ORIGINAL ARTICLE

Validity and reliability of Turkish Caregiver Burden Scale among family caregivers of haemodialysis patients

Ayse Cil Akinci and Rukiye Pinar

Aims and objectives. To investigate the validity and reliability of the Caregiver Burden Scale in family members who provide primary care for haemodialysis patients.

Background. In Turkey, there is a need for a multi-dimensional instrument to evaluate the caregiver burden in people who provide care for patients with chronic diseases.

Design. A methodological study.

Methods. The study sample consisted of 161 family members who provide primary care for haemodialysis patients. The forward-backward translation method was used to develop the Turkish Caregiver Burden Scale. The reliability was based on internal consistency investigated by Cronbach's alpha and item–total correlation. The factorial construct validity of the scale was tested with confirmatory factor analysis. By means of convergent and divergent validity, correlation between Caregiver Burden Scale and 36-Item Short Form Health Survey (SF-36) and correlation between Caregiver Burden Scale and the Maslach Burnout Scale were investigated.

Results. Cronbach's alpha and item–total correlations results suggested that there was good internal reliability. We found five underlying factors similar to original Scale's five-factor solution. The confirmatory factor analysis five-factor model represented an acceptable fit. Factor loadings were significant, with standardised loadings ranging from 0·43–0·81. By means of divergent validity, all sub-dimension scores and the total score of the Caregiver Burden Scale were negatively correlated with the SF-36, whereas there was a positive correlation with the emotional exhaustion and depersonalisation subscales of the Maslach Burnout Scale as expected.

Conclusion. These results suggest that the Caregiver Burden Scale is a reliable and valid instrument which can be used with confidence in Turkish caregivers for haemodialysis patients to screen caregiver burden.

Relevance to clinical practice. The burden experienced by people who provide care for patients with chronic diseases can be evaluated with the Caregiver Burden Scale. Additionally, the Caregiver Burden Scale can be used in the evaluation of the effectiveness of attempts to decrease caregiver burden.

Key words: caregiver burden, end-stage renal disease, haemodialysis, nursing, reliability, validity

Introduction

Currently, the care needs of most people with a chronic disease are provided by family members (Canam & Acorn 1999). The family caregiver's role is often unrecognised and invisible. However, hopelessness, depression, difficulty in decision-making, increased stress levels, decreased time for leisure activities, social isolation, decreased quality of life

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(QOL) and increased physical health problems may set on later among family caregivers (Pinquart & Sorensen 2003, Bertrand *et al.* 2006, Martinez-Martin *et al.* 2008, Akkus 2010, Bartolo *et al.* 2010). Additionally, the affective problems experienced frequently by caregivers decrease the QOL and increase the burden of caregiving (Bertrand *et al.* 2006, Martinez-Martin *et al.* 2008). The burden of caregiving can be described as the negative objective and subjective results of caregiving including psychological distress, physical health problems, economic problems, social problems, disruption of family relationships and the sense of losing control (Collins *et al.* 1994). Caregiving sometimes may have positive effects on caregivers. In a study made on caregivers for seniors living in the community, caregivers reported positive aspects of caregiving (Cohen *et al.* 2002). In another study made on caregivers for schizophrenic spectrum disorders, it has been reported that caregiving gains is prevalent (Chen & Greenberg 2004). It is known that caregiving burden is a real problem, although limited studies on positive aspects of caregiving are present. Some factors related to patient and caregiver can affect the burden of caregiving. It is known that the burden of caregiving increases with the severity of disease and decreased levels of physical independency in patients (Martinez-Martin *et al.* 2008, Carod-Artal *et al.* 2009, Bartolo *et al.* 2010). In addition, the psychological state and gender of caregivers affect the burden of caregiving. For instance, depression and being female increase the burden of caregiving (Carod-Artal *et al.* 2009, Bartolo *et al.* 2010). It should be noted that studies on the burden of caregiving have been generally conducted with people who provide care for patients with neurological diseases. The number of studies on the burden in caregivers who provide care for dialysis patients is limited, and the results of these studies seem different from each other. It has been reported that the QOL in people who provide care for dialysis patients tends to decrease as the burden of caregiving increases (Alvarez-Ude *et al.* 2004). Belasco *et al.* (2006) reported that people who provide care for older dialysis patients, especially peritoneal dialysis, experience a significant amount of caregiver burden and this affects the caregivers' QOL in a negative way. Shimoyama *et al.* (2003) showed that the caregiver burden in people who provide care for peritoneal dialysis patients with end stage renal diseases (ESRD) is higher than those who provide care for patients with dementia and stroke. Another study reported that the relatives of patients with ESRD have a better QOL and exhibit low or no caregiver burden at all and that caregiver burden does not differ according to the type of dialysis (peritoneal dialysis or haemodialysis) (Wicks *et al.* 1997). According to the Turkish Society of Nephrology, 46,650 patients received dialysis because of ESRD in Turkey

at the end of the year 2009 and approximately 80% of these patients were middle-aged and old-aged. Similar to other chronic diseases, family members provide primary care for patients with ESRD (Turkish Society of Nephrology 2009 Annual Registry Report). Therefore, it has been assumed that family members who provide care for Turkish haemodialysis patients also experience a large amount of caregiver burden.

Although the QOL in people who provide care for patients with ESRD in Turkey has been evaluated (Acaray & Pinar 2005), as far as we know, there are no studies investigating the caregiver burden. The evaluation of the caregiver burden in people who provide care for patients with chronic diseases such as the ESRD is very important for planning attempts of decreasing the caregiver burden and assessing the effectiveness of planned interventions (Schulz & Sherwood 2008). Two scales are used in the evaluation of caregiver burden in Turkey (Inci & Erdem 2008, Kucukguclu *et al.* 2009). One of these scales is used for measuring the caregiver burden in people who provide care for patients with cognitive disorders (Kucukguclu *et al.* 2009). The other scale evaluates the caregiver burden in one dimension (Inci & Erdem 2008). Measuring the caregiver burden only in one dimension may prevent the assessment of the sub-dimensions and the relationship between these sub-dimensions. It also prevents the precise determination of the problematic areas in caregivers (Novak & Guest 1989, 1992). The Caregiver Burden Scale (CBS), which was developed by Elmstahl *et al.* (1996), is a multi-dimensional instrument for evaluating the caregiver burden in people who provide care for patients with a chronic disease. However, validity and reliability procedures should be conducted for using this scale in the Turkish population.

Purpose

The purpose of this study was to made reliability and validity of the CBS.

Methods

Design

The methodological model was used.

Participants

The study was performed with 161 family members who provided primary care for haemodialysis patients registered at several haemodialysis centres in a province. Sample inclusion criteria were having provided care for at least six months, being 18 years old or older, not having a physical

or psychiatric disorder that would prevent the interview, not having problems in understanding, and talking and writing in Turkish. The study was conducted according to Helsinki Declaration (World Medical Association 2008). The participants were informed about the study and were assured of confidentiality. Informed written consent was obtained from all subjects before their participation in the study. Data were gathered in June–October 2010.

We distributed the questionnaires to the participants in haemodialysis centres. The researchers read the questionnaire verbatim to people who were unable to self-complete the questionnaire without assistance. Data collection took approximately 30 minutes on average.

Instruments

Data were collected via three instruments. Those were the CBS, Maslach Burnout Scale (MBS) and The Medical Outcomes Study 36-Item Short Form Health Survey (SF-36).

Caregiver Burden Scale contains 22 items. Every item has a score ranging from 1 (not at all) to 4 (frequently). The scale includes five sub-dimensions that are general strain, isolation, disappointment, emotional involvement and environment. The general strain sub-dimension contains eight items, whereas the disappointment sub-dimension has five items; isolation, emotional involvement and environment contain three items in each. The sub-dimension scores are calculated by adding up the relevant items and then dividing this score with the number of items in each sub-dimension. Higher scores indicate high levels of caregiver burden, whereas lower scores indicate low levels of caregiver burden. The internal consistency of the general strain, isolation, disappointment, emotional involvement and environment sub-dimensions is reported as 0·87, 0·70, 0·76, 0·70 and 0·53, respectively (Elmstahl *et al.* 1996).

Maslach Burnout Scale, which was developed by Maslach and Jackson (1981), contains 22 items. The scale's Turkish adaptation, validity and reliability have been conducted by Ergin (1993). Each item has a score ranging from 0 (never) to 4 (always). The scale contains three sub-dimensions, which are emotional exhaustion, depersonalisation and personal accomplishment. Obtaining high scores from the emotional exhaustion and depersonalisation subscales and low scores from personal accomplishment indicate burnout. In addition, the items in the emotional exhaustion and depersonalisation sub-dimensions are scores straight whereas the items in personal accomplishment are scored reversely and the total score is calculated by adding up the item scores which range from 0–4. The Cronbach's alpha coefficients of the sub-dimensions are 0·83 for emotional exhaustion, 0·65 for depersonalisation and

0·72 for personal accomplishment (Ergin 1993). In our study, Cronbach's alpha coefficients of the sub-dimensions are 0·80 for emotional exhaustion, 0·70 for depersonalisation and 0·81 for personal accomplishment, respectively.

SF-36 was developed by Ware and Sherbourne (1992), and Turkish adaptation of the scale was conducted by Pinar (2005). The SF-36 is a multipurpose, 36-item survey that measures eight domains of health: physical functioning, role limitations because of physical health, bodily pain, general health perceptions, vitality, social functioning, role limitations because of emotional problems and mental health. Two core components of health (physical component summary; mental component summary) can be derived from these eight scales. Assessment is done on a Likert-type scoring except for some items, and the last four weeks are taken into account while answering the questions. Subscale and final two summary component's scores for the SF-36 range from 0–100, a score of 100 indicates the best level of health, whereas a score of 0 indicates the worst level of health (Ware & Sherbourne 1992, Pinar 2005). In the Pinar's study, Cronbach's alpha coefficient for the physical and mental health domain was 0·87 and 0·89, respectively. In the current study, Cronbach's alpha coefficient for the physical and mental health domain was 0·78 and 0·76, respectively.

Procedures

The adaptation of the scale was based on validity and reliability studies following translation of the CBS into Turkish. The forward-backward translation method was used to develop the Turkish CBS. Translations were done by bilingual translators who were familiar with English and Turkish cultures. We followed several steps to translate CBS into Turkish. Those are (1) translation from English into Turkish by three people and backward translation from Turkish into English by two independent people, (2) examination by an expert panel of the original English, Turkish and back-translated English forms for clarity, discrepancies, and meaning errors and resolution of all differences in the forms, (3) reviewing back-translated English form and original English form by Elmstahl *et al.* (1996) and (4) finally, consisting final Turkish version. After completing the translation procedure, we started to collect data to test validity and reliability of CBS.

Internal consistency (Cronbach's alpha and item–total correlation) was evaluated for reliability. Nunnally and Bernstein (1994) regarded a reliability coefficient of 0·90 as the minimum acceptable value for making decisions about individuals but noted that, for comparing groups, > 0·80 is adequate and 0·70 is acceptable. Others consider that an acceptable minimum reliability coefficient can be 0·70–0·80,

or even lower for short subscales (Todd & Bradley 1994). In the present analysis, for the total scale, a minimum Cronbach's alpha of 0·90 was regarded as ideal, but reliability coefficients of 0·80 were considered very acceptable and reliability coefficients > 0·70 were considered acceptable. We considered a Cronbach's alpha values > 0·60 for the subdimensions in the CBS were acceptable because of limited numbers of items in sub-dimensions. To determine the ability of the items in the scale to measure similar behaviours, we calculated item–total correlation by using Pearson's correlation. Acceptable corrected item–total correlations were those > 0·20 (Streiner & Norman 2003).

Additionally, to determine the competency of each item in terms of being able to discriminate the caregiver burden of individuals, the significance of the difference between the upper 27% and lower 27% groups' item scores was examined. We expected t values would be significant.

By means of validity, factorial construct validity and convergent/divergent validity procedures were conducted. Confirmatory factor analysis (CFA) was used to test the factorial construct validity of the CBS. We expected that the subscales, originally defined by Elmstahl *et al.* (1996), would emerge from CFA and items relating to a particular scale would be grouped together within a single factor. Factor loadings were taken as the recommended minimum 0·30 (Streiner & Norman 2003). Several goodness-of-fit indices were examined in evaluating CFA. These were χ^2//df, Comparative Fit Index (CFI), Normed Fit Index (NFI), Non-Normed Fit Index (NNFI), standardised root mean square residual (SRMR), and root mean square error of approximation residual (RMSEA). It was considered that $\chi^2/df < 2$, CFI > 0·97, NFI > 0·95, NNFI > 0·97, SRMR < 0·05 and RMSEA < 0·05 indicate perfect fit, whereas $\chi^2/df < 3$, CFI > 0·95, NFI > 0·90, NNFI > 0·95, SRMR < 0·10 and RMSEA < 0·08 indicate acceptable fit (Schermelleh-Engel *et al.* 2003). We also expected that there would be positive correlations between sub-dimensions.

Convergent/divergent validity was investigated by correlation between CBS and Turkish SF-36, and correlation between CBS and the MBS. Pearson's correlation coefficient was used to correlate the scores with each other. It is expected that there would be negative correlations between CBS and SF-36, CBS and personal accomplishment in the MBS (divergent validity), while there would be positive correlation between CBS and emotional exhaustion and depersonalisation in the MBS (convergent validity).

Data were analysed using SPSS 15.0 for windows (SPSS Inc., Chicago, IL, USA). The CFA was calculated using LISREL version 8 (Scientific Software International, Inc., Lincolnwood, IL, USA).

Results

The characteristics of the caregivers and patients

The characteristics of the caregivers and patients are shown in Table 1. The caregivers sample included 161 people with mean age 45·4 years. The majority were female, were married and had primary school education level. Half of the caregivers were spouses of the patients, and the duration of caregiving was 4·9 years. Almost 92% of patients received haemodialysis three times a week and received haemodialysis for 4·3 years. It is found that 86·3% of patients discontinued working after starting haemodialysis and 50·9% of those semi-dependent or dependent to meet their daily life requirements.

Table 1 Characteristics of the caregivers and patients

	n (%)	Range	Mean	SD
Characteristics of the caregivers				
Age (years)		18–80	45·4	15·3
Gender				
Female	100 (65·2)			
Male	56 (34·8)			
Marital status				
Married	126 (78·3)			
Unmarried	35 (21·7)			
Educational level				
Literate	31 (19·3)			
Primary school (5 years education)	77 (47·8)			
Secondary school (8 years education)	14 (8·7)			
High school (11–12 years education)	26 (16·1)			
University	13 (8·1)			
Relation to the patient				
Spouse	81 (50·3)			
Mother	25 (15·5)			
Father	18 (11·2)			
Sister/brother	9 (5·6)			
Others	28 (17·3)			
Duration of caregiving (years)		0·5–20	4·9	4
Characteristics of the patients				
The frequency of dialysis				
2 times/week	13 (8·1)			
3 times/week	148 (91·9)			
Duration of dialysis treatment (year)		5–20	4·3	3·4
To continue to work after dialysis				
Continued	22 (13·6)			
Discontinued	139 (86·3)			
Meeting daily requirements				
Independent	79 (49·1)			
Semi-dependent	65 (40·3)			
Dependent	17 (10·6)			

Reliability

Reliability results are shown in Table 2. The Cronbach's alpha coefficient for the 22 items was 0·91. The Cronbach's alphas for the general strain, isolation, disappointment, emotional involvement and environment sub-dimensions were 0·83, 0·74, 0·69, 0·61 and 0·63, respectively. The item–total correlations for all the items in the scale ranged from 0·37–0·70, and *t* values were all significant ($p < 0.001$).

Validity

We performed CFA to assess the factorial construct validity of the CBS. Using the data from current sample, two models were tested. In comparison with single factor model, five-factor model with 22 items provided an acceptable fit to the data except χ^2/df. χ^2/df indicated perfect fit (Table 3). In this CFA model, items relating to a particular scale grouped together within a single factor. Factor loadings were significant, with standardised loadings ranging from 0·43–0·81. All factors in the CBS were correlated with each other in a positive direction (Fig. 1).

By means of divergent validity, as seen in Table 4, all sub-dimension scores and the total score of the CBS were negatively correlated with the physical and mental components of the SF-36, whereas a positive correlation with the emotional exhaustion and depersonalisation subscales of the MBS showed convergent validity. All correlations were statistically significant. There was very weak no significant correlation between CBS and personal accomplishment subscale in MBS.

Discussion

The burden experience is so common among family members who provide care for haemodialysis patients. For that reason, it is necessary to evaluate caregiving burden as routine basis, initiate preventive intervention and evaluate effectiveness of nursing interventions. An appropriate assessment tool should be used to measure such needs and interventions. The results of this study proved the sufficient reliability and validity of the CBS-Turkish version.

Reliability

In this study, reliability results of the Turkish CBS showed satisfactory results. Reliability coefficient for the total CBS was ideal, Cronbach's alpha value for the general strain was very acceptable (Nunnally & Bernstein 1994), and finally, Cronbach's alpha values for the rest of sub-dimensions in CBS were acceptable (Todd & Bradley 1994). Our results were comparable with findings from Elmstahl *et al.* (1996), who found that Cronbach's alpha coefficient was 0·89 for the overall scale and ranged from 0·87, 0·70, 0·76, 0·70 and

Table 2 Reliability results of Caregiver Burden Scale

Item no.	Item–total correlation[†]	*t* (lower 27%–upper 27%)[‡]	Cronbach's α
General strain			
GS1	0·52	−7·504***	0·83
GS2	0·66	−11·756***	
GS3	0·54	−8·793***	
GS4	0·44	−6·449***	
GS5	0·70	−15·938***	
GS6	0·56	−9·962***	
GS7	0·51	−7·080***	
GS8	0·68	−13·825***	
Isolation			
I1	0·62	−10·185***	0·74
I2	0·63	−11·065***	
I3	0·52	−8·075***	
Disappointment			
D1	0·42	−5·526***	0·69
D2	0·48	−8·189***	
D3	0·57	−10·791***	
D4	0·40	−5·251***	
D5	0·38	−4·912***	
Emotional involvement			
EI1	0·58	−8·639***	0·61
EI2	0·65	−14·357***	
EI3	0·56	−8·748***	
Environment			
E1	0·37	−6·345***	0·63
E2	0·44	−7·300***	
E3	0·66	−13·439***	
[†]n = 161	[‡]n₁ = n₂ = 44	***$p < 0.001$	0·91

GS, general strain; I, isolation; D, disappointment; EI, emotional involvement; E, environment.

Table 3 Results of confirmatory factor analysis

	χ^2/df	CFI	NFI	NNFI	SRMR	RMSEA
Model 1 (one factor model)	1·88	0·86	0·74	0·85	0·067	0·074
Model 2 (five-factor model)	1·76	0·96	0·92	0·96	0·066	0·068

df, degree of freedom; CFI, Comparative Fit Index; NFI, Normed Fit Index; NNFI, Non-Normed Fit Index; SRMR, standardised root mean square residual; RMSEA, mean square error of approximation residual.
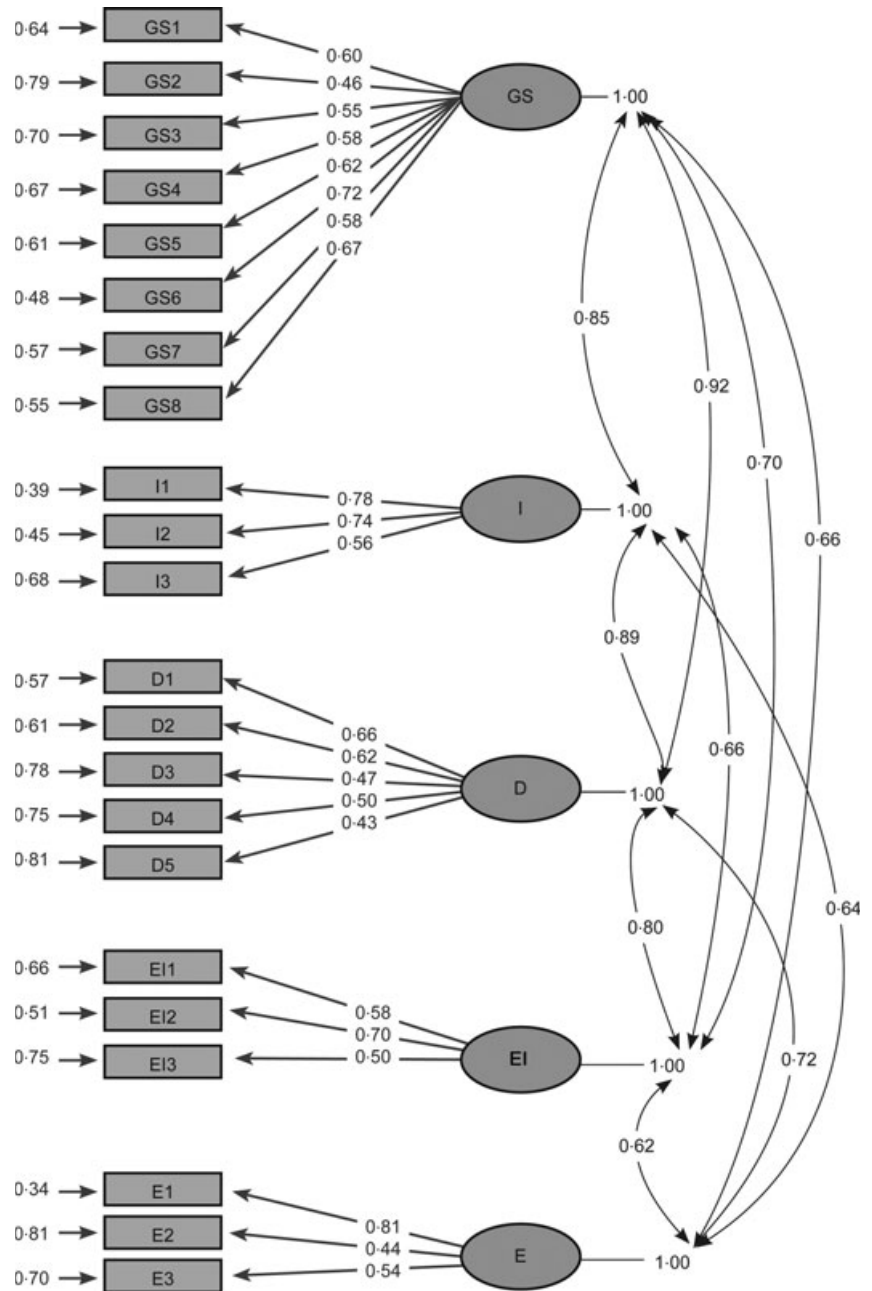
Figure 1 The results of CFA of the five-factor model.

0·53, for the general strain, isolation, disappointment, emotional involvement and environment sub-dimensions, respectively.

The item–total correlations for all the items in the scale exceeded the accepted standard (Streiner & Norman 2003), and *t* values were all significant. Based on reliability studies, we can conclude that five subscales in the CBS have been consistent and replicated as well as each items in the related sub-dimension can discriminate the caregiver burden of individuals.

Validity

Factorial construct validity
The goodness-of-fit indices determine whether a model is supported by a data set at an acceptable level. There are various goodness-of-fit indices; however, the RMSEA is one of the most sensitive indices for models with non-specified factor loadings (Hu & Bentler 1999). Toyoda (1998) suggested that RMSEA is least affected by degree of freedom and the most reliable among the fit indices and that structural

Table 4 The results of convergent and divergent validity

	CBS					
	GS	I	D	EI	E	Total score
SF-36						
Physical component	−0·54*	−0·49*	−0·53*	−0·34*	−0·39*	−0·58*
Mental component	−0·60*	−0·55*	−0·58*	−0·41*	−0·46*	−0·65*
MBS						
Emotional exhaustion	0·79*	0·61*	0·69*	0·54*	0·47*	0·79*
Depersonalisation	0·49*	0·36*	0·52*	0·50*	0·39*	0·55*
Personal accomplishment	−0·01	0·03	0·05	0·12	0·12	0·05

CBS, Caregiver Burden Scale; MBS, Maslach Burnout Scale; GS, general strain; I, isolation; D, disappointment; EI, emotional involvement; E, environment.
*$p < 0.001$.

equation modelling is acceptable if RMSEA is not larger than 0·10 regardless of the other fit indices. Our study confirmed that the Turkish 22 Item CBS has five factors with perfect/acceptable fit indices, especially by means of RMSEA. All items in the CBS contributed to only one factor as originally defined by Elmstahl *et al.* (1996). All items had also factor loading of >0·30, thus satisfying the criteria that predictive items have loadings (Streiner & Norman 2003). These results suggest that the underlying components of the Turkish adapted CBS were similar with original CBS. Positive relationships between sub-dimensions of the CBS, in the present study, also further suggest factorial construct validity of CBS.

Convergent/divergent validity
The MBS and the Turkish SF-36 were used for evaluating the convergent and divergent validity of the scale, and the correlations between the scores were assessed. In our study, scores of the CBS showed significant negative correlations with the SF-36 as expected. In another saying, when caregiver burden increased QOL decreased. Our results correlate well with the previous studies. Similar to our findings, in a study of caregivers who provide care for dialysis patients, it has been reported that caregivers with a higher caregiver burden have a lower QOL (Alvarez-Ude *et al.* 2004). Suri *et al.* (2011) investigated burden on caregivers as perceived by haemodialysis patients and found that burden score was inversely associated with SF-36 and directly associated with depression. Belasco and Sesso (2002) and Belasco *et al.* (2006) found that perceived burden by caregivers had adverse effect on QOL. Similar results were also found by Wicks *et al.* (1997).

Burnout, which is measured by MBS in the current study, is a psychological term for the experience of long-term exhaustion and diminished interest by a heavy workload (Maslach & Leiter 1997). According to Stress Research Institute (2010), burnout is described as a condition of emotional

and physical exhaustion as well as a long-term process in which the everyday environment is seen to be in contrast to idealistic commitment. As we mentioned before, caregiving burden is a negative objective and subjective results of caregiving including psychological distress, physical health problems, economic problems, social problems, disruption of family relationships and the sense of losing control (Collins *et al.* 1994). For that reason, as expected, we found a direct link between burnout sub-domains including emotional exhaustion and depersonalisation with caregiving burden.

As conclusion, we found that caregivers appeared to have more caregiving burden, more burnout and worse QOL. All expected relationship between caregiving burden and burnout, caregiving burden and QOL, which found in this study, proved convergent and divergent validity.

Conclusion

The CBS, which consisted of five factors, is a reliable and valid instrument for evaluating the caregiver burden of Turkish people who provide care for haemodialysis patients with ESRD.

Limitation of the study

One possible limitation of the study is that mostly caregivers (65·2%) are female. Hence, generalisation of the results of the study may be somewhat limited. The fact that the test–retest method was not used for evaluating reliability can be considered another limitation. Further research is warranted to use test–retest method to examine stability of the CBS.

Relevance to clinical practice

The burden experienced by people who provide care for patients with chronic diseases can be evaluated with the

multidimensional CBS. Additionally, the CBS can be used in the evaluation of the effectiveness of nursing interventions to decrease caregiver burden.

Acknowledgement

Contributions

Study design: ACA, RP; data collection and analysis: ACA and manuscript preparation: ACA, RP.

Conflict of interests

The authors declare that they have no conflict of interest.

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