Burden in family caregivers: The psychometric properties of Polish version of the Zarit Burden Interview

Karolina Szatkowska, Małgorzata Anna Basińska

Department of Clinical Psychology, Faculty of Psychology, Kazimierz Wielki University

Summary

Aim. The aim of the study was to estimate the reliability, validity and internal structure of the Polish version of the *Zarit Burden Interview* scale (ZBI).

Material and method. The participants in the study were 504 Polish family caregivers (spouses, parents, children and other family members) of chronically ill patients. The *Burnout Scale* version for caregivers (SWS) and the *Resilience Assessment Questionnaire* (KOP-26) were used.

Results. The Polish version of the *Zarit Burden Interview* demonstrated good psychometric properties. Confirmative factor analysis confirmed the presence of a three-factor second-order structure, the model proved to be quite well suited to the data (CFI = 0.941; TLI = 0.931; SRMR = 0.045; RMSEA = 0.061). Also, the results of the theoretical validity analysis proved to be satisfactory. Cronbach's α coefficient for the general result was 0.91; for individual subscales: "Negative image of the patient" – 0.85, "Frustration" – 0.82 and "Losses" – 0.85.

Conclusions. The Polish version of the ZBI scale can be used as a reliable and accurate diagnostic tool to measure the burden among carers of chronically ill people. Qualitative analysis of the response content also allows to identify areas requiring the implementation of activities in the field of psychological support for the surveyed caregivers.

Key words: burden, family caregivers, *Zarit Burden Interview*

Introduction

Family is a natural environment for humans; it performs multiple functions, including caregiving, especially towards its sick and disabled members. This is an extremely important task, especially when we consider the fact that statistical data confirm an increasing number of cases of chronic diseases resulting from the ageing of populations [1]. Healthcare services provided at home are aimed at reducing the cost of treatment (so far most frequently offered in hospitals or outpatient clinics) and

improving the comfort and quality of life of patients who do not require longer hospital stays. However, in order for a person to be able to continue treatment at home, it is necessary that another person is the caregiver.

When undertaking home care for a chronically ill person, the family assumes responsibility for the person, providing him or her 24-hour supervision. In the case of patients with special medical needs (e.g., in the terminal stage of cancer or those on mechanical ventilation) caregivers perform numerous care and treatment activities, monitor vital signs, and learn to help in situations threatening the health and life of the patient [2]. In their new role, not only do they change their life routines, but often face financial difficulties related to increased expenditure on medicines, care products and dressings, or rehabilitation, concurrently limiting their professional activity or entirely resigning from work. In addition, caregivers can face consequences such as less time for other family members, and their social contacts may be less frequent [2, 3]. This specificity of care, requiring the ability to cope with various, at times non-standard tasks, is a stressful situation, which in the long run may trigger the feeling of physical and mental burden in the caregiver [3, 4]. Nevertheless, as a result of anticipated or real costs (financial, organizational or emotional) of caring for a close family member, some families in Poland do not offer such care and place their relatives in various special care centers [5].

Caregiver burden

Initially, the concept of the feeling of burden was used in relation to mental illnesses, mainly schizophrenia [6] and Alzheimer's disease [7]. Nowadays, it is recognized that the concept of the feeling of burden is a multidimensional construct and can assume various forms. It covers needs reported by a patient, disturbance in daily family life, household duties and professional roles of the caregiver, financial expenditure related to treatment or emotional difficulties associated with the course of the disease in a family member [8, 9]. Thus, the burden of care can generally be defined as the entirety of all the difficulties and challenges with which the family is faced and which result from the illness of its member [9, 10].

The feeling of burden is operationalized in a variety of ways, which is related to its multidimensionality [8, 10, 11]. However, the so far unresolved issue is the level of generality of suggested research methods. Tools for measuring a general feeling of burden enable to compare groups of caregivers of patients with various diseases, at the same time ignoring the specificity of the disease, which may be related to the burden characterizing a given context of caregiving. Yet, specific scales to test the feeling of burden enable the identification of factors that are a burden for caregivers and which are typical of a given disease, but they do not allow to compare the experience of care provided to patients with different chronic illnesses [10].

The multidimensionality of the concept of the burden of care and the number of stressors that may be conducive to it lead to the conclusion that the key role for its development is the perception of personal experience of caregiving and its impact on daily functioning. The severity of the feeling of burden can result, in the long run, in

the occurrence of burnout syndrome. In a situation where the caregiver's difficulties with undertaking caregiving procedures are increasing and are time-extended, and the caregiver does not have adaptive coping skills, the level of burnout can reach such an extent that further caregiving will not be possible [12]. Therefore, it seems to be particularly important to assess the feeling of burden that accompanies the caregivers of chronically ill persons in order to offer relevant psychological assistance to this specific group.

Due to the absence of a reliable Polish measurement tool to assess the feeling of burden of care in family caregivers, efforts aiming at the cultural adaptation of the *Zarit Burden Interview* (ZBI), developed by Steven H. Zarit [7], were undertaken. This scale is widely used in the research on caregivers of persons struggling with various diseases, including dementia [9], heart failure [13], amyotrophic lateral sclerosis [14] and among the caregivers of mechanically ventilated patients [15].

Material and methods

Participants and procedures

The study was divided into two stages. In both stages participated two groups of adult family (non-professional) caregivers who provided care to their chronically ill or disabled relatives. 80 persons participated in the first pilot stage; this group included 54 women (67%) and 26 men (33%). The mean age of the subjects was 53 ($M = 53.04$; $SD = 14.11$). A total of 504 caregivers participated in the study, including 413 women (82%) and 91 men, aged 19–87 ($M = 53.00$, $SD = 14.00$). The majority of respondents had higher ($n = 272$; 54%), secondary ($n = 176$; 35%) and vocational education ($n = 40$; 8%), while the number of persons who had primary education was the lowest ($n = 16$; 3%). The majority of the study subjects lived in a large city with over 250,000 inhabitants ($n = 161$), then in the countryside ($n = 126$; 25%), in a city with population of 100–250,000 inhabitants ($n = 121$; 24%) and, finally, in a town of up to 100,000 inhabitants ($n = 96$; 19%). Nearly three-fourths of the study participants were married ($n = 363$; 72%), other persons were single ($n = 55$; 11%), in a non-marital relationship ($n = 45$; 9%) or divorced ($n = 30$; 6%); the lowest number of persons were widowed ($n = 11$; 2%). The subjects were members of extended families of the relative to whom they provided care. The largest group were daughters of sick or disabled parents ($n = 167$; 33%), followed by wives ($n = 101$; 20%), mothers ($n = 75$; 15%), daughters-in-law ($n = 40$; 8%)), husbands ($n = 25$; 5%), sons ($n = 25$; 5%), sisters ($n = 20$; 4%), granddaughters ($n = 20$; 4%), aunts ($n = 11$; 2%)), fathers ($n = 5$; 1%), fiancées ($n = 5$; 1%), mothers-in-law ($n = 5$; 1%), and grandmothers ($n = 5$; 1%). All surveyed caregivers lived with sick family members. Conducted study follows the principles of the Declaration of Helsinki.

<center>Measures</center>

The *Zarit Burden Interview* (ZBI) developed by Zarit [7] consists of 22 items referring to the experiences associated with negative consequences of being a caregiver of a sick person and understood as the feeling of burden. Answers are given on a 5-point Likert scale. For questions from 1 to 21 the subjects' responses range from 0 – "never" to 4 – "nearly always," while question No 22 regarding the general level of the feeling of burden of care triggers a potential response between 0 – "not at all" and 4 – "extremely." The overall outcome is the score sum ranging between 0 to 88. Higher scores indicate a higher level of burden of care, however, the author of the original scale initially did not provide cut-off points for individual levels of severity of the burden of care [7]. A later interpretation of the severity of the feeling of burden [16] indicated a burden that might be defined as significant with scores ranging between 61 to 88, moderate – 41 to 60, mild – 21 to 40, and minor – below 20. However, this division has been criticized for being too arbitrary [17].

The inventory is characterized by satisfactory psychometric properties; internal cohesion (Cronbach's α) was 0.87–0.93. In order to assess the internal consistency of the scale, a test-retest was performed. The value of the Cohen's kappa was 0.71 ($r = 0.71$) [17]. Although the original scale is characterized by a consistent univariate structure, the results of subsequent studies on the psychometric properties of this scale indicate the occurrence of the ZBI structure that can range from a two-factor [18] to five-factor structure [19].

The measures used to verify the validity of the Polish language version of the *Zarit Burden Interview* were as follows:

(a) convergent validity – the *Burnout Scale* version for caregivers (SWS) by Steuden and Okła [20] as adapted by Karolina Szatkowska and Małgorzata A. Basińska. It is used to study the experience and commitment associated with caregiving and resultant fatigue. It consists of 58 items, and responses are given on a 5-point Likert scale. The score sum obtained in all questions is the overall result of burnout caused by the provided care. It is a scale with very good parameter properties (α = 0.95).

(b) discriminant validity – the *Resilience Assessment Questionnaire* developed by Gąsior, Chodkiewicz and Cechowski (KOP-26) [21]. It is used to measure resilience defined as personal, family and social competences, and includes 26 items evaluated on a 5-point scale. The higher the score, the greater resilience. This questionnaire has satisfying psychometric properties (α = 0.90).

<center>Adaptation of the ZBI into Polish</center>

Adaptation procedures started from the approval of the author of the scale to carry out the Polish adaptation. Since the Polish language version available from the owner of the ZBI copyrights (The Mapi Research Trust) raised doubts about the linguistic correctness at the initial stage, the forward–backward translation was made. Next, this version of the scale was used for carrying out the pilot study in a group of 80

caregivers of chronically ill persons. The obtained psychometric properties provided assumptions to continue adaptation.

Statistical analyses

Prior to the analysis, it was investigated whether the collected data was complete. For the final analysis, the results obtained from 504 caregivers were used. Statistical calculations were made using the IBM SPSS Amos 25 and lavaan package in R environment.

Results

Items included in the ZBI were analyzed. The distribution of results obtained for the items differs from the normal one as it is characterized by significant dispersion, the rightward skewed asymmetry and platykurtosis. Three test items (7, 20 and 21) reached the discriminant power value below the acceptable one (0.40). They were removed from further statistical analyses; however, they remain in the structure of the questionnaire, adequate to the original, and their qualitative analysis is recommended.

Factor analysis

In connection with numerous reports on the various factor structure in previous European adaptations of the *Zarit Burden Interview* [22, 23] the exploratory factor analysis (EFA) was conducted. The principal component method with Oblimin rotation were used to provide more realistic representation of relation of dimensions of measured construct [24]. The results of this analysis indicate the adoption of a three-factor structure, which is confirmed by the adopted criteria: Kaiser's criteria regarding loadings with eigenvalue greater than 1, and the obtained scree-plot – Cattell's criterion. Items with factor loadings exceeding 0.50 were assigned to each factor. This resulted in a three-factor structure consisting of 19 items (Table 1).

Table 1. **Principal component analysis of the Polish version of the Zarit Burden Interview (N = 504)**

Factors	Eigenvalue	Variance (%)	Cumulative variance (%)		
I Negative image of the patient	8.49	44.67	44.67		
II Frustration	1.45	7.64	52.32		
III Losses	1.10	5.80	58.12		
Factors and items			Factor I	Factor II	Factor III
I Negative image of the patient					
1. Do you feel that your relative asks for more help than he/she needs?			0.636	0.374	-0.141
4. Do you feel embarrassed about your relative's behavior?			0.766	0.085	0.211

table continued on the next page

5. Do you feel angry when you are around your relative?	0.704	0.037	0.385
6. Do you feel that your relative currently affects your relationship with other family members?	0.787	0.191	0.268
9. Do you feel strained when you are around your relative?	0.668	0.200	0.326
11. Do you feel that you don't have as much privacy as you would like, because of your relative?	0.700	0.337	0.165
13. Do you feel uncomfortable having your friends over because of your relative?	0.627	0.149	0.330
II Frustration			
2. Do you feel that, because of the time you spend with your relative, you don't have enough time for yourself?	0.273	0.637	0.224
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0.276	0.702	0.354
8. Do you feel that your relative is dependent upon you?	-0.088	0.741	0.090
10. Do you feel that your health has suffered because of your involvement with your relative?	0.275	0.705	0.189
12. Do you feel that your social life has suffered because you are caring for your relative?	0.165	0.677	0.345
14. Do you feel that your relative seems to expect you to take care of him or her, as if you were the only one he or she could depend on?	0.300	0.617	0.093
22. Overall, how burdened do you feel in caring for your relative?	0.200	0.662	0.474
III Losses			
15. Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?	0.016	0.207	0.502
16. Do you feel that you will be unable to take care of your relative much longer?	0.214	0.123	0.726
17. Do you feel that you have lost control of your life since your relative's illness?	0.290	0.446	0.627
18. Do you wish you could leave the care of your relative to someone else?	0.379	0.061	0.739
19. Do you feel uncertain about what to do about your relative?	0.312	0.093	0.736

The presented three-factor solution served as the basis for developing a path model of confirmatory analysis (CFA). Due to non-fulfillment of conditions of a multidimensional normal distribution, values of the model parameters were estimated using the Robust Maximum Likelihood (MLR) [25]. The following models were tested: 1-factor and 3-factor models as well as a 3-factor hierarchical model. The analysis of indicators showed that the 1-factor model turned out to be inaccurate. On the other hand, the 3-factor model and the 3-factor hierarchical model (with first-order factors: "Negative image of the patient," "Frustration" and "Losses," and the overall burden as a second-order factor) obtained comparable model fit parameters (Table 2). Nevertheless, the

result of the chi-square test for the difference assumed that the second-order 3-factor model obtained a significantly better fit to the data ($\Delta\chi^2(2) = -17.845$; $p <0.001$). In the case of the general factor, all items were significant ($p < 0.001$). It should be noted that the level of statistical significance for the χ^2 test suggesting a poor fit of the model to the data may result from a large sample size, to which the statistics of this analysis are sensitive. Therefore, parameters such as χ^2/df and Holter's N were analyzed, which indicated the correct estimation of the model parameters ($\chi^2/df = 2.886$, Holter's $N >200$) [25]. After estimating the goodness of fit of the model, internal consistency and construct validity of the scale were verified.

Table 2. **Summary specifications and invariance analyses of the Polish version of the ZBI responses for the tested models (N = 504)**

Model	df	χ^2	p	X^2/df	RMSEA (90% CI)	CFI	TLI	SRMR	Holter's N p <0.01
3-factor second-order	146	421.325	<0.001	2.886	0.061 (0.540–0.068)	0.941	0.931	0.045	231
3-factor	149	510.258	<0.001	3.424	0.069 (0.063–0.076)	0.923	0.912	0.049	226
1-factor	152	810.211	<0.001	5.330	0.093 (0.087–0.099)	0.721	0.775	0.098	122

df– degrees of freedom; RMSEA – Root Mean Square Error of Approximation; CFI, TLI – goodness of fit index; SRMR – Standardized Root Mean Square Residual

Reliability and validity analysis

Descriptive statistics of the ZBI and the reliability coefficient (internal consistency) for individual subscales are presented in Table 3. The presented values of skewness and kurtosis of individual subscales indicated the necessity of the root transformation of the results before proceeding with further analyses to perform Pearson's *r* correlation analyses.

Table 3. **Descriptive statistics and reliability coefficient**

ZBI scale/subscale	M	SD	Min	Max	Skewness	Kurtosis	α
Negative image of the patient	8.47	6.24	0	28	0.69	-0.26	0.85
Frustration	16.33	6.41	0	20	-0.24	-0.36	0.85
Losses	6.94	5.06	0	28	0.51	-0.75	0.82
ZBI overall	41.30	15.97	0	76	0.30	-0.60	0.91

ZBI overall – overall result of the feeling of burden; α – Cronbach's alpha coefficient

Both the overall score of the entire scale and the subscales are characterized by satisfying internal consistency (α: 0.75–0.91), whereas the subscales should be con-

sidered homogeneous due to the value above 0.70 [26]. Cronbach's α coefficient for the general result of the Polish language version (0.91) turned out to be similar to the original version of the scale (0.87–0.93).

In the next step, the analysis of the correlation of individual subscales with each other was made. Positive moderate correlations between the subscales were obtained, with the weakest connection being the "Negative image of the patient" and "Losses" ($r = 0.62$), followed by the "Negative image of the patient" and "Frustration" subscales ($r = 0.66$), while the "Losses" and "Frustration" subscales were most closely correlated ($r = 0.70$).

To estimate the construct validity of the scale, 372 caregivers of chronically ill and disabled people (334 women and 38 men) aged 19 to 84 years ($M = 50.01$; $SD = 14.05$) have been surveyed to date. According to the ZBI author's understanding of the burden of care, it was expected that it would be positively moderately or highly correlated with burnout, and moderately negatively correlated with resilience. The results of the correlation analysis that was carried out are presented in Table 4.

Table 4. **Pearson correlation coefficients between the ZBI and other scales**

Variable	ZBI overall	Negative image of the patient	Frustration	Losses
SWS overall	0.77***	0.60***	0.71***	0.66***
KOP-26 overall	-0.55**	-0.42***	-0.56*	-0.48***
KOP-26 FR	-0.54***	-0.43***	-0.52***	-0.46***
KOP-26 PC	-0.47**	-0.35*	-0.49***	-0.41***
KOP-26 SC	-0.38*	-0.27**	-0.42**	-0.35**

***p <0.001; **p <0.01; *p <0.05; ZBI overall – overall result of the feeling of burden; SWS overall – general result of burnout; KOP-26 overall – overall resilience result, KOP-26 FR – Family relations; KOP-26 PC – Personal competences; KOP-26 SC – Social competences.

The obtained results of the construct validity analysis are satisfying. As expected, the value of correlation coefficients between the general result of the ZBI and its individual subscales and the general score of the *Burnout Scale* (SWS) is positive and strong or moderate (Pearson's r: 0.60–0.77). The strongest positive correlation was observed for the general result of the ZBI and the overall result of the SWS ($r = 0.77$), which corroborates that these scales measure similar properties (convergent validity). The weakest positive correlation was observed between the subscale "Negative image of the patient" and the SWS overall result ($r = 0.60$). The validity test yielded negative weak and moderate values of correlation coefficients between the general score of the ZBI and its individual subscales, and the overall score and subscales of the *Resilience Assessment Questionnaire* (KOP-26) (Pearson's r: – 0.27–0.57). The strongest negative relationship was observed between the subscale of "Frustration" and the KOP-26 overall ($r = – 0.56$), while the "Negative image of the patient" and "Social competencies" subscales show the weakest negative correlation ($r = – 0.27$). The results of the analysis are consistent with the expected results.

Discussion

The main aim of the presented research was to carry out the Polish adaptation of the *Zarit Burden Interview* (ZBI) developed by Zarit [7] which is used to measure the sense of care burden among family caregivers. Other questionnaires used in scientific research include: *Caregiver Strain Index* (CSI) developed by Robinson [30], *Caregiver Burden Inventory* (CBI) by Novak and Guest [31], *Caregiver Reaction Assessment* (CRA) by Charles and Barbara Given [32], and the *Caregiver Burden Scale* (CBS) developed by Elmståhl, Malmberg and Annerstedt [33]. Although they were used in studies among Polish caregivers [34–36], the lack of their validation significantly limits the possibility of comparing the obtained results. Considering the above, the scale used to measure the burden, translated into many languages, and used in many countries and different cultures, was adopted [5, 13, 14, 17, 22].

The results obtained in our study in terms of the reliability of the tool are similar to those obtained in the English language version [37]. The obtained results testify to the good psychometric properties of the Polish version of the ZBI. Nevertheless, the analyses indicate a complex factor structure of the scale. The Polish version of the ZBI is characterized by a three-factor hierarchical structure (overall burden, subscales: "Negative image of the patient," "Frustration," "Losses"), confirmed by the confirmatory analysis, revealing a relatively good fit of the obtained data to the model. Previous reports indicated varied results of the structural analysis of the ZBI scale from one to five factors [22, 23]. Nevertheless, the three-factor structure of the tool corresponds to the results obtained in European adaptations, e.g., British or Spanish [37, 38], and in the group of carers of people with ALS [39] or dementia [40].

The results regarding internal consistency and construct validity are also satisfactory and prove the good psychometric properties of the Polish version of the questionnaire. Therefore, it is justified to use the ZBI scale in studies of caregivers, as it is a good source of information on the sense of care burden experienced by them. However, it seems necessary to continue research on the Polish version of the questionnaire and to observe its use in scientific research. In addition, the next steps should be the creation of norms for the scale and a short version validation for screening care burden in clinical practice.

Study limitations

The limitation of the presented studies is the number and representativeness of the tested sample. The caregivers under study took care of their close relatives who suffer from various chronic diseases such as Alzheimer's disease (AD) and dementia, Parkinson's disease (PD), chronic obstructive pulmonary disease (COPD), neuromuscular diseases (e.g., ALS – amyotrophic lateral sclerosis, SMA – spinal muscular atrophy, DMD – Duchenne muscular dystrophy), ischemic stroke, cerebral palsy (CP), Huntington's disease (HD), and schizophrenia. Thus, the lack of homogeneity of the caregivers' sample and equipotence of the subgroups prevented the comparison of the studied groups. Another limitation is the absence of measurement of time stability of the

scale with the test-retest method. However, taking into account theoretical foundations of the construct adopted by the author of the original scale [9], which indicate situational conditions and fluctuations in the feeling of burden of care over time, this method of assessing reliability was abandoned due to the risk of underestimating its value [28].

Conclusions

Family caregivers of their relatives with chronic illnesses undoubtedly experience a significant level of stress and difficulties in this field [29, 30]. In addition to coping with the diagnosis of a life-threatening or incurable illness of a close family member, they must adapt to changes in the day-to-day functioning of the family as well as roles and tasks related to care provision, which may enhance the feeling of the burden of care [9]. Therefore, for the caregiver to function properly it seems extremely important to recognize signals that evidence the feeling of increasing burden and the introduction of adequate psychological assistance. The Polish version of the *Zarit Burden Interview* appears to be a valid and reliable diagnostic tool in the discussed area.

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Address: Karolina Szatkowska
Department of Clinical Psychology, Faculty of Psychology
Kazimierz Wielki University in Bydgoszcz
85-867 Bydgoszcz, Leopolda Staff Street 1
e-mail: szatkowska_karolina@wp.pl