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Subjective burden of family caregivers with Turkish immigration background in Germany

Validation of the Turkish version of the Burden Scale for Family Caregivers

Introduction

Providing nursing care for a relative is frequently associated with a high risk of stress [15]. As reported in a review by Etters et al. [11] psychological distress in caregiving relatives is a common phenomenon and has been demonstrated in numerous studies. The burden of family caregivers with Turkish immigration background living in Germany has been studied by means of qualitative studies (e. g. [21]). To date, there are no quantitative data on this topic, particularly with regard to the connection between the caregiving burden and health. There is also no measure that can be applied to determine the subjective burden of this group of persons. At the same time it can be expected that the importance of informal care will increase among immigrants, as the number of migrants who are 60 years or older is expected to rise to 24 % by 2030 [3].

The aim of the present study was to develop a standardized measure of caregiver burden that would be reliable and valid. For the results of the same instrument to be comparable in different languages and cultures, the content must be equivalent and the quality of the psychometric properties of the measure must be tested. To be able to use the existing German

scale internationally, the Burden Scale for Family Caregivers (BSFC) [13] was translated into Turkish and validated in a sample of Turkish immigrants living in Germany who provide care for relatives at home. The BSFC complete with scoring instructions is freely available on the Internet in 20 European languages including Turkish at www.caregiver-burden.eu.

Material and methods

Study design

A cross-sectional study using standardized measures was conducted for the first time in Turkish family caregivers living in Germany in order to obtain insights into the homecare situation and validation data for the Turkish version of the BSFC (BSFC_{tr}). The data were collected in personal interviews with caregiving relatives who were recruited via outpatient nursing services run by Turkish managers. This procedure was chosen on the basis of the assumption that outpatient care services managed by persons with Turkish immigration background would have a greater number of Turkish clients. A total of three nursing services in northern Germany cooperated with the personnel who managed the study and people with Turkish immigration back-

ground and long-term nursing care needs who were looked after at home by a caregiving relative were included in the study. A total of 15 family caregivers were interviewed in Berlin, 5 in Hamburg and 29 in Bönen (North Rhine-Westphalia).

At the beginning of the interview, the interviewees were informed that participation was voluntary and that the interview could be terminated at any time without providing a reason. They were assured that the information they supplied would not be linked to their names, that the data analysis would be conducted anonymously and that the results would be published only for scientific purposes. Their consent to this procedure was documented. The study was carried out in accordance with the procedure approved by the Ethics Committee of the Friedrich-Alexander University of Erlangen-Nürnberg (No. 227_14 B). This study was carried out in line with the regulations laid down in the Declaration of Helsinki.

Measures

All 28 items from the BSFC [13, <http://www.caregiver-burden.eu>] measure the subjective burden of family caregivers who provide homecare for a chronically ill person at home. The items ask about the domains “consumption of mental and

Table 1 Characteristic features of subjects included in the study

	Mean (SD) or n (%)
Characteristics of the family caregivers	
Age (years)	49.1 (16.5)
Gender (female)	38 (78 %)
<i>Level of education</i>	
Illiteracy ^a	7 (14 %)
Primary school	18 (38 %)
Secondary school/vocational school	8 (16 %)
Grammar school/university degree	16 (33 %)
Employment (yes)	12 (25 %)
<i>Marital status</i>	
Married	39 (80 %)
Not married	7 (14 %)
Divorced	2 (4 %)
Widowed	1 (2 %)
Characteristics of the patients	
Age (years)	61.6 (14.2)
Gender (female)	29 (59 %)
<i>Relationship: patient is</i>	
Spouse (investigation group)	23 (47 %)
Mother (in-law)/father (in-law) (investigation group)	20 (41 %)
Other persons ^b	6 (12 %)
<i>Diseases</i>	
Cardiovascular diseases (e.g. stroke, hypertension, partially with comorbidities, such as diabetes mellitus)	17 (35 %)
Mental disorders (e.g. dementia, depression)	4 (8 %)
Cancer	3 (6 %)
Nephrectomy	3 (6 %)
Rheumatism	2 (4 %)
Gonarthrosis	1 (2 %)
Physical disability following a traffic accident	1 (2 %)
Blindness	1 (2 %)
Unknown	17 (35 %)
Characteristics of the caregiving situation	
<i>Care level</i>	
No care level	7 (14 %)
Care level 1	14 (29 %)
Care level 2	20 (41 %)
Care level 3	8 (16 %)
Duration of care (years)	8.6 (7.1)
Informal help ^c (yes)	31 (63 %)
Formal help ^d (yes)	28 (57 %)
<i>SD</i> standard deviation, <i>n</i> frequency	
^a primary illiteracy (no school) or secondary illiteracy (no reading or writing skills at the moment)	
^b brother (in-law) or sister (in-law), uncle or aunt	
^c support of other family members	
^d home nursing, day hospital, sheltered workshop	

physical energy”, the “relationship between caregiver and patient”, “changes in the socioeconomic situation”, “excessive demands” and “role identification”. The items are rated on a scale ranging from 0 (strongly disagree) to 3 (strongly agree) and 11 of the 28 items are reverse coded. The scores range from 0 to 84 points where higher scores indicate greater caregiver burden. For psychometric criteria see Gräßel [13] and Grau et al. [16].

For the development of the Turkish version of the BSFC, the forward-backward translation method was employed. The scale was translated in four steps: (1) translation from German into Turkish by three people independently, (2) arrival at a consensus on the most accurate version when the translations differed, (3) back translation of this version into German by two independent translators, (4) comparison with the original German version and adaptation of the Turkish version for the validation study. The information obtained from the following validation study was used to develop the final Turkish version.

The Giessen complaints questionnaire (GCB-24) [7] is a standardized scale for the measurement of 24 physical symptoms in terms of the extent to which they are completely or partly psychosomatically induced. The scale comprises four domains “physical exhaustion”, “stomach complaints”, “aching limbs” and “heart problems”, each of which consists of six items. The current extent of impairment due to a symptom can be rated as not at all (0), hardly (1), moderate (2), considerable (3) or severe (4). A subscore of between 0 and 24 points is calculated for each domain. A total score (ranging from 0 to 96 points) is also calculated from all 24 physical symptoms. Higher values are indicative of more severe impairment due to physical symptoms. Cronbach’s alpha for the total score is 0.94 [7]. Sociodemographic variables and data on the caregiving situation were also documented. The care level assessed by the Medical Service of Health Insurance (*Medizinischer Dienst der Krankenversicherung*, MDK), ranges from none (level 0) through mild (level 1), moderate (level 2) and great need for care (level 3).

Statistical analyses

Reliability and item analysis

Cronbach's alpha was computed as a measure of internal consistency. Bortz and Döring [6] recommend an alpha of 0.8 or higher for well-designed scales. The difficulty indices, discriminatory powers and Cronbach's alpha for "if item deleted" were calculated for each item. Because a 4-point response format (0–3 points) is used for the items of the BSFC_{tr}, the ratio of the sum of the subject's squared points to the sum of the squared item maximum ($\frac{\sum x^2}{\sum x_{max}^2}$) [12] was used to compute the difficulty indices. Bortz and Döring [6] recommend item difficulties of between 0.2 and 0.8. Discriminatory power was calculated as the correlation between the item and the total score when the item was deleted. According to Bortz and Döring [6] a discriminatory power of 0.3–0.5 is rated as moderate, and a power of greater than 0.5 is rated as high.

Validity

The following three hypotheses on the construct validity of the BSFC_{tr} were examined:

- Hypothesis 1 (H1): the caregiver burden will increase with increases in the demands placed on the family caregiver by the caregiving situation, operationalized by the care level [27].
- Hypothesis 2 (H2): the caregiver burden will increase as the emotional involvement of the family caregiver increases, i. e. the closer the relationship to the person requiring care. It is assumed that the burden of caring for an elderly family member will on average be greater for a caregiving spouse or partner than for a caregiving child or child-in-law [31].
- Hypothesis 3 (H3): the caregiver burden will increase with more severe impairments to the person's physical health [23]. In the present study, physical health was operationalized with the GBB-24. It was hypothesized that the total physical symptoms score is significantly correlated with caregiver burden when adjusted for other significant predictors of physical health.

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Subjective burden of family caregivers with Turkish immigration background in Germany. Validation of the Turkish version of the Burden Scale for Family Caregivers

Abstract

Background. Subjective burden is a central variable for describing the situation of family caregivers. Up to now the subjective burden of family caregivers with Turkish immigration background in Germany has not been quantitatively investigated.

Objectives. The aim of this study was the validation of the Turkish version of the Burden Scale for Family Caregivers (BSFC_{tr}).

Material and methods. In order to measure the subjective burden of family caregivers with Turkish immigration background, the BSFC was translated into Turkish. The internal consistency of the 28-item BSFC_{tr} was calculated using Cronbach's alpha. The difficulty indices and discriminating powers of the items were analyzed. The construct validity was examined by using three hypotheses of association.

Results. The cross-sectional study was conducted on 49 family caregivers with a Turkish immigration background in Germany who care for older, chronically ill persons. Cronbach's alpha for the total scale was 0.89. The caregiver burden was greater when the care recipient had substantial regular nursing care needs and when the spouse or partner had assumed the care as compared with the children or children-in-law. Caregiver burden significantly increased with the extent of psychosomatic symptoms of the caregiver. **Conclusion.** The Turkish version of the BSFC proved to be a reliable and valid measure for determining the subjective burden of family caregivers.

Keywords

Aged · Home nursing · Cross-sectional study · Validity · Chronic illness

Subjektive Belastung pflegender Angehöriger mit türkischem Migrationshintergrund in Deutschland. Validierung der türkischsprachigen Fassung der Häusliche-Pflege-Skala

Zusammenfassung

Hintergrund. Die subjektive Belastung ist eine wichtige Variable, mit der die Situation pflegender Angehöriger charakterisiert wird. Bisher ist die subjektive Belastung pflegender Angehöriger mit türkischem Migrationshintergrund in Deutschland nicht quantitativ untersucht worden.

Zielsetzung. Ziel der Studie war es, die türkischsprachige Fassung der Häusliche-Pflege-Skala (HPS_{tr}) zu validieren.

Material und Methoden. Um die subjektive Belastung pflegender Angehöriger mit türkischem Migrationshintergrund erfassen zu können, wurde die HPS ins Türkische übersetzt. Zur Bestimmung der internen Konsistenz der 28-Item-Version der HPS_{tr} wurde Cronbachs Alpha berechnet. Der Schwierigkeitsgrad und die Trennschärfe der Items wurden analysiert. Auf der Grundlage von drei Zusammenhangshypothesen wurde die Konstruktvalidität untersucht.

Ergebnisse. An der Querschnittstudie nahmen 49 pflegende Angehörige mit

türkischem Migrationshintergrund teil, die in Deutschland eine ältere, chronisch kranke Person pflegten. Cronbachs Alpha der Gesamtskala betrug 0,89. Die subjektive Belastung der pflegenden Angehörigen war größer, wenn der pflegebedürftigen Person eine Pflegestufe zugeordnet war. Hatte ein (Ehe-)Partner die Pflege übernommen, war die Belastung im Vergleich zur häuslichen Pflege durch Kinder oder Schwiegerkinder ebenfalls größer. Die subjektive Belastung korrelierte positiv mit dem Ausmaß der psychosomatischen Beschwerden der pflegenden Angehörigen.

Schlussfolgerung. Die HPS_{tr} erwies sich als ein reliables und valides Instrument zur Erfassung der subjektiven Belastung türkischstämmiger pflegender Angehöriger.

Schlüsselwörter

Ältere Menschen · Häusliche Pflege · Querschnittsstudie · Validität · Chronische Erkrankung

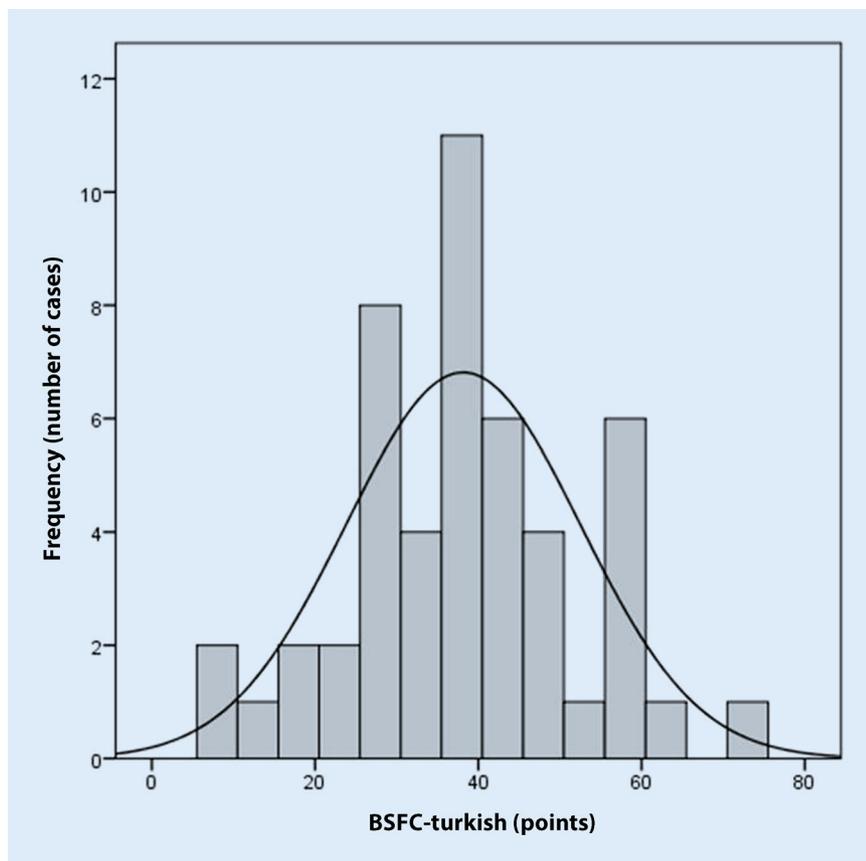


Fig. 1 ▲ Distribution of the BSFC_{tr} score in this study population

In order to determine the correlation with the BSFC_{tr} score, Pearson's r or η (for nominally measured variables) was calculated. The association between the BSFC_{tr} score and the total extent of the physical symptoms on the GBB-24 (raw data) was analyzed with multivariate procedures. In a first step, a correlation analysis was applied to all the variables to test for a correlation with the GBB-24 score, always adjusting for age and gender because physical symptoms are dependent on age and gender. In a second step, a multiple linear regression analysis was performed with the GBB-24 score as the dependent variable. Only the variables that had been found to be significantly correlated in the first step were included in the multivariate regression analysis and analyzed using the enter method. Prior to this, a multicollinearity analysis was performed in order to discover independent variables that were at least moderately correlated (>0.50) with each other. The level of significance was set at $p = 0.05$.

Results

Sample

A total of 49 family caregivers with Turkish immigration background were interviewed, 38 (78 %) of whom were women. The average age of the family caregivers was 59.1 years ($SD = \pm 16.5$). The care receivers were 61.6 years old on average ($SD = \pm 14.2$) and represented the wide range of diseases found in older age groups (Table 1).

Distribution of the BSFC_{tr} score

The distribution of the BSFC_{tr} score (Fig. 1) covered almost the entire range of 0 to 84 points (observed range 8–75 points). The values were approximately normally distributed (Kolmogorov-Smirnov test $p = 0.84$) with a mean score of 38.1 points ($SD = \pm 14.3$) and a median of 38 points (25th percentile 29 and 75th percentile 47).

Item analysis and reliability

The difficulties of the 28 BSFC_{tr} items ranged between 0.14 and 0.75 (Table 2). Of the items 5 showed values ≤ 0.20 : feeling of being used, forced into caregiving situation, unreasonable wishes of care recipient, relationship with care recipient deteriorating and problems with the family. Together with the mean item scores, which were less than 1.0 this means that on average these items showed only a very low level of burden. By contrast, the items sleep deprivation, not being able to switch off, difficulties with providing care, wish to take a break and sadness about the fate of the care recipient were the five items of the BSFC_{tr} that showed the highest average burden (mean item score ≥ 1.9) and had difficulties greater than 0.45.

At 0.886 Cronbach's alpha of the total score was distinctly higher than 0.80. Of the 28 items 13 showed high discriminatory powers between 0.50 and 0.80 and a further 8 items showed moderate but still significant values between 0.30 and 0.49. Low values of less than 0.30 were only found for items that were not significantly correlated with the total score. This was also evident in Cronbach's alpha scores for "if item deleted", which were higher than Cronbach's alpha scores for the total score. Only two items (communication deficit and bothered by outsiders) were not correlated at all with the total score ($r_p = 0.03$ and 0.04 , respectively), which is why Cronbach's alpha for "if item deleted" was distinctly higher (0.05 and 0.07, respectively) than Cronbach's alpha for the total score (Table 2).

Construct validity

Hypothesis 1

In the cases in which there was no level of care ($n = 7$), a mean caregiver burden of 32.0 ($SD = 17.4$) was found. At care level 1 ($n = 14$) the mean caregiver burden was 37.9 ($SD = 14.7$), at care level 2 ($n = 20$) 39.4 ($SD = 12.9$) and at care level 3 ($n = 8$) 41.0 ($SD = 15.7$). The correlation between caregiver burden and care level was not significant ($p = 0.64$, $\eta = 0.19$) as the subjective burden within the three care levels (1, 2 and 3) did not

Table 2 Characteristics of the items of the BSFC _{tr}					
Item summary	Mean (SD)	Item difficulty	Discriminatory power	p-value	Cronbach's alpha "if item deleted"
<i>1 Sleep deprivation</i>	1.9 (1.0)	0.52	0.35	0.013	0.885
2 Reduced life satisfaction	1.3 (1.0)	0.30	0.46	0.001	0.882
3 Physically exhausted	1.8 (0.9)	0.47	0.48	< 0.001	0.882
4 Wish to run away	1.3 (1.1)	0.31	0.55	< 0.001	0.880
5 Communication deficits	1.2 (0.9)	0.25	0.03	0.84	0.891
<i>6 Not enough time for own interests</i>	1.8 (0.9)	0.45	0.27	0.07	0.886
7 Feeling of being used	0.8 (1.0)	0.19	0.28	0.05	0.886
<i>8 Not being able to switch off</i>	1.9 (0.9)	0.47	0.36	0.010	0.884
<i>9 Difficulties providing care</i>	2.0 (1.1)	0.55	0.53	< 0.001	0.881
10 Depersonalization	1.2 (1.1)	0.29	0.55	< 0.001	0.880
<i>11 Care not adequately acknowledged</i>	1.0 (1.0)	0.21	0.37	0.010	0.884
12 Decreased standard of living	1.6 (1.0)	0.40	0.48	0.001	0.882
13 Forced into caregiving situation	0.9 (1.0)	0.19	0.48	< 0.001	0.882
<i>14 Unreasonable wishes of care receiver</i>	0.9 (0.9)	0.19	0.19	0.20	0.888
<i>15 Not having the care situation under control</i>	1.3 (1.0)	0.30	0.45	0.001	0.882
16 Health affected by caregiving	1.4 (1.1)	0.34	0.80	< 0.001	0.873
<i>17 Incapable of feeling joyful</i>	1.4 (1.2)	0.36	0.53	< 0.001	0.880
18 Giving up future plans	1.5 (1.2)	0.39	0.53	< 0.001	0.880
<i>19 Bothered by outsiders</i>	1.1 (1.2)	0.29	0.04	0.80	0.893
20 Caregiving is sapping strength	1.4 (1.1)	0.35	0.57	< 0.001	0.879
21 Conflicting demands	1.1 (1.1)	0.28	0.54	< 0.001	0.880
<i>22 Relationship with care receiver deteriorating</i>	0.8 (1.0)	0.19	0.16	0.27	0.889
23 Problems with the family	0.7 (0.9)	0.14	0.60	< 0.001	0.879
24 Wish to take a break	1.9 (1.0)	0.49	0.55	< 0.001	0.880
25 Worried about the future	1.1 (1.1)	0.28	0.66	< 0.001	0.877
26 Relationships with others are suffering	1.1 (1.1)	0.26	0.70	< 0.001	0.876
27 Sadness about the fate of the care receiver	2.3 (1.0)	0.68	0.19	0.20	0.888
<i>28 Fulfilment of other obligations difficult</i>	1.7 (1.0)	0.41	0.59	< 0.001	0.879

reverse coded items are in italics (agreement means not burdened)
Cronbach's alpha (28 items) 0.886
SD standard deviation, **p** p-value of discriminatory power (**p** < 0.05 are in bold)

continue to increase. While hypothesis 1 was therefore not supported, two different categories of caregiver burden were evident on a descriptive level. There was a clear difference between the lower subjective burden of family caregivers whose chronically ill family member did not meet the requirements for any care level and the higher subjective burden of family caregivers who were confronted with

care needs that met the criteria of at least care level 1.

Hypothesis 2

The mean caregiver burden of the 23 spouses or partners was significantly higher than the mean of the 20 caregiving children or children-in-law (44.1 ± 11.9 versus 31.3 ± 14.8 , $p = 0.003$, $r_p = 0.44$). Hypothesis 2 was therefore sup-

ported. Caregiver burden was found to be greater when the relationship between the family caregiver and the care recipient was closer.

Hypothesis 3

The subjective burden of family caregivers with Turkish immigration background was significantly correlated with the GBB-24 score ($r = 0.51$, $p < 0.001$), even when adjusted by age and gender (Table 3). Moreover, family caregivers with more than 10 years of education showed significantly fewer physical symptoms than relatives with a lower level of education ($p = 0.015$).

In the multivariate regression analysis, subjective burden was a significant predictor of the GBB-24 score ($p < 0.001$, Table 4). These results provided support for hypothesis 3, which had predicted that more severe physical symptoms would be associated with higher subjective burden values.

Discussion

The aim of the study was to validate the Turkish language version of the BSFC (BSFC_{tr}). Of the three hypotheses regarding the construct validity of the BSFC_{tr}, two were confirmed and hypothesis 1 only partially confirmed. Thus, this self-rating scale permits the valid assessment of the subjective burden of family caregivers with Turkish immigration background both in counseling settings and for research purposes.

Items 5 "communication deficit" and 19 "bothered by outsiders" could have been left out due to a lack of discriminatory power. We recommend that the complete version with 28 items be used to ensure comparability of the results. For reasons of cultural sensitivity, the wording of item 13 "I feel that I was forced into this caregiving situation" has now been revised as follows: "I feel that I was free to decide whether to take on the care". The reservations about the original wording expressed by some of the interviewees were thus addressed.

The study showed that informal care of chronically ill Turkish immigrants in Germany who are the spouse or partners or the parents or parents-in-law of the

Table 3 Correlation with physical complaints (GBB-24 score)			
	Unstandardized beta (95 % CI)	Beta	p
Variables for adjustment			
Age of family caregiver	0.42 (0.04–0.80)	0.32	0.031
Gender of family caregiver	–19.59 (–34.35 to –4.83)	–0.38	0.010
Age and gender-adjusted variables			
<i>Caregiver characteristics</i>			
Subjective burden (BSFC _{tr})	0.67 (0.26–1.07)	0.44	0.002
Education: illiteracy (yes/no)	0.10 (–20.15–20.34)	< 0.01	0.99
Education: grammar school or university degree (yes/no)	–15.66 (–28.13 to –3.19)	–0.34	0.015
Employment (yes/no)	5.82 (–9.15–20.80)	0.12	0.44
Marital status: married (yes/no)	13.17 (–2.79–29.14)	0.25	0.10
Relationship: spouse (yes/no)	–1.88 (–21.79–18.04)	–0.04	0.85
<i>Patient characteristics</i>			
Age	0.31 (–0.18–0.80)	0.21	0.21
Gender	–4.40 (–17.30–8.50)	–0.10	0.50
<i>Characteristics of the care situation</i>			
Care level (yes/no)	6.52 (–10.15–23.18)	0.11	0.44
Duration of care	–0.54 (–1.38–0.29)	–0.18	0.20
Informal help (yes/no)	5.73 (–7.43–18.89)	0.13	0.39
Formal help (yes/no)	8.76 (–3.07–20.58)	0.20	0.14
<i>p</i> < 0.05 are in bold			
95 % CI 95 % confidence interval			

Table 4 Multivariate regression analysis with the GBB-24 score as the dependent variable			
Independent variable^a	Unstandardized beta (95 % CI)	Beta	p
Age of family caregiver	0.27 (–0.14–0.68)	0.21	0.19
Gender of family caregiver	–21.56 (–26.99 to –6.13)	–0.42	0.007
Caregiver burden (BSFC _{tr})	0.60 (0.16–1.03)	0.40	0.008
Education: illiteracy (yes/no)	–12.34 (–31.23–6.56)	–0.20	0.20
Education: grammar school or university degree (yes/no)	–11.35 (–24.28–1.57)	–0.25	0.08
<i>p</i> < 0.05 are in bold			
95 % CI 95 % confidence interval			
^a the multicollinearity analysis established no variable to be excluded from multivariate regression analysis because of a correlation coefficient ≥ 0.50 . All correlation coefficients of the independent variables were ≤ 0.43			

family caregivers is mainly carried out by women (78 %). This parallels the situation for the German population with no immigration background [28]. In contrast to other studies, in this study the average age of the persons with Turkish immigration background in need of care was almost 20 years lower (62 years) than those of German nationality or persons of other nationalities requiring care (80 years) [22]. This could be explained by the fact that on average persons with

Turkish immigration background living in Germany are more frequently affected by chronic and psychosomatic illnesses and at an earlier age than the German reference population [2, 4, 20, 33]. As a result the caregiving spouse or partner and children or children-in-law would also be younger. The low proportion of very old people (80 years and older) in our study can be attributed to the fact that most people with a Turkish immigration background in Germany have not

yet reached this old age. From 1960 onwards, mostly young adults below the age of 30 years immigrated to Germany [18]; therefore, the proportion of very old people among Germans is currently about three times higher than among non-Germans (5.6 % vs. 1.8 %) [25]. Due to the small proportion of very old people the number of dementia cases in the sample is also low.

No significant differences were found between caregiver burden and the different levels of care, which were used in Germany to establish eligibility for nursing care benefits. An increase in the subjective burden was already discernible at the transition from the status “missing care level” to “care level 1”. In this context the results of other studies become relative and have shown that the amount of daily effort put toward providing care has an effect on the level of burden felt by the caregiver [8, 17, 24]. We did not find this association in family caregivers with Turkish immigration background in Germany.

As expected and as has been confirmed by other studies, spouses experienced greater amounts of subjective burden than caregiving children or children-in-law [9, 10]. The kind of family relationship between caregiver and care recipient has an effect on how the burden is perceived [1, 29]. These differences are partly due to the fact that caregiving partners and spouses, who usually live in the same household as the care recipient, assume more care tasks than children or children-in-law. Caregiving partners and spouses also assume a self-sacrificing role insofar as they are constantly available 24 h per day and 7 days per week [19].

In the sample of family caregivers with Turkish immigration background we found a moderately strong significant correlation between subjective burden and self-rated physical symptoms. The correlation of 0.51 shows that the caregiver burden and physical symptoms must be two different concepts. It can be hypothesized that they are reciprocally linked [14]. For example, if family caregivers have more physical symptoms due to a disease, the caregiving burden may increase. Conversely, stressful caregiving

situation may lead to psychosomatically induced physical symptoms. Whether this interpretation is in fact correct and there is a causal relationship between subjective burden and self-rated physical symptoms can only be established in a longitudinal study.

In the present study the BSFC_{tr} and GBB-24 were used to quantitatively measure the burden of care of family caregivers with Turkish immigration background for the first time. The psychosomatic component of the caregiving situation was examined with the GBB-24. Previously in Germany there had not been a valid instrument that explicitly addressed the subjective burden of family caregivers with Turkish immigration background. The validation of the Turkish version of the BSFC will help to close this gap. A strength of this study was that the interviews were carried out by an interviewer who spoke Turkish and was familiar with the culture because one goal of the study was not to exclude persons with little knowledge of the German language or who were illiterate. A lack of translated measures, language barriers, and a lack of transcultural skills in interviewers have been the main reasons for the considerable dearth of conclusive empirical studies in this field [5, 26].

Sampling was conducted with an active recruitment strategy. This reaching out approach made it possible to reach this target group, which is otherwise difficult to access. The potential participants were found through outpatient nursing services managed by persons with Turkish immigration background, then contacted by telephone and finally visited in person. The reaching out approach provides clear advantages over the relatively anonymous method of contacting people by post, particularly for Turkish immigrants [32]; however, the possibility of response bias (e.g. the effect of social desirability) cannot be excluded.

The conclusiveness of the results is also limited by the small number of cases in this selective sample (recruitment through outpatient nursing services). A sample of family caregivers who have not made use of the support offered by nursing services may have different characteristics. The present study, therefore,

does not claim to be representative but using a convenience sampling, such as used here enabled us to calculate item characteristics and to analyze hypotheses on construct validity. Additionally, the results provide some previously unavailable information on the burden experienced by family caregivers with Turkish immigration background in Germany. The reported causes of the care needs of the care receivers were measured on the basis of the limited knowledge of the family caregivers; therefore, the study does not permit a comparison between different groups of diseases behind the need for homecare in older people.

Conclusion

The BSFC_{tr} for Turkish-speaking family caregivers is now available as a valid instrument for measuring subjective burden (www.caregiver-burden.eu). As the BSFC_{tr} was well-accepted by the respondents and was practical to utilize, it can be employed both for research and as a screening measure for identifying family caregivers who are suffering from caregiving stress. These vulnerable family caregivers should be a target group for the early provision of relief measures. To increase the level of acceptance of such measures, care must be taken to provide culture-specific measures and convey them in a culturally sensitive way [30].

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Compliance with ethical guidelines

Conflict of interest. N. Ulusoy and E. Graessel state that there are no conflicts of interest.

The study was carried out in accordance with the procedure approved by the Ethics Committee of the Friedrich-Alexander University of Erlangen-Nürnberg. All procedures were carried out in accordance with the Helsinki Declaration of 1975 (in its most recently amended version). Informed consent was obtained from all patients included in the study.

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Weltweite Studie zu Patienten- und Angehörigenbetreuung in der Intensivstation

Teilnahme erwünscht!

Die World Federation of Societies of Intensive and Critical Care Medicine (WFSICCM) bittet nationale wissenschaftliche Fachgesellschaften weltweit um Umsetzungsbeispiele für patienten- und familienzentrierte Betreuung. Immer mehr Studien attestieren, dass die patientenzentrierte Pflege und Strategien zur Einbeziehung der Familienangehörigen die Therapieresultate für schwerkranke Patienten fördern. Dennoch ist nicht bekannt, zu welchem Grad bestimmte Arten dieser Betreuungspraktiken weltweit umgesetzt werden.

Die Studie „Patient and Family Centered Care in the ICU: Worldwide Exemplars“ soll nun eben diese Informationen sammeln. Zur Datenerhebung kommt bei dem Projekt eine sichere, web-basierte Anwendung zum Einsatz – die sogenannte Research Electronic Data Capture (REDCap™).

Die Informationen können einfach online hinterlegt werden:
<https://redcap.rush.edu/redcap/surveys/?s=JJ4RLREEXY>

Quelle: Deutsche Interdisziplinäre Vereinigung für Intensiv- und Notfallmedizin (DIVI) 23.05.2017