behavior	0.73	0.81	1.8
I feel ashamed of my care receiver	0.73	0.80	1.9
I resent my care receiver	Excluded	Excluded	3.1
I do not feel good when I communicate less with my friends due to caregiving	0.86	0.82	3.9
I sometimes get angry about my care receiver's behavior	0.73	0.8	2.8

CVR: Content validity ratio, CVI: Content validity index

factor analysis was 588.33 (df = 95; P = 0.039), and GFI was 0.92, both confirming the model goodness of fit. Other model fit indices were as the following: RMSEA = 0.03; CFI = 0.92; NFI = 0.91; and TLI = 0.93. All these indices show the goodness of fit of the extracted model [Figure 1].

The results of reliability assessment

The Cronbach's alpha of the 22-item CBI and its dimensions were 0.907 and 0.894–0.921, respectively. The greatest dimensional Cronbach's alpha values were related to the developmental and the physical dimensions [Table 4]. Moreover, test-retest stability assessment revealed that there was no significant difference between the test and the retest readings (P = 0.45), and the test-retest ICC was 0.90. These findings confirmed the internal consistency and the stability of the Persian CBI.

Floor and ceiling effects were also assessed using the data collected from the same 125 parents in exploratory factor analysis. The relative frequencies of participants with the lowest and the highest possible total scores of CBI were equal to zero, implying no floor and ceiling effects.

Table 2: The relationships of participants' mean caregiver burden inventory score with their sociodemographic characteristics

Characteristics	*n* (%)	Mean ± SD	*P*
Parent's age			
18-26	94 (37.60)	68 ± 2.48	0.042[a]
27-35	102 (40.80)	58 ± 2.01	
36-44	50 (20)	61 ± 1.04	
45-53	4 (1.6)	72 ± 3.87	
Parent's gender			
Female	130 (52)	58.91 ± 4.02	0.843[b]
Male	120 (48)	56.21 ± 3.11	
Parent's educational level			
Primary school	33 (13.20)	72.17 ± 1.89	0.012[a]
Guidance school	41 (16.40)	68.98 ± 1.24	
High school	102 (40.80)	62.31 ± 1.01	
College	74 (29.60)	57.91 ± 1.03	
Parent's employment status			
Employee	110 (44.00)	54.31 ± 1.87	0.010[a]
Laborer	88 (35.20)	58.91 ± 1.24	
Unemployed	52 (20.80)	65.31 ± 1.48	
Child's gender			
Male	140 (56)	66.72 ± 1.02	0.553[b]
Female	110 (44)	65.68 ± 2.11	
Parent's marital status			
Married	234 (93.60)	59.01 ± 2.14	0.021[a]
Widowed	10 (4)	65.93 ± 1.12	
Divorced	6 (1.27)	60.36 ± 1.58	
Place of residence			
Shiraz city	120 (48)	63.01 ± 3.51	0.843[b]
Other cities	130 (52)	67.92 ± 1.36	
Cancer type			
Leukemia	153 (61.20)	68.28 ± 2.15	0.010[a]
Lymphoma	41 (16.40)	64.11 ± 1.36	
Other cancers	56 (22.40)	59.78 ± 2.11	
Monthly income (euros)			
106-212	57 (22.8)	72.98 ± 2.04	0.037[a]
212-318	121 (48.40)	68.21 ± 1.97	
318-424	52 (20.80)	64.37 ± 1.08	
>424	20 (8.00)	59.41 ± 1.21	

[a]The results of the one-way analysis of variance; [b]The results of the independent-sample *t*-test. SD: Standard deviation

Discussion

This study aimed to Evaluation of psychometric properties of the caregiver burden inventory in parents of Iranian children suffering from cancer. CBI was translated into Persian, and its validity and reliability were assessed. The CBI items were comprehensible for the parents of children with cancer and were appropriate for the Iranian culture and context. In qualitative content validity assessment, two items were deleted, and in quantitative content validity assessment, the CVR and the CVI values of all remaining 22 items were acceptable. In exploratory factor analysis, the five factors of time-dependent burden (five items), developmental burden (four items), physical burden (four items), social burden (five items), and emotional burden (four items) were identified to explain 64.26% of the total variance. Confirmatory factor analysis also confirmed the five-factor structure of CBI. These findings denote that the Persian CBI is appropriate for the assessment of caregiver burden among the parents of children with cancer in Iran. None of the previous studies assessed the psychometric properties of CBI among the caregivers of patients with cancer. Therefore, the results of the present study are compared with the results of the studies which assessed the psychometric properties of CBI among the caregivers of patients with other health conditions.

In a study conducted by Novak and Guest, CBI was identified to have five dimensions, each accounting for 9%–12% of the total variance and all accounting for 66% of the total variance.[23] Chou *et al*. assessed the content and the construct validity of the Chinese CBI among the caregivers of elderly people with dementia and reported that the CVI of CBI was 0.958 and that the inventory had the same five dimensions identified by Novak and Guest. Of course, the item "I've had problems with my marriage" was allocated to the emotional burden dimension rather than the social burden dimension, and none of the items were excluded.[15] However, in the present study, items "I resent my care receiver" and "I feel that I am missing out on life" were deleted

Table 3: Factor loading values of the caregiver burden inventory items (*n*=250)

Items of the scale	Factor 1 Time-dependent	Factor 2 Developmental	Factor 3 Physical	Factor 4 Social	Factor 5 Emotional
My care receiver needs my help to perform many daily tasks	0.54				
My care receiver is dependent on me	0.62				
I have to watch my care receiver constantly	0.70				
I have to help my care receiver with many basic functions	0.46				
I do not have a minute's break from my caregiving chores	0.42				
I wish I could escape from this situation		0.68			
My social life has suffered		0.59			
I feel emotionally drained due to caring for my care receiver		0.55			
I expected that things would be different at this point in my life		0.60			
I'm not getting enough sleep			0.55		
My health has suffered.			0.48		
Caregiving has made me physically sick			0.52		
I'm physically tired			0.51		
I do not get along with other family members as well as I used to				0.52	
My caregiving efforts are not appreciated by others in my family				0.49	
I have had problems with my marriage				0.69	
I do not as good a job at work as I used to				0.54	
I feel resentful of other relatives who could but do not help				0.48	
I feel embarrassed over my care receiver's behavior					0.43
I feel ashamed of my care receiver					0.42
I do not feel good when I communicate less with my friends due to caregiving					0.45
I sometimes get angry about my care receiver's behavior					0.48
Variance (%)	23.05	11.02	10.11	10.07	10.01

Table 4: The mean scores and the Cronbach's alpha values of the Persian caregiver burden inventory and its dimensions

Dimensions	Mean ± SD	Cronbach's alpha
Time-dependent	14.21 ± 3.29	0.902
Developmental	12.87 ± 2.44	0.921
Physical	10.54 ± 2.11	0. 918
Social	9.35 ± 3.28	0.901
Emotional	9.11 ± 2.01	0.894
Total	56.08 ± 13.13	0.907

SD: Standard deviation

from the emotional and the developmental dimensions, respectively. This contradiction between the studies may be due to the difference between the samples of the studies. The present study was conducted on the parents of children with cancer. Parents may feel greater responsibility toward their ill children and spend a greater deal of time to care for them.

Valer *et al*. assessed the validity and the reliability of CBI in Brazil. To confirm content validity, they adapted the following items to suit the immediate culture and context: "I feel embarrassed over the care receiver's behavior," "I feel ashamed of my care receiver," "I resent my care receiver," "I feel uncomfortable when I have friends over," and "I feel angry about my interactions with my care receiver." Accordingly, they confirmed the qualitative content validity of CBI. Moreover, the inter-expert agreement level in content validity assessment was 80%. Concurrent validity assessment in that study revealed that the ICC between the scores of CBI and the Burden Interview scale was 0.8, and construct validity assessment with no item exclusion showed that the Brazilian CBI had the same five factors as the original CBI. All ICCs between the score of each item and the total score of CBI were more than 0.4.[24] In the present study, the factor structure of the Persian CBI was also similar to that of the original version; however, two items were excluded, and two were revised. The difference between the Persian and the Brazilian CBI versions is attributable to the differences between the studies in terms of their samples and cultural contexts.

Greco *et al*. studied the psychometric properties of CBI among the caregivers of patients with cardiac disorders in Italy and reported the same dimensions as reported by Novak and Guest with no item exclusion or re-allocation.[2] However, four items in the Persian CBI were either revised or deleted because the target population was the parents of children with cancer, while caregivers in previous studies into the psychometric properties of CBI had no family relationships with care receivers.

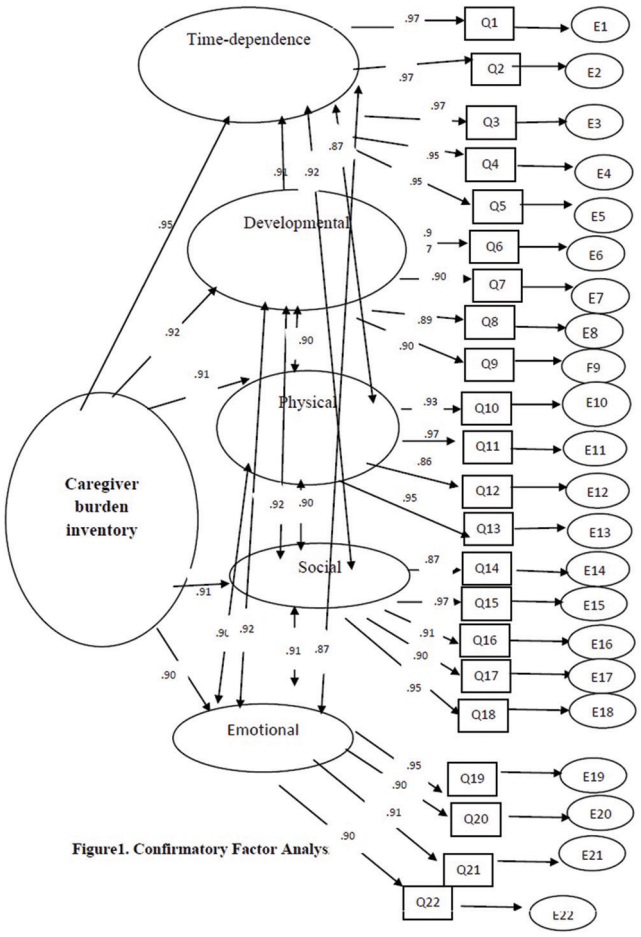

Figure 1: The confirmatory factor analysis model

Study findings also revealed that the Cronbach's alpha of CBI was 0.907, and the greatest dimensional Cronbach's alpha values were related to the developmental and the physical burden dimensions. In line with these findings, Novak and Guest reported that the Cronbach's alpha of the inventory was good, factors time-dependence and developmental obtained an alpha value of 0.85 each. Factors physical, social, and emotional had alpha values of 0.86, 0.73, and 0.77, respectively. In addition, the greatest alpha was related to the physical burden dimension.[23] Other studies also reported that the Cronbach's alpha values of the Brazilian, Chinese, and Italian versions of CBI were 0.936,[24] 0.90,[15] and 0.96,[2] respectively. The highest dimensional Cronbach's alphas in those versions of CBI were also related to the developmental and the physical,[24] the physical,[15] and the emotional and the developmental[2] dimensions, respectively. The high reliability of CBI confirmed in different studies implies the comprehensiveness of its questions.

We also found that the mean of participants' CBI scores had significant relationships with their educational level, marital status, monthly income level, employment status, age, and cancer type in their children. Higher monthly income enables parents to provide more appropriate care to their children. Moreover, a better educational level is associated with better salaries in Iran. Young- and middle-aged parents in the present study reported that they could better tolerate caregiving to their children. Similarly, a study reported that younger parents had more physical ability and greater emotional resilience and hence, had greater ability to care for their cancer-afflicted children.[25] In the Iranian culture, caregiver burden is more on the shoulders of mothers than fathers, particularly in the physical, psychological, and caring dimensions. Compared with divorced and widowed women, married women receive greater family, psychological, and financial support and hence, have greater ability to care for their ill children.[3,7] Cancer type in children also had a significant relationship with caregiver burden. This is in agreement with the findings of a former study which reported that the type of childhood cancer affected the course of the disease and the type of care and treatment for children. That study reported that more severe cancers as well as cancers with longer treatment courses were associated with lower quality of life and poorer health status for both parents and their children and lower care delivery tolerance among parents.[25] One of the study limitations was that the study participants were recruited only from two public health-care centers. The inclusion of parents from private health-care centers could enrich the findings. Countrywide multicenter studies are recommended to improve the generalizability of the findings obtained from CBI application.

Conclusion

This study concludes that the 22-item Persian CBI has acceptable validity and reliability. Nurses can use this inventory to identify the needs of the parents of children with cancer and assess the effects of their interventions on their caregiver burden. Subsequently, they can use need-based interventions to reduce parents' stress and caregiver burden and improve their quality of life.

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Conflicts of interest

There are no conflicts of interest.

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