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A scale development study: Primary Caregiver Burden Scale Individuals Receiving Hemodialysis Treatment

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Abstract

Introduction: As hemodialysis is a long-term treatment method requiring significant self-management skills, it affects both the patient and the caregiver in many ways. It is inevitable that changes in the burden perceived by the caregiver over time will not affect the patient's health care outcomes. The aim of this study was to develop an up-to-date scale by examining the psychometric properties of items created specifically for the care burden perceived by individuals who provide care for patients receiving hemodialysis treatment.

Methods: This study is a methodological study with the use of the COSMIN Checklist. The sample of the study included 404 individuals who were the primary caregivers of patients receiving hemodialysis treatment. Data were collected using descriptive characteristics form and the draft form of the Primary Caregiver Burden Scale Individuals Receiving Hemodialysis Treatment. Exploratory and confirmatory factor analysis and predictive validity were used to evaluate validity. The Cronbach's alpha reliability coefficient, item analysis, and test–retest method were employed to evaluate reliability.

Results: According to exploratory factor analysis, a scale structure with four subdimensions was determined, and goodness of fit was achieved using confirmatory factor analysis. The Cronbach's alpha coefficient of the final form of the scale consisting of 34 items was found to be 0.95 for the total scale, 0.93 for the self-management support subscale, 0.91 for the psychological support subscale, 0.91 for the caregiver symptom subscale, and 0.93 for the caregiver individual coping subscale.

Conclusion: The Primary Caregiver Burden Scale Individuals Receiving Hemodialysis Treatment, which was found to meet the validity and reliability criteria, has a four-point Likert-type scoring structure, 34 items, and four subdimensions. It is thought that the scale can make significant contributions to the international literature if its validity and reliability are established with nursing practices and research.

KEYWORDS
burden, caregiver, hemodialysis, scale, treatment

1 | INTRODUCTION

Hemodialysis (HD) is a treatment method that prolongs the life of a patient with chronic kidney disease (CKD) but results in dependency on the treatment center for life. It is a treatment process where adherence to medical nutrition and drug treatments is of great importance in terms of the expected benefit, quality of life, and life expectancy and which can be accompanied by complications and requires multidimensional self-care and self-management skills [1, 2]. In this context, it negatively affects both patients and caregivers in many ways. Studies have shown that problems, such as fatigue, pain, weakness, and sleep disorders, are detected in people who provide care for chronic patients [3–5]. The "caregiver" refers to the person undertaking the role of helping the sick individual, meeting their basic needs, following hospital procedures, and providing home care, for example, carrying out the informal care process. On the one hand, informal caregivers experience the fear of losing their loved ones, while on the other, this relationship can turn into a one-way, intense and long-term obligation that makes the caregiver's life difficult in time. In the literature, the concept covering all these obligations is confronted as "care burden." The caregivers can be overwhelmed by the consequences of the caregiver responsibilities they undertake, and the physical and emotional effects they experience [6].

Care burden is defined as the strain, stress, and pressure that a person who provides care for a family member or relative in need of care feels and the burden he/she undertakes. It is also a comprehensive response experienced in physical, spiritual, economic, and social areas as a result of caregiving. The objective dimension of the care burden can be easily determined, as it includes changes and restrictions in the caregiver's life, but the subjective dimension may be difficult to detect because it involves the caregiver's attitudes and feelings [4]. In a previous study, caregiver burden was detected in 80% of individuals who provide care for patients with CKD. Anxiety and depression levels of these caregivers were also found to be quite high. [7]. In another study, it was found that 23.1% of family members providing care for older patients receiving HD treatment had mild, 51.9% had moderate, and 25% had severe caregiver burden [8]. Mashayekhi et al. stated that 72.5% of caregivers of patients receiving HD treatment reported moderate to severe caregiver burden [9]. In a meta-analysis by del-Pino-Casado et al., there was a strong positive relationship between the subjective care burden and anxiety symptoms of caregivers of patients receiving HD treatment, and subjective caregiver burden was found to be an important risk factor for anxiety in caregivers [2].

In this context, it is important to evaluate the caregiver burden in individuals who provide primary informal care, both objectively and subjectively. There are caregiver burden scales that have been developed mostly for older people [1] or individuals with dementia [10, 11] and general caregiver burden scales for the caregivers of patients receiving HD treatment in the international literature. There are some scales that are used to evaluate the care burden of individuals providing care for patients receiving HD treatment in Turkish society. One of these was developed to evaluate caregiver burden in stroke patients [12] and its Turkish validity and reliability study was performed for caregivers of patients receiving HD treatment [13]. Apart from this, there are scales that have been developed and adapted for the caregivers of older people [14] and people with stroke [15] and dementia [16]. In a systematic review about the examination of the caregiver burden scales used in our country, it was stated that the specific caregiver burden scales for medical diagnosis groups were very limited [17]. Therefore, the aim of this study was to develop an up-to-date scale by examining the psychometric properties of items created specifically for the care burden perceived by individuals who provide primary care for patients receiving HD treatment.

2 | METHODS

2.1 | Type of study

This research was conducted methodologically to evaluate the validity and reliability of the Primary Caregiver Burden Scale in Patients Receiving Hemodialysis Treatment. It was designed and reported according to the COSMIN Reporting Guideline Checklist (Table S1).

2.2 | Population and sample of the study

The study population consisted of the primary caregivers of patients receiving treatment in the hemodialysis unit and internal medicine clinic of a public hospital in a province in the south of our country. It is recommended that the sample size be five times the number of scale items and over 300 to reveal the factor structure in methodological studies. Considering the possibility of missing data, the sample of this research consisted of 404 people who were the primary caregivers of patients receiving HD treatment [18, 19]. The adequacy of the sample size was also confirmed with exploratory and confirmatory factor analysis. The study inclusion criteria were being the primary caregiver of the patient on HD treatment for

at least 1 year, not giving the care for a fee, and voluntarily agreeing to participate in the research. The study exclusion criteria were defined as caregivers with a diagnosis of cancer or psychiatric disease, those who had disabilities or did not agree to participate in the study, or whose patient had a diagnosis of cancer, had an amputation, or had a disability.

2.3 | Data collection tools

2.3.1 | Descriptive information form

Descriptive information form was created by the researchers based on the literature [2, 7–9]. It included the characteristics of the patients' relatives who participated in the study (age, gender, education level, and income level), the patient they provided care for (age, gender, education level, employment status, and frequency of dialysis sessions), and their caring features (degree of relationship to the patient and duration of caregiving).

2.3.2 | Primary Caregiver Burden Scale Individuals Receiving Hemodialysis Treatment (HD-PCBS) draft form

With reference to the relevant literature, an item pool consisting of 54 items was created. Seven experts were consulted about the items so that the content validity rate of the item pool could be calculated. The experts evaluated each scale item on a four-point Likert scale (1 = not appropriate, 2 = the item needs to be changed appropriately, 3 = appropriate but a minor change is needed, and 4 = appropriate) and item-level content validity ratios (I-CVR) and the scale-level content validity ratio (S-CVR) were calculated. I-CVR and S-CVR were calculated using the following formulas: I-CVR = number of experts who gave 3 and 4 to the item/number of all experts; S-CVR = total of I-CVRs/total number of items. As a result, the I-CVR was found to range between 0.71 and 1.00 and the S-CVR was 0.92. For the evaluation of the content validity ratio, it is recommended that the I-CVR be at least 0.78 if there are six or more experts [20]. Therefore, any item with an I-CVR value of 0.71 was removed from the scale. It is recommended that the S-CVR be 0.90 and above [20–23]. Accordingly, it was determined that the content validity ratio values of 53 items were appropriate. The necessary corrections were made to the items based on the feedback from the experts. Following the expert opinions, the 53-item pool was applied to 20 people who were the primary

caregivers of patients on HD treatment, and they were asked to evaluate the items in terms of clarity and comprehensibility. Research data were collected using this 53-item draft form, which was then finalized as a result of the content validity index and pilot application studies.

2.4 | Data analysis

Data were analyzed with IBM SPSS version 15 and AMOS version 26. The descriptive characteristics of patients receiving HD treatment and their caregivers were stated using frequency, percentage, mean, and standard deviation values. The reliability of the scale was tested for internal consistency with analyses using Cronbach's alpha reliability coefficient, item-total score reliability, lower-upper-group item analysis, and test–retest reliability.

The validity of the scale was tested with content and construct validity. For content validity, the draft form was submitted to experts and the content validity index was calculated. Exploratory and confirmatory factor analyses were conducted for construct validity. The "direct oblimin" rotation method was used for exploratory factor analysis, and model fit, and factor loadings were analyzed using confirmatory factor analysis on AMOS software.

Data analysis started with item-total score correlations. Items with a correlation value of <0.25 were removed from the scale one by one and the correlation was reevaluated. At this stage, eight items were removed from the scale. Then, the Cronbach's alpha coefficient was calculated. Items with a Cronbach's alpha value greater than the alpha value of the total scale were removed from the draft scale and the test was repeated each time. At this stage, five items were removed from the scale.

Exploratory factor analysis was performed following the reliability analyses. Using the "direct oblimin" rotation method in exploratory factor analysis, the items were first released and then distributed to the subdimensions. At this stage, items grouped under two or more factors at the same time were gradually removed from the scale and the test was repeated, and five items were removed from the scale. Since two items were grouped under the fifth subdimension, which emerged with the "direct oblimin" rotation method, the number of factors was determined as four. The "direct oblimin" rotation method was performed again, and it was seen that these two items were grouped under one of the four factors, and the scale was decided to have four factors. After the subdimensions were determined, the model fit was examined with confirmatory factor analysis. The test–retest correlation was examined to test the

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TABLE 1 Sociodemographic characteristics of patients receiving hemodialysis treatment and their caregivers ($n = 404$).

	Mean ± SD	Min.–max.
Caregiver		
Age (years)	42.86 ± 8.12	17–80
Gender	*n*	%
Female	219	54.2
Male	185	45.8
Education		
Literate	15	3.7
Elementary school/primary school	322	79.7
High school or equivalent school graduate	60	14.9
College/faculty graduate	7	1.7
Income level		
Income < expenses	120	29.0
Income = expenses	205	50.7
Income > expenses	79	19.6
Relation to the patient		
Mother	27	6.7
Father	56	13.9
Sibling	183	45.3
Spouse	117	29.0
Father-in-law	7	1.7
Mother-in-law	2	0.5
My relative	12	3.0
Duration of caregiving		
1–5 years	332	82.2
>5 years	72	17.8
Patient		
Age (years)	50.08 ± 9.90	30–80
Gender		
Female	210	52.0
Male	194	48.0
Education		
Literate	33	8.2
Elementary school/primary school	73	18.1
High school or equivalent school graduate	238	58.9
College/faculty graduate	55	13.6
Post-graduate	5	1.2
Employment status		
Yes	291	72.0
No	113	28.0

(Continues)

TABLE 1 (Continued)

	Mean ± SD	Min.–max.
Frequency of dialysis sessions		
Three times a week	365	90.3
Two times a week	39	9.7

time-dependent invariance of the scale. For this purpose, the final version of the scale, consisting of four subdimensions and 34 items, was applied twice, 3 weeks apart, to 30 primary caregivers of patients receiving HD treatment, and the relationship between the measurements was evaluated with Pearson's product–moment correlation coefficient.

Item analysis was conducted based on the difference between the lower and upper-group mean values to determine how well the primary caregiver burden scale could discriminate primary caregivers in terms of the feature it was intended to measure, for example, caregiver burden. To determine the discriminating power of the scale items, an independent group *t*-test was applied to the mean scores of the groups constituting the lower 27% and upper 27% when the scores obtained on an item basis were ranked from the lowest to the highest.

The effect of independent variables, including characteristics of caregivers and patients, on the caregiver burden was evaluated using multiple linear regression and hierarchical regression analysis. The appropriateness of the data set for regression analysis was determined by the assumptions of sample size, multicollinearity or singularity (VIF, tolerance values), the effect of extreme values, and the independence of residuals.

3 | RESULTS AND DISCUSSION

3.1 | Characteristics of primary caregivers and care recipients

The mean age of the caregivers of patients on HD treatment was 42.86 ± 8.12 years, 79.7% had an education level of primary school or secondary school, and 50.7% had equal income and expenses. Of the participants, 45.3% were caregivers for their siblings, 29.0% for their spouses, and 13.9% for their fathers. It was reported by 82% of the participants that they had been providing care for 1–5 years. The mean age of patients receiving HD treatment was 50.08 ± 9.90 years and 52.0% were female. Of the patients, 58.9% had an education level of high school, 72.0% were employed, and 90.3% received HD treatment three times a week (Table 1).

In this study, 54.2% of the primary caregivers were female and 46.4% were male. Both international [9, 24, 25] and national literature [26–28] has shown that most caregivers are female. Since the number of males and females in this study was quite similar and there was no significant difference between genders in terms of the total HD-PCBS score ($t = 0.637$, $p = 0.527$), the scale was considered to adequately measure the burden of caregiving for both genders.

3.2 | Validity

Validity can be broadly defined as the degree to which a measurement tool can measure the feature to be measured accurately without confusing it with another feature [29, 30]. Although there are many methods to determine the validity of a scale, it is generally recommended to use at least two methods. In this research, explanatory factor analysis and confirmatory factor analysis were used. The Kaiser-Meyer-Olkin sampling adequacy test value, which is examined in the first stage in explanatory factor analysis, is interpreted in the literature as follows: 0.90–1.00, excellent; 0.80–0.89, very good; 0.70–0.79, good; 0.60–0.69, moderate; 0.50–0.59, poor [31–33]. In this study, the Kaiser-Meyer-Olkin value was found to be 0.953, showing that the sample size was excellent and adequate for factor analysis. The result of the Bartlett test, which is used to examine whether the data has normal distribution, is expected to be significant in the literature [33, 34]. In the current study, the Bartlett sphericity test result was determined as $\chi^2 = 10\,546.103$, df = 561, and $p = 0.000$, so it was decided that the dataset was suitable for factor analysis (Table 2).

According to the literature, variance rates between 40% and 60% are considered adequate in scale development and adaptation studies. In this study, the variance ratio was determined to be adequate, as four factors with factor Eigen values of one and above, explaining 64.867% of the total variance, were obtained [34, 35]. The examples in literature of explained variance ratios of caregiving scales used in different groups (older individuals,

dementia, heart failure, stroke, etc.) have been reported as 53.55% [36], 52.2% [16], 57.86% [37], 62.8% [38], and 41.4% [39]. Thus, it can be said that the explained variance ratio of this scale was good compared to the average variance of caregiving burden scales in the literature.

The relationship of items with factors shows the factor load value. The minimum value required for an item to be included in any factor should be 0.30. Generally, a factor load of 0.30–0.59 is considered moderate, and a factor load of 0.60 and above is high [31, 34]. Since the factor loads in this research varied between 0.389 and 0.826 (Table 3), it is possible to say that the items served the conceptual structure of the scale at moderate to high levels. Examples in the literature of factor loads of caregiving burden scales (in older people, dementia, heart failure, cancer, and stroke groups) have been reported as 0.46–0.88 and 0.51–0.93 [36, 37], 0.42–0.82 and 0.33–0.84 [16, 40], 0.46–0.90 [38], 0.65–0.91 [41], and 0.26–0.84 [39]. The explanatory factor analysis factor loads determined in the current study were observed to be close to the factor loads of the caregiving burden scales in the literature.

In confirmatory factor analysis, the researcher tests the accuracy of a previously determined relationship [31, 35]. According to the confirmatory factor analysis results of this study, the fit indices of the scale ($\chi^2/df = 2.427$: good fit; RMSE = 0.06: good fit; GFI = 0.838: adequate fit; AGFI = 0.814: acceptable fit; CFI = 0.928: good fit) were found to be appropriate in line with the literature [18, 42, 43]. According to confirmatory factor analysis, the factor loads varied between 0.530 and 0.911. The resulting path diagram is shown in Figure 1. Examples of the fit indices in the models established for caregiver burden scales in the literature were as follows: Cil and Pinar, "$\chi^2/df = 1.76$, CFI = 0.96" [13]; Aslan and Ayaz, "$\chi^2/df = 1.42$, RMSEA = 0.054, CFI = 0.96" [16]; Lu et al., "RMSEA = 0.077, CFI = 0.841, GFI = 0.886" [44]; Peipert et al., "RMSEA = 0.05, CFI = 0.94" [11]; Greco et al., "CFI = 0.94; RMSEA = 0.051" [45]; Jaracz et al., "$\chi^2/df = 3.641$, RMSEA = 0.084, CFI = 0.856" [39]; Valer et al., "RMSEA = 0.065, CFI = 0.935" [46]. It can be said that the fit indices determined for this scale reinforced the factor structure of the scale revealed by explanatory factor analysis.

3.3 | Reliability

Reliability means ensuring invariance, consistency, accuracy, and stability in a measurement tool. The invariance and consistency of a measurement tool is that it produces similar results in repeated measurements. Accuracy shows the ability to determine the real measurement value [29, 47]. In this study, the Cronbach alpha coefficient of

TABLE 2 | KMO and Bartlett's test results of the Primary Caregiver Burden Scale in Patients Receiving Hemodialysis Treatment.

KMO	0.953
Bartlett's test	
χ^2	10 546.103
Degrees of freedom (Df)	561
p	0.000

TABLE 3 Factor structure and reliability analyses of the Primary Caregiver Burden Scale in Patients Receiving Hemodialysis Treatment ($n = 404$).

Factor	Item number	Factor load	Eigenvalue	Explained variance (%)	Cronbach's alpha
Self-management support	1 (1)	0.564	14.070	41.382	0.931
	2 (2)	0.593			
	3 (3)	0.602			
	4 (4)	0.501			
	5 (7)	0.535			
	6 (8)	0.428			
	7 (9)	0.680			
	8 (10)	0.614			
	9 (11)	0.652			
	10 (12)	0.683			
	11 (13)	0.625			
	12 (14)	0.647			
	13 (15)	0.634			
Psychological support	14 (24)	0.628	1.537	4.521	0.919
	15 (25)	0.743			
	16 (26)	0.787			
	17 (27)	0.794			
	18 (28)	0.741			
Caregiver symptom	19 (39)	0.613	2.018	5.936	0.907
	20 (40)	0.664			
	21 (41)	0.662			
	22 (42)	0.629			
	23 (43)	0.675			
	24 (44)	0.597			
	25 (45)	0.602			
Individual caregiver coping	26 (29)	0.747	4.430	13.028	0.938
	27 (30)	0.814			
	28 (31)	0.826			
	29 (32)	0.782			
	30 (33)	0.729			
	31 (34)	0.644			
	32 (35)	0.641			
	33 (36)	0.590			
	34 (46)	0.389			
Total scale				64.867	0.95

the final version of the scale consisting of 34 items was determined to be 0.95 for the total scale, 0.931 for self-management support (SMS), 0.919 for psychological support (PS), 0.919 for caregiver symptom (CGS), and 0.938 for caregiver individual coping (CGIC). The alpha value is interpreted as follows: $0.00 \leq \alpha < 0.40$, unreliable; $0.40 \leq \alpha < 0.60$, low reliability; $0.60 \leq \alpha < 0.80$, quite reliable; $0.80 \leq \alpha < 1.00$, highly reliable [42, 47, 48]. Accordingly, the total scale and its subscales provided a high degree of reliability. Examples in the literature of the Cronbach alpha value for the total and subscales of caregiver burden scales have been reported as follows: Cil and Pinar, 0.89 and 0.53–0.87 for five subdimensions [13]; Aslan and Ayaz, 0.88 and 0.51–0.85 for four
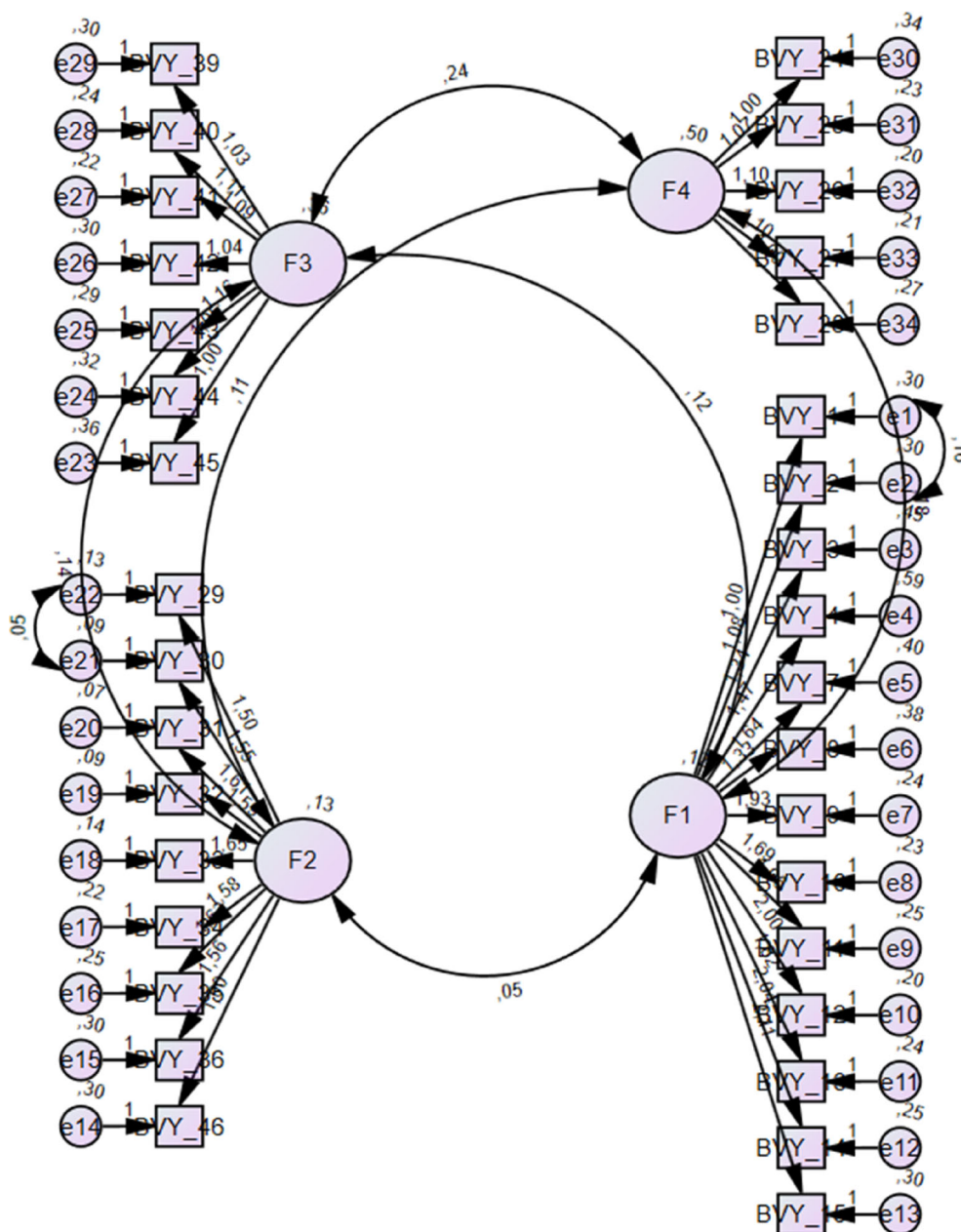
FIGURE 1 Confirmatory factor analysis of the Primary Caregiver Burden Scale in Patients Receiving Hemodialysis Treatment.

subdimensions [16]; Lee et al., 0.83 and 0.72–0.89 for three subdimensions [41]; Jaracz et al., 0.92 and 0.72–0.87 for subdimensions [39]; Hipolito et al., 0.79 and 0.74–0.93 for subdimensions [49]. In the current study, it is possible to say that the scale had a good level of measuring caregiver burden, especially at the subdimension level, as the alpha coefficient and subdimension reliability coefficients were high compared to the literature.

The item-total score correlation coefficients of the resulting 34-item scale were determined to range from 0.497 to 0.714 (Table 4). Pearson's correlation coefficient values in item analyses are interpreted as follows: 0.26–0.49, weak; 0.50–0.69, medium; 0.70–0.89, high; 0.90–1.00, very high [50, 51]. Accordingly, the correlation

coefficients of the scale items were generally at a medium level. Examples in the literature of correlation coefficients of caregiver burden scale studies have been reported as follows: Inci and Erdem, 0.43–0.85 [36]; Cil and Pinar, 0.37–0.70 [13]; Zhong et al., 0.31–0.66 [52]; Al-Rawashdeh et al., 0.39–0.76 [38]; Jaracz et al., 0.32–0.74 [39]. The item-total score correlation coefficients of the caregiver burden scale in this study were similar to those in the literature.

The capacity of a scale to discriminate individuals with the lowest and highest scores in measuring caregiver burden is evaluated using item analysis based on the mean values of lower-upper groups [31]. In the current study, there was determined to be a significant difference

TABLE 4   Item analysis and internal consistency coefficients of the primary caregiver burden scale in patients receiving hemodialysis treatment ($n = 404$).

Item number	Items	Item-total score correlation coefficients	Item discriminating power (27% upper-lower group)	Cronbach's alpha coefficient of the scale when item is omitted
1 (1)	To provide fluid control	0.544***	10.336***	0.956
2 (2)	To comply with potassium and phosphorus restrictions in the diet	0.587***	11.165***	0.955
3 (3)	To comply with the salt restriction in the diet	0.559***	10.957***	0.956
4 (4)	For daily weight tracking	0.534***	10.363***	0.956
5 (7)	To exercise regularly in accordance with his/her capacity	0.594***	12.314***	0.955
6 (8)	To ensure regular use of medications (antipotassium, antiphosphorus, etc.)	0.497***	9.543***	0.956
7 (9)	To protect and secure the vascular access route	0.698***	16.333***	0.954
8 (10)	To see the physician regularly	0.636***	14.385***	0.955
9 (11)	To help cope with the side effects of hemodialysis (sleep problems, itching, headache, fatigue, etc.)	0.658***	14.445***	0.955
10 (12)	To search and learn about appropriate nutrition (from a doctor, nurse, or dietitian)	0.714***	16.895***	0.954
11 (13)	To shop for food suitable for his/her diet	0.615***	13.693***	0.955
12 (14)	To prepare diet-friendly meals	0.679***	19.280***	0.954
13 (15)	Economic support for meeting needs	0.676***	17.672***	0.954
14 (24)	Giving support to reduce anxiety	0.667***	15.232***	0.955
15 (25)	Talking about concerns	0.703***	17.466***	0.954
16 (26)	Making feel he/she is supported	0.712***	18.268***	0.954
17 (27)	Talking about his/her feelings, such as distress, sadness, or grief	0.672***	16.725***	0.955
18 (28)	Taking an understanding attitude	0.689***	16.902***	0.955
19 (39)	Distractibility	0.665***	16.557***	0.955
20 (40)	Forgetfulness	0.684***	18.547***	0.955
21 (41)	Fatigue	0.674***	15.521***	0.955
22 (42)	Insomnia	0.624***	15.305***	0.955
23 (43)	Weakness	0.656***	15.844***	0.955
24 (44)	Uneasiness	0.623***	14.109***	0.955
25 (45)	Anxiety	0.572***	13.058***	0.955
26 (29)	Burnout	0.607***	12.059***	0.955
27 (30)	Helplessness	0.656***	14.341***	0.956
28 (31)	Irritability	0.653***	13.636***	0.955
29 (32)	Anger	0.656***	13.324***	0.955
30 (33)	Unhappiness	0.636***	13.968***	0.955
31 (34)	Sadness	0.615***	12.947***	0.955
32 (35)	Inadequacy	0.666***	14.741***	0.955
33 (36)	Loneliness	0.645***	13.639***	0.955
34 (46)	Difficulty adapting to changes in family structure	0.562***	10.357***	0.95

Note: *** $p < 0.001$.

($p < 0.005$) between the mean scores obtained from the upper ($n = 109$) and lower ($n = 109$) 27% of groups for all test items (Table 4). Thus, it was found that the scale had discriminating power in measuring the caregiver burden between high and low scores obtained from the scale. It is possible to say that the scale items could discriminate individuals in terms of caregiving burden.

The results obtained from repeated measurements using the test–retest method on the same individuals are expected to be consistent [32, 35]. It has been stated that a test–retest correlation coefficient of at least 0.70 is adequate [42]. In this study, the correlation coefficient between the two applications was $r = 0.92$ ($p = 0.000$) for the total score, $r = 0.90$ ($p = 0.000$) for the SMS score, $r = 0.88$ ($p = 0.000$) for the PS score, $r = 0.89$ ($p = 0.000$) for the CGS score, and $r = 0.78$ ($p = 0.000$) for the CGIC score. The coefficient for each item varied between 0.75 and 0.92. Accordingly, the HD-PCBS met test–retest consistency. In the literature, test–retest reliability values on a scale basis have been reported as follows: Inci and Erdem, 0.90 [36]; Aslan and Ayaz, 0.83 [16]; Abdollahpour et al., 0.93 [53]; Valer et al., 0.79 [46]; Hipolito et al., 0.92 [49]. It

was seen that HD-PCBS in the current study produced test–retest findings similar to those of other caregiver burden scales in the literature.

3.4 | Predictive validity: multiple linear and hierarchical regression analysis findings

It has been shown in the literature that some factors, such as age, education level, employment status, income status, and duration of caregiving, have an impact on caregiver burden [28, 54–57]. In this study, four models established in the multiple linear regression analysis conducted to investigate the effect of the characteristics of the caregiver (employment status, income level, duration of caregiving) and the patient (age, gender, education level, and frequency of dialysis treatment) on the primary caregiver burden were found to be statistically significant. According to Model 1, three independent variables reflecting primary caregiver characteristics explained 11% of the variance in caregiver burden. When the age

TABLE 5 Effect of independent variables on the Primary Caregiver Burden Scale in Patients Receiving Hemodialysis Treatment: multiple linear regression analysis results ($n = 404$).

	Dependent variable	Independent variable	β	SE	Beta	t	p	F	R^2	DW
Model-1	HD-PCBS	Caregiver's working status	8.114	1.912	0.214	4.245	0.000	17.256	0.115	1.828
		Caregiver's income status	4.473	1.250	0.182	3.569	0.000			
		Duration of caregiving	5.351	1.135	0.120	2.506	0.013			
Model-2	HD-PCBS (Ages of the patient and caregiver is under control)	Caregiver's working status	7.262	1.92	0.192	3.783	0.000	14.371	0.141	1.866
		Caregiver's income status	3.531	1.27	0.144	2.776	0.006			
		Duration of caregiving	4.433	1.28	0.102	2.08	0.038			
Model-3	HD-PCBS	Patient's age	0.250	0.082	0.146	2.572	0.010	15.908	0.138	1.830
		Gender	4.094	1.535	0.120	2.491	0.013			
		Education	4.967	1.158	0.237	4.288	0.000			
		Frequency of dialysis sessions	9.515	2.708	0.165	3.513	0.000			
Model-4	HD-PCBS (The patient's age is under control)	Patient's gender	4.614	1.601	0.136	2.882	0.004	13.798	0.197	1.839
		Education	3.462	1.169	0.165	2.962	0.003			
		Frequency of dialysis sessions	9.831	2.543	0.171	3.719	0.000			
		Caregiver's working status	6.753	1.863	0.178	3.624	0.000			
		Income level	3.165	1.252	0.129	2.507	0.013			
		Duration of caregiving	4.194	1.063	0.094	2.033	0.033			

Abbreviation: HD-PCBS, Primary Caregiver Burden Scale Individuals Receiving Hemodialysis Treatment.

variable of the patient and the caregiver was controlled in Model 2, it was determined that three independent variables reflecting the characteristics of the primary caregiver explained 14% of the variance in caregiver burden. In Model 3, it was determined that four independent variables representing patient characteristics explained 13% of the variance in caregiver burden. In Model 4, the effects of a total of six independent variables related to the patient and the primary caregiver on the caregiver burden were examined together by controlling the age of the patient, and it was determined that they explained 19% of the variance in the caregiver burden (Table 5). Therefore, based on the literature it can be said that the HD-PCBS is a valid tool for detecting caregiver burden in patients receiving HD treatment.

3.5 | Limitations of the study

The limitation of the study is that it was conducted in only one public hospital in our country, as conducting a study in more than one center would be able to provide data diversity. Despite this, it was observed that the emerging factors explained 64.867% of the caregiver burden.

4 | CONCLUSION

Different scales are used throughout the world and in Turkish society to evaluate the care burden of individuals providing care for patients receiving HD treatment. The results of this study demonstrated that the "Primary Caregiver Burden Scale Individuals Receiving Hemodialysis Treatment," which was developed to evaluate the caregiver burden perceived by individuals providing primary care for HD patients, met the validity and reliability criteria. In conclusion the scale can be used in nursing practices and research, and if its validity and reliability are established, it can make significant contributions to the international literature. It is recommended that this primary caregiver burden scale we developed be tested psychometrically in different HD populations.

4.1 | Contribution to applications

It is thought that the scale can contribute to the literature for studies aimed at evaluating the impact of changes in caregiver burden on HD patients and the effectiveness of interventions aimed at caregiver burden on both the patient and the caregiver.

CONFLICT OF INTEREST STATEMENT
The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT
The data that support the findings of this study are available from the corresponding author upon reasonable request.

ETHICS SATEMENT
Approval for the study was granted by the Non-invasive Clinical Research Ethics Committee of Burdur Mehmet Akif Ersoy University (Date: 11.05.2022, number: 2022/729). During the data collection process, the subject, purpose, and benefits of the research were explained to the patient's caregivers, and those who agreed to participate in the research completed the descriptive characteristics form and the draft form of the Primary Caregiver Burden

Scale in Patients Receiving Hemodialysis Therapy through face-to-face interviews. Since the research involved a human element, it was conducted in accordance with the principles of the Declaration of Helsinki 2008. Publication ethics were followed in the study.

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REFERENCES

1. Lin LN, Wu SC. Structure of caregiver burden. Geriatr Gerontol Int. 2014;14:176–84.
2. del-Pino-Casado R, Priego-Cubero E, Loʻpez-Martıʻnez C, Orgeta V. Subjective caregiver burden and anxiety in informal caregivers: a systematic review and meta-analysis. PLoS One. 2021;16(3):1–20.
3. Akyol GT, Erdoğan Z, Özdemir B, Çoban G, Aksu N. Quality of life of caregivers of chronic renal failure patients. Nefroloji Hemşireliği Dergisi. 2018;2(13):91–7. (article in Turkish with an abstract in English).
4. Liu Z, Heffernan C, Tan J. Caregiver burden: a concept analysis. Int J Nurs Sci. 2020;7(4):438–45.
5. Raza H, Nasır M, Rashıd Z, Rahat Shamim R, Alam B, Khan A, et al. Assessment of anxiety and burden on caregivers for haemodialysis patients in southern Punjab, Pakistan. FABAD J Pharm Sci. 2023;48(1):53–60.
6. Uğur Ö, Fadıloğlu Z. Kanser hastasına bakım verenlere uygulanan planlı eğitimin bakım veren yükü üzerine etkisi. Cumhuriyet Hemşirelik Dergisi. 2012;1(2):53–8. (article in Turkish with an abstract in English).
7. Akçin M. Evaluation of care burden and quality of life in caregivers of patients receiving services from dialysis unit. Medical specialization thesis (medical specialization thesis in Turkish). Samsun: T.C. University of Health Sciences; 2020.
8. Senmar M, Rafiei H, Yousefi F, Razaghpoor A, Bokharaei M. Caregiver burden among family caregivers of older patients receiving hemodialysis and its relevant factors. J Nephropharmacol. 2019;8(1):1–12.
9. Mashayekhi F, Pilevarzadeh M, Rafati F. The assessment of caregiver burden in caregivers of hemodialysis patients. Mater Sociomed. 2015;27(5):333–6.
10. Graessel E, Berth H, Lichte T, Grau H. Subjective caregiver burden: validity of the 10-item short version of the Burden Scale for Family Caregivers BSFC-s. BMC Geriatr. 2014;14:23.
11. Peipert JD, Jennings LA, Hays RD, Wenger NS, Keeler E, Reuben DB. A composite measure of caregiver burden in dementia: the Dementia Burden Scale Caregiver. J Am Geriatr Soc. 2018;66:1785–9.
12. Elmståh S, Malmberg BO, Annerstedt L. Caregiver's burden of patients 3 years after stroke assessed by a novel caregiver burden scale. Arch Phys Med Rehabil. 1996;77(2):177–82.
13. Cil AA, Pinar R. Validity and reliability of Turkish Caregiver Burden Scale among family caregivers of haemodialysis patients. J Clin Nurs. 2014;23(3–4):352–60.
14. İnci FH, Erdem M. Adaptation of the caregiving burden scale into Turkish, validity and reliability. J Atatürk Univ School Nurs. 2008;11(4):85–95.
15. Karaman S, Karadakovan A. Validity and reliability study of the readiness to care scale of patient relatives caring for stroke patients. Ege Univ J Nurs Faculty. 2015;31(1):1–10.
16. Aslan S, Ayaz R. Development of the burden scale for caregivers of dementia patients. Turk J Geriatr. 2018;21(3):456–66.
17. Cevik ÖHN, Şenol S. A systematic overview of care burden assessment scales. Izmir Kâtip Çelebi Univ J Faculty Health Sci. 2019;4(2):61–8. (article in Turkish with an abstract in English).
18. Çapık C, Gözüm S, Aksayan S. Stages of cross-cultural scale adaptation, language and culture adaptation: an updated guide. Florence Nightingale J Nurs. 2018;26(3):199–210.
19. International Test Commission (ITC). Guidelines for translating and adapting tests. Int J Test. 2018;18(2):101–34. https://doi.org/10.1080/15305058.2017.1398166
20. Polit DF, Beck CT. The content validity index: are you sure you know what's being reported? Critique and recommendations. Res Nurs Health. 2006;29:489–97.
21. Polit DF, Beck CT, Owen SV. Focus on research methods: is the CVI an acceptable indicator of content validity? Appraisal and recommendations. Res Nurs Health. 2007;30:459–67.
22. Bolarinwa OA. Principles and methods of validity and reliability testing of questionnaires used in social and health science researches. Niger Postgrad Med J. 2015;22:195–201.
23. Almanasreh E, Moles R, Chen TF. Evaluation of methods used for estimating content validity. Res Soc Adm Pharm. 2019;15:214–21.
24. Connors MH, Seeher K, Teixeira-Pinto A, Woodward M, Ames D, Brodaty H. Dementia and caregiver burden: a three-year longitudinal study. Int J Geriatr Psychiatry. 2020;35(2):250–8.
25. Riffin C, Van Ness PH, Wolff JL, Fried T. Multifactorial examination of caregiver burden in a national sample of family and unpaid caregivers. J Am Geriatr Soc. 2019;67(2):277–83.
26. Eğilli CS, Sunal N. Determination of care burden and factors affecting caregivers of patients with dementia. J Acad Res Nurs. 2017;3(2):83–91.
27. Cagan O, Unsal A, Celik N, Ture Yılmaz A, Culha I, Kök EH. Care burden of caregivers of hemodialysis patients and related factors. Int J Caring Sci. 2018;11(1):273–384.
28. Gok MZ, Helvacı A. Perceived care burden and affecting factors in family members caring for heart failure patients. Turk J Cardiovasc Nurs. 2019;10(22):59–66.
29. Esin MN. Reliability and validity of data collection tools. In: Erdogan S, Nahcivan N, Esin N, editors. Nursing research process application and critical. İstanbul: Nobel Medical Bookstores; 2014. p. 216–32.
30. Jebb AT, Ng V, Tay L. A review of key Likert scale development advances: 1995–2019. Front Psychol. 2021;12:1–14.
31. Streiner DV, Norman GR, Cairney C. Health measurement scales: a practical guide to their development and use. Oxford: Oxford University Press; 2015.
32. Gungor D. Guidelines for the development and application of measurement tools in psychology. Türk Psikoloji Yazıları. 2016;19(38):104–12.
33. Ozdemir Z. Likert type attitude scale development in health sciences. J Hacet Univ Faculty Nurs. 2018;5(1):60–8.

34. Clark LA, Watson D. Constructing validity: basic issues in objective scale development. In: Kazdin AE, editor. Methodological issues and strategies in clinical research. Washington: American Psychological Association; 2016.

35. Devellis RF, Thorpe CT. Scale development theory and applications. 5th ed. California: SAGE Publications; 2022.

36. Inci FH, Erdem M. The Turkish version of the care burden scale reliability and validity. Atatürk Univ Nurs School J. 2008; 11(4):85–95.

37. Iecovich E. Psychometric properties of the Hebrew version of the Zarit Caregiver Burden Scale short version. Aging Ment Health. 2012;16(2):254–63.

38. Al-Rawashdeh SY, Lennie TA, Chung ML. Psychometrics of the Zarit burden interview in caregivers of patients with heart failure. J Cardiovasc Nurs. 2017;31(6):1–10.

39. Jaracz K, Grabowska-Fudala B, Kleka P, Tomczak M, Smelkowska A, Pawlicka A, et al. Development and psychometric properties of the caregiver burden scale in Polish caregivers of stroke patients. Psychol Res Behav Manag. 2022;15:665–75.

40. Martín-Carrasco M, Otermin P, Pérez-Camo V, Pujol J, Agüera L, Martín MJ, et al. EDUCA study: psychometric properties of the Spanish version of the Zarit Caregiver Burden Scale. Aging Ment Health. 2010;14(6):705–11.

41. Lee KC, Yiin JJ, Chao YF. Development of an experience-based caregiver burden scale in advanced cancer. Cancer Nurs. 2016; 39(1):12–20.

42. Şencan H. Reliability and validity in social and behavioral measurement. 1st ed. Ankara: Seçkin Publishing; 2005.

43. Erkorkmaz U, Etikan I, Demir O, Ozdamar K, Sanisoglu SY. Confirmatory factor analysis and fit indices. Turkiye Klinikleri J Med Sci. 2013;33(1):210–23.

44. Lu L, Wang L, Yang X, Feng Q. Zarit caregiver burden interview: development, reliability and validity of the Chinese version. Psychiatry Clin Neurosci. 2009;63:730–4.

45. Greco A, Pancani L, Sala M, Annoni AM, Steca P, Paturzo M, et al. Psychometric characteristics of the caregiver burden inventory in caregivers of adults with heart failure. Eur J Cardiovasc Nurs. 2017;16(6):502–10.

46. Valer DB, Aires M, Fengler FL, Girardi Paskulin LM. Adaptation and validation of the Caregiver Burden Inventory for use with caregivers of elderly individuals. Rev Lat Am Enfermagem. 2015;23(1):130–8.

47. Kula KS, Mor DE. Historical development of the concept of validity and the most preferred method in reliability: Cronbach's alpha coefficient. Abant Izzet Baysal Univ J Faculty Educ. 2016;16(4):1865–79.

48. Rattray J, Jones MC. Essential elements of questionnaire design and development. J Clin Nurs. 2007;16:234–43.

49. Hipolito N, Martins S, Ruivo A, Flora S, Silva CG, Marquesf A. Construct validity and reliability of the informal caregiver burden assessment questionnaire (QASCI) in caregivers of patients with COPD. Respir Med. 2022;205:1–8.

50. Akgül A. Statistical analysis techniques in medical researches: SPSS applications. 3rd ed. Ankara: Emek Ofset Ltd. Şti; 2005. p. 440–55.

51. Büyüköztürk Ş. Data analysis handbook for social sciences: statistics, research design, SPSS applications and interpretation. 8th ed. Ankara: Pegem Akademi; 2007. p. 167–82.

52. Zhong M, Evans A, Peppard R, Velakoulis D. Validity and reliability of the PDCB: a too for the assessment of caregiver burden in Parkinson's disease. Int Psychogeriatr. 2013;25(9): 1437–41.

53. Abdollahpour I, Nedjat S, Noroozian M, Golestan B. Development of a caregiver burden questionnaire for the patients with dementia in Iran. Int J Prev Med. 2010;1(4):233–41.

54. Vahidi M, Mahdavi N, Asghari E, Ebrahimi H, EivaziZiaei J, Hosseinzadeh M, et al. Other side of breast ancer: factors associated with caregiver burden. Asian Nurs Res. 2016;10(3): 201–6.

55. Kaya UU, Taylan HH. Factors affecting the care burden of family members providing primary care giving to Alzheimer patients. J Acad Social Sci Stud. 2018;71:513–31.

56. Hançerlioğlu S, Toygar İ, Ayhan A, Yilmaz İ, Orhan Y, Özdemir GS, et al. Burden of diabetic foot patients' caregivers and affecting actors: a cross-sectional study. Int J Low Extrem Wounds. 2023;22(4):680–6.

57. Putri YSE, Putra IGNE, Falahaini A, Wardani IY. Factors associated with caregiver burden in caregivers of older patients with dementia in Indonesia. Int J Environ Res Public Health. 2022;19:1–13.

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.