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RESEARCH

DEVELOPMENT OF THE BURDEN SCALE FOR CAREGIVERS OF DEMENTIA PATIENTS

ABSTRACT

Introduction: The purpose of this study is to develop Scale of Care Burden of Caregivers of Dementia Patients.

Materials and Method: This methodically planned study, 145 caregivers who the care of patients with a diagnosis of dementia in Dementia Outpatient Clinic of Turgut Ozal Medical Center were included. 30-item question pool which was created as a result of literature review, was presented to five specialists in order to evaluate language and content validity. After the arrangements made in accordance with expert opinion, 29-item scale draft has begun to be implemented between the dates of November 2015 and January 2016. In order to determine the construct validity and sub-scales of the scale, factor analysis was conducted. To measure the scale's internal consistency, item analysis (item-total correlations) and Cronbach Alpha Reliability Coefficient were evaluated. In order to conduct reliability study and for invariance principle according to time, after 30 days the data has been reached again and the correlation coefficient was calculated by using retest method.

Results: Cronbach's Alpha value was found to be .88. For construct validity of the scale, as a result of the factor analysis, care burden scale is consisted by four factors as social (7 items), psychological (10 items), physical (4 items) and economic (3 items). As a result of factor analysis, the questionnaire was evaluated over 24-items. When the invariance according to time of the scale was evaluated with test and re-test analysis, there was no difference between the both two applications ($p>0.05$).

Conclusion: The scale was found highly valid and reliable.

Keywords: Dementia; Caregivers; Nursing

ARAŞTIRMA

DEMANS LI HASTALARA BAKIM VERENLERDE BAKIM YÜKÜ ÖLÇEĞİNİN GELİŞTİRİLMESİ

Öz

Giriş: Bu araştırma demanslı hastalara bakım verenlerde oluşan bakım yükü ölçeğinin geliştirilmesi amacıyla planlanmıştır.

Gereç ve Yöntem: Metodolojik olarak planlanan bu çalışmaya Turgut Özal Tıp Merkezi Demans Polikliniğinde demans tanısı almış hastalara bakım veren 145 bakımveren alınmıştır. Literatür taraması sonucuyla oluşturulan 30 maddelik soru havuzu beş uzmana dil, içerik ve kapsam geçerliliği'ni değerlendirmek üzere sunulmuştur. Uzman görüşleri doğrultusunda yapılan düzenlemeler sonrası 29 maddelik olan ölçek taslağı Kasım 2015-Ocak 2016 tarihleri arasında uygulamaya başlanmıştır. Ölçeğin yapı geçerliği ve ölçek alt boyutlarının belirlenmesi için faktör analizi yapılmıştır. Ölçeğin iç tutarlılığını değerlendirmek üzere madde analizi (madde toplam puan korelasyonu) ve Cronbach Alfa Güvenirlik Katsayısı değerlendirilmiştir. Güvenirlik çalışması için zamana göre değişmezlik ilkesi için 30 gün sonra örnekleme tekrardan ulaşılmış ve test tekrar test yöntemi kullanılarak korelasyon katsayısı hesaplanmıştır.

Bulgular: Cronbach Alpha değeri .88 olarak bulunmuştur. Ölçeğin yapı geçerliliği için açıklayıcı faktör analizi sonucunda bakım yükü ölçeği sosyal (7 madde); psikolojik (10 madde), fiziksel (4 madden) ve (3 mddde) olmak üzere dört faktörden oluşmaktadır. Alt boyutların Cronbach Alfa iç tutarlılık değerleri incelendiğinde sosyal alt boyutu için 0.85; psikolojik alt boyutu için 0,84; ekonomik alt boyutu için 0.74 ve fiziksel alt boyutu için 0.51 olarak saptanmıştır. Yapılan faktör analizi sonucunda anket soruları 24 madde üzerinden değerlendirilmiştir. Ölçeğin zamana göre değişmezliği test-tekrar test analizi ile incelendiğinde her iki uygulama arasında fark olmadığı saptanmıştır ($p>0.05$).

Sonuç: Demans hastalarına bakım verenlerde bakım yükünü ölçeği geçerli ve güvenilir bir ölçme aracı olduğu söylenebilir.

Anahtar sözcükler: Demans; Bakım yükü; Hemşirelik



INTRODUCTION

Increasing awareness of preserving and maintaining health, facilities provided by advances in technology, developments in the field of medicine and the delivery of quality healthcare services have led to an increase in life expectancy at birth and the proportion of elderly people. There has been a significant increase in the proportion of elderly people, particularly in developed countries (1). According to data from the Turkish Statistical Institute, the proportion of people aged ≥ 65 years was 8.3% in 2016 (2). Due to a significant increase in the proportion of elderly people, chronic conditions commonly occurring at older ages have become an important issue in society. Dementia, which is one of these conditions, has gradually become a significant problem threatening the health of the elderly (3). It is estimated that 30 million people have dementia worldwide. Furthermore, this number is expected to double every 20 years (4-6). Chronic and progressive courses of dementia increase the responsibility of caregivers of dementia patients (7). People with dementia often require high-level care, and most dementia patients are provided care informally or by family members. Burnout and depression are among the most common negative consequences in individuals providing care to the elderly and people with chronic diseases such as dementia. Caregiver burden negatively affects caregivers' social, occupational and personal roles, and it is considered to be the initial symptom of depression. Caregivers suffer from stress, depression and other health problems. Burnout and stress in caregivers result in various adverse outcomes including depression in patients and caregivers and a reduced quality of life (8).

Various scales such as the Zarit Caregiver Burden Scale and Caregiver Self-Assessment Questionnaire have been developed and are widely used to measure burnout in caregivers of patients with dementia and those with chronic diseases. However, these scales are more suitable for use in Western communities. Asian cultures differ from Western cultures in terms of providing care to elderly family members. Healthcare professionals provide care to the elderly in Western communities, whereas family

members and relatives play an important role in taking care of the elderly in Asian communities (9). In Turkish society, providing care to the diseased and elderly people at home is a widely accepted norm owing to the cultural fabric (10). Abstract concepts such as providing care and coping with stress, anxiety and pain are frequently measured in nursing studies (11,12). To measure abstract variables, scales have been developed to address different aspects and involve multiple indirect indicators of the variable (11,13). Healthcare professionals can determine the difficulty of caregiving using clinical data and measurement tools and provide appropriate nursing care (12,14).

Although no scale has been developed to evaluate the burden of caregivers of dementia patients in Turkey, there are many scales for which validity and reliability studies have been conducted; in contrast, numerous scales have been developed in other countries (11-16).

The present study aimed to develop a scale to measure the burden of caregivers of dementia patients and to evaluate its reliability and validity.

MATERIALS AND METOD

The research population comprised caregivers of dementia patients who resided in Malatya city centre and who were diagnosed with dementia in Dementia Outpatient Clinics of the Department of Neurology at Turgut Özal Medical Center. The study was conducted between February 2015 and February 2016. According to the records of the Dementia Outpatient Clinics, 480 patients were diagnosed with dementia in 2015. Caregivers who died and whose contact information changed during the study period and those who did not provide consent to participate were excluded. The sample of the study was included 145 caregivers who at least six months in the care of patients with dementia. The sample size in the study was determined according to the formula that requires the sample size to be more than five times the number of items and less than 10 times the number of items. As a result, the sample size was set as 5 times the number of items ($29 \times 5 = 145$) (17-21).

Measurement of the Burden Scale for Caregivers of Dementia Patients Literature Review and Constructing the Item Pool

An item pool for the Burden Scale for Caregivers of Dementia Patients was constructed following an extensive literature review (9-11). To determine the extent of correspondence between the items and the characteristics to be measured, expert opinion was taken and the content validity of the items was evaluated. The question item pool of the scale was sent to five experts. Each expert was requested to rate each item on a scale from 1 to 4 (1-Item is

relevant, 2-Item needs partial revision, 3-Item needs complete revision, 4-Item is not relevant). Items for which experts requested revision were changed based upon their feedback. To evaluate the content validity of the draft items, Lawshe's Content Validity Ratio (CVR) were used.

$$\text{For each item, } CVR = NG / (N/2) - 1$$

where NG is the number of experts who indicated all items as essential and N is the number of experts who presented their opinions about a particular item.

Table 1. Calculation of CVR.

Items	Revelant 3 or 4	Non relevant 1 or 2	CVR	Items	Revelant 3 or 4	Non relevant 1 or 2	CVR
Item 1	5	0	1.00	Item 16	4	1	.80
Item 2	4	1	.80	Item 17	4	1	.80
Item 3	4	1	.80	Item 18	4	1	.80
Item 4	5	0	1.00	Item19	4	1	.80
Item 5	4	1	.80	Item 20	4	1	.80
Item 6	4	1	.80	Item 21	5	0	1.00
Item 7	4	1	.80	Item 22	4	1	.80
Item 8	5	0	1.00	Item 23	4	1	.80
Item 9	4	1	.80	Item 24	4	1	.80
Item 10	4	1	.80	Item 25	4	1	.80
Item 11	4	1	.80	Item 26	5	0	1.00
Item 12	5	0	1.00	Item 27	4	1	.80
Item 13	4	1	.80	Item 28	4	1	.80
Item 14	5	0	1.00	Item 29	4	1	.80
Item 15	4	1	.80	Item 30	3	2	.60
Total							.84

After revising the draft scale and decreasing the number of items based on expert opinions, the scale was administered to a pilot study group of

20 subjects and the intelligibility of the scale was evaluated.



Factor analysis was used to determine construct validity and various sub-dimensions of the scale. Item analysis (item-total correlation) and Cronbach's alpha reliability coefficient were used to evaluate the internal consistency of the scale. To measure reliability and the invariance principle, the subjects were contacted 30 days after the completion of the study and the correlation coefficient was measured using the test-retest method.

Ethical principles

Ethical approval was obtained from the Editorial and Scientific Board Ethics Committee of Inonu University. Official approval was obtained from the Neurology Department of Turgut Özal Medical Center for conducting the study. The study aim was explained to the caregivers who met the study criteria and volunteered to participate. In addition, the subjects were informed that they had a right to withdraw from the study at any time. Caregivers' written consent was obtained in line with the confidentiality principle, and they were assured that their personal information would be protected.

RESULTS

One of the methods used for content validity was the Davis technique. The Davis technique evaluates expert opinion on a scale from 1 to 4 points: 1-Item is relevant, 2-Item needs partial revision, 3-Item needs complete revision, 4-Item is not relevant. In this technique, the CVR is calculated by dividing the number of experts rating as 1) and 2) to the total number of experts for each item, and the ratio was measured to be 0.80 and above (17). The CVR of the 30th item, which was below 0.80, was revised according to feedbacks. Following the evaluation of expert opinions, the final scale was composed of 29 items (Table 1).

Cronbach's alpha reliability coefficient was calculated to confirm the internal consistency and homogeneity of the scales. This coefficient was 0.88 for the Burden Scale for Caregivers of Dementia Patients (Table 2). When Cronbach's alpha values of different sub-dimensions of the Burden Scale for Caregivers of Dementia Patients were evaluated, they were 0.85 for the social sub-dimension, 0.84 for the psychological sub-dimension, 0.74 for the economic sub-dimension and 0.51 for the physical sub-dimension (Table 2).

Table 2. Internal consistency of overall and sub-dimensions of the Burden Scale for Caregivers of Dementia Patients.

Sub-dimensions	Number of questions	Cronbach's alpha
Social	7	0.85
Psychological	10	0.84
Economic	3	0.74
Physical	4	0.51
Total	24	0.88

Principal component analysis was used to determine the construct validity of the Burden Scale for Caregivers of Dementia Patients (varimax rotation). The Kaiser-Meyer-Olkin (KMO) test and

Bartlett's sphericity test were used to measure the applicability of principal component analysis (Table 3).

Table 3. Results of the KMO test and Bartlett's sphericity test.

KMO test measure of sampling adequacy		0.85
Bartlett's sphericity test	Chi-Square	1388.299
	df	276
	Sig.	0.001

Exploratory factor analysis was used to evaluate the construct validity of the Burden Scale for Caregivers of Dementia Patients, the number of items of which was reduced to 24 following item analysis. Principal component analysis and varimax rotation were used to analyse the factor structure of the scale. Following the application of varimax rotation in principal component analysis, the items of the Burden Scale for Caregivers of Dementia Patients were divided into four factors. The results of exploratory factor analysis are shown in Table 4. Factor loadings ranged from 0.33 to 0.84.

The Burden Scale for Caregivers of Dementia Patients was composed of 29 items. This is a five-point Likert-type scale: Always (5), Usually (4), Sometimes (3), Rarely (2) and Never (1). Following

factor analysis, questions 15 and 17 were omitted as their factor loadings were below 0.50; questions 2, 27 and 29 were also omitted as their factor loadings were below 0.25 and they had similar coefficient loadings for multiple values. As a result, the final version of the scale was composed of 24 items. As a result of the item-total correlation analysis of the scale, the reliability coefficients were found to be between $r=0.08$ and $r=0.717$ and statistically significant in the positive direction ($p<0.05$) (Table 5). Furthermore, the 'Alpha if Item Deleted' value was measured to test to what extent and in what way each item affected Cronbach's alpha reliability coefficient. These values demonstrated the internal consistency of the remaining items when an item is excluded.

**Table 4.** Exploratory factor analysis of the Burden Scale for Caregivers of Dementia Patients.

Items	Component			
	1. factor	2. factor	3. factor	4. factor
Item 20	0.79			
Item 22	0.78			
Item 21	0.68			
Item 25	0.62			
Item 23	0.60			
Item 19	0.43			
Item 9	0.35			
Item 13		0.73		
Item 14		0.64		
Item 6		0.61		
Item 11		0.59		
Item 18		0.58		
Item 12		0.54		
Item 7		0.52		
Item 10		0.52		
Item 24		0.45		
Item 1		0.41		
Item 26			0.84	
Item 28			0.81	
Item 16			0.64	
Item 5				0.74
Item 3				0.55
Item 8				0.42
Item 4				0.33
Eigen value	4.20	3.63	2.92	1.76
Total variance explained %	17.50	15.13	12.20	7.37

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalization.

Table 5. Item-total correlation of the Burden Scale for Caregivers of Dementia Patients.

Items	Item-total correlation	Alpha if Item Deleted'
Item 1	0.53	0.87
Item 3	0.08	0.89
Item 4	0.09	0.88
Item 5	0.24	0.88
Item 6	0.49	0.87
Item 7	0.55	0.87
Item 8	0.43	0.87
Item 9	0.37	0.88
Item 10	0.47	0.87
Item 11	0.53	0.87
Item 12	0.58	0.87
Item 13	0.64	0.87
Item 14	0.39	0.88
Item 16	0.30	0.88
Item 18	0.32	0.88
Item 19	0.52	0.87
Item 20	0.71	0.87
Item 21	0.63	0.87
Item 22	0.63	0.87
Item 23	0.62	0.87
Item 24	0.53	0.87
Item 25	0.56	0.87
Item 26	0.44	0.87
Item 28	0.51	0.87

Confirmatory Factor Analysis (CFA) was conducted using LISREL 8.7 (Scientific Software International, Inc., Lincolnwood, IL, USA) with

covariance matrices serving as the input; solutions were generated based on the maximum likelihood.



Table 6. Goodness-of-Fit Indices for the Burden Scale for Caregivers of Dementia Patients.

Goodness-of-Fit Indices	Value
RMSEA	0.054
NNFI	0.96
CFI	0.96
IFI	0.96
RMR	0.072
RFI	0.88
X^2/df	1.42

According to CFA, the X^2/df rate was 1.42, and all indices (RMSEA=0.054, NNFI=0.96, CFI=0.96, IFI=0.96, RMR=0.072 and RFI=0.88) had an acceptable fit between the four-dimensional model and the observed data. A diagram of the four-

dimensional model is shown in Figure 1. Coefficients of the observed data were between 0.29 and 0.78. According to these results, the four-dimensional structure of the Burden Scale for Caregivers of Dementia Patients was validated.

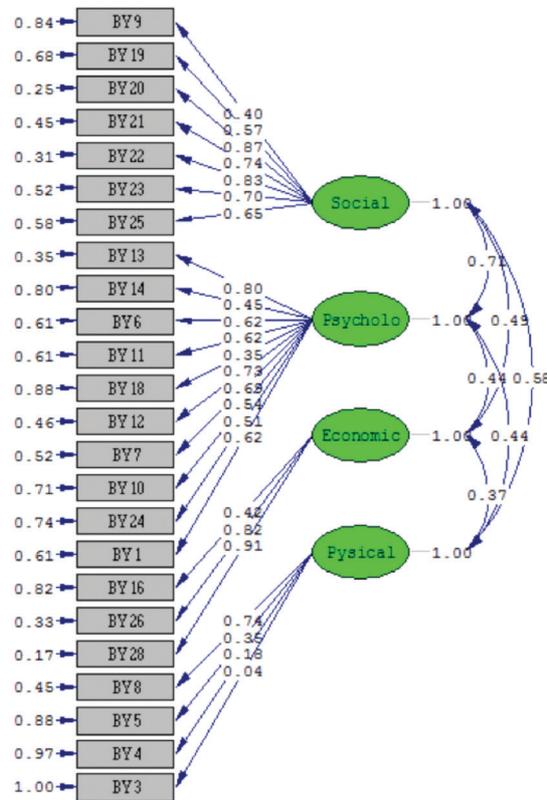


Figure 1. The burden Scale for Caregivers of Dementia Patients confirmatory factor analysis.

The test-retest method was used to test scale invariance (22). The scale was assessed for the second time with 32 caregivers after the initial research. When the test-retest scores of the Burden Scale for Caregivers of Dementia Patients were

evaluated in comparison with the initial scores, we found a positive relationship between the correlation analysis of social, psychological, economic, physical and total scores at an alpha level of 0.01 ($p > 0.05$, $r = 0.83$) (Table 7).

Table 7. Sub-dimensions of the Burden Scale for Caregivers of Dementia Patients according to test-retest results and evaluation of the total average score (n=32).

Sub-dimensions	First adminst. X± sd	Test-retest adminst. X±sd	Cronbach's alpha (n=145)	Test-retest Cronbach's alpha (n=32)	r*	p
Social	20.90±8.48	21.43±8.48	0.85	0.88	0.88	0.001
Psychological	23.90±9.38	24.68±10.16	0.84	0.91	0.79	0.001
Economic	6.12±3.38	6.15±3.53	0.74	0.74	0.64	0.001
Physical	16.00±2.99	15.34±3.16	0.51	0.48	0.59	0.001
Total	66.93±18.96	67.62±20.36	0.88	0.92	0.83	0.001

* ICC (Intraclass Correlation Coefficient)

DISCUSSION

Cronbach's alpha value was measured to determine the internal consistency and homogeneity of the Burden Scale for Caregivers of Dementia Patients. Cronbach's alpha values were 0.85 for the social sub-dimension, 0.84 for the psychological sub-dimension, 0.74 for the economic sub-dimension, 0.51 for the physical sub-dimension and 0.88 for the overall scale (Table 2). Cronbach's alpha values should preferably be close to 1. If the value is between 0.80 and 1.00, the scale is considered to be highly reliable; if the value is between 0.60 and 0.79, the scale considered to be very reliable; if the value is between 0.40 and 0.59, the scale considered to be less reliable; and if the value is between 0.00 and 0.40, the scale considered to be not reliable (23). Therefore, the present scale was found to be highly reliable (Table 2).

KMO factor analysis is an essential index for measuring the adequacy of sampling. If the KMO value is close to 1, sampling is considered adequate for factor analysis. KMO values between 0.90 and 1.00 indicate perfect sampling, between 0.80 and 0.89 indicate very good sampling, between 0.70 and 0.79 indicate good sampling, between 0.60 and 0.69 indicate moderate sampling, between 0.50 and 0.59 indicate poor sampling and below 0.50 indicate unacceptable sampling (21). According to these evaluation criteria, the KMO score of the Burden Scale for Caregivers of Dementia Patients was 0.85, indicating very good sampling for factor analysis (Tables 3). Besides the adequacy of sampling, Bartlett's sphericity test, which determines the relevance of the correlation matrix of items in the scale, was used to evaluate the adequacy of the scale (24). The result of Bartlett's sphericity test in the present study was



extremely relevant ($X^2=1388.299$, $p=0.001$), and the scale was suitable for factor analysis (Table 3).

The Eigenvalue coefficient is used to determine the number of substantial factors and measure the variance ratio represented by each factor in factor analysis. It is recommended to select factors with an eigenvalue coefficient of >1 (24). Higher variance ratios indicate stronger factor structure of the scale. Variance ratios between 40% and 60% are considered adequate (18). In the present study, the ratio was 52.2% (Table 4).

As shown in Table 4, four factors were identified with an initial variance of >1 . The variance of the first factor was 17.50%, that of the second factor was 32.6%, that of the third factor was 44.8% and that of the fourth factor was 52.2%. The first factor in the scale represented the social sub-dimension and was composed of item numbers 9, 19, 20, 21, 22, 23 and 25. The second factor in the scale represented the psychological sub-dimension and was composed of item numbers 1, 6, 7, 10, 11, 12, 13, 14, 18, and 24. The third factor represented the economic sub-dimension and was composed of item numbers 16, 26 and 28. Finally, the fourth factor represented the physical sub-dimension and was composed of item numbers 3, 4, 5 and 8.

Subsequent to exploratory factor analysis, we designated the four factors as 'social', 'psychological', 'economic' and 'physical'. When we investigated the sub-dimensions of other burden scales, we found that the Burden Scale Inventory that was created by Novak and Guest in 1989 and the Turkish version of which was confirmed to be reliable and valid by Kucukguclu et al. was composed of five dimensions of burden: time-dependence, physical, social, developmental and emotional. The total Cronbach's alpha coefficient of the inventory was 0.94, with Cronbach's alpha of time-dependency as 0.94, of social burden as 0.82, of physical burden as 0.94, of emotional burden as

0.94, and of developmental burden as 0.94 (10). The Burden Scale for Caregivers of Dementia Patients developed by Taameeyapradit et al. is composed of 18 items and three sub-dimensions: psychological, economic and physical burden (9). The burden scale created by Zarit, Reever and Bach-Peterson and the Turkish version of which was tested for validity and reliability by Inci and Erdem is composed of 22 items and a single sub-dimension. The internal consistency coefficient of the scale was 0.95 (11).

In item-total correlation analysis, the consistency coefficient of the Burden Scale for Caregivers of Dementia Patients was calculated to be between 0.085 and 0.71 and a significant positive relationship was found (Table 5). The lower limit of the item-total score correlation coefficient differs according to various sources. An item-total score correlation coefficient of >0.20 may be problematic (25). When an item with a low correlation coefficient is to be excluded, Cronbach's alpha coefficient and the change in the overall score should be considered (25). When we excluded items 3 and 4, Cronbach's alpha coefficient did not change; consequently, we decided to not exclude these items from the scale.

To evaluate scale invariance, we re-administered the test to 32 caregivers 2 weeks after the initial test. The test-retest reliability coefficient of the scale varied from $r=0.59$ to $r=0.88$ between the items and was $r=0.83$ for the overall scale ($p<0.05$) (Table 7). In the present study, as there was a relevant interval between the two measurements and consistency did not show any changes within this interval, the scale was determined to be consistent; in other words, the scale was invariant.

In conclusion, we suggest that the scale developed in the present study is a reliable and valid measurement tool to evaluate the Burden Scale for Caregivers of Dementia Patients.

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