



## Validity and Reliability of the Greek Version of the ZBI in Informal Carers of Adults with Intellectual Disabilities

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### Abstract

**Background:** The Zarit Burden Interview is one of the most common tools used in the research field measuring burden. The aims of the present study were to translate and validate the Zarit Burden on caregivers of adults with intellectual disabilities in Greece.

**Methods:** One hundred and eighty family caregivers of adults with intellectual disabilities were recruited. All participants completed: the Zarit Burden Interview and the revised 15-item Bakas Caregiving Outcomes Scale. Reliability was assessed by the internal consistency and test/retest of the instrument. Validity was assessed with construct validity using Bakas Caregiving Outcomes Scale and known groups validity.

**Results:** Factor analysis resulted in a 4-factor model. Construct validity has shown satisfactory correlations with Bakas Caregiving Outcomes Scale ( $p < 0.005$ ,  $p < 0.05$  respectively).

**Conclusions:** The Greek-Zarit Burden Interview showed satisfactory psychometric properties in Greek caregivers caring adults with intellectual disabilities.

### Keywords

Validity; Reliability; Intellectual disability; Family burden; Informal carers; ZBI

### Introduction

In recent decades there has been a growing interest around people with intellectual disabilities, and their families [1]. Taking care of a child or an adult with an intellectual disability in the home may be associated with higher levels of burden for the family and their carers [2].

The line of research that began in the mid-1950s and early 1960s concerning the mental illness within the family and the consequences to the person and his/her caregivers is of particular importance. Over the years, when a family member had a mental illness, some other disability, chronic or life threatening illness, carers have more care responsibilities than in the past. These changes came due to a change in health law, social policy, technological and medical developments

and achievements, which have increased the average life expectancy of people with intellectual and other disabilities and diseases [3].

Worldwide millions of people have an intellectual disability and the prevalence in the general population was estimated at around 3% in developed countries, without including people in the developing world who face similar difficulties, and for which there are no official records [4]. The prevalence of intellectual disability varies from country to country. In a recent survey by the World Health Organization (WHO) with a systematic review of the literature up to 2011, the prevalence of intellectual disability, in 52 studies included in the meta-analysis, was 10.37/1000 on population [5].

The term “intellectual disability” is used widely in the UK, the U.S. and other countries. The most common terms presented in the literature are “mental retardation” and “developmental disability” [6].

According to the international classification manuals (*Diagnostic and Statistical Manual of Mental Disorders*, Fifth edition (DSM-V), the International Classification of Diseases-11th revision (ICD-11), “Intellectual disability” (intellectual developmental disorder) is a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains’ [7,8].

The burden of care is a conceptualization that describes the emotional, psychological, physical and economic experience of a caregiver during the care of a member of their family. The concept of burden is considered multidimensional. The potential difficulties include direct arising from disease care needs, the interruption routine and daily activities of the house, economic concerns, related medical costs and loss of income and emotional stress triggered by the occurrence and presence of the disease [9]. Several studies have shown that parents experience greater stress and burden when the person with intellectual disabilities has behavioral problems or other health issues [10].

Providing care to family members with a chronic illness can result in the burden or strain and stress on carers minimizing their quality of life [11]. Within this framework, a set of social factors can be seen as potential catalysts that contribute to family stress and burden; the prolonging of the average life for both caregivers and the chronically ill that increases the care range; second, smaller in size families and those living within a greater geographic dispersion, further intensify the problems of family members in which there is a care necessity; third, changes in the health system, such as deinstitutionalization and controlled care, have caused a shift of chronically ill family members to return to their homes. Then, technological developments in outpatient care require by patients and their families to engage in more complex models of care. Finally, the complex and rapidly coming changes in management strategies and methods within the existing health system are present [12].

In addition, there was an attempt to measure burden felt by those who care people with intellectual disabilities. However some platitudes were identified: 1) most are multi-dimensional, 2) they count dimensions of the objective and subjective burden, 3) they consist mostly of negative items / questions, 4) they are a composite of several dimensions and 5) they are usually administered only to the main carer, who happens to be the parent [13].

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Researchers [14] were turning to the creation or adaptation of existing research tools in order to measure better and more efficiently the caregivers' burden. Some of the most representative valid questionnaires used in research are: the Bakas Caregiving Outcomes Scale (BCOS) [15], Burden Assessment Scale (BAS) [16], and the ZBI-The Zarit Burden Interview [17]. The latter, is one of the most common tools used in the research field measuring burden which has been validated in several countries [18-21]. Although the ZBI has originally been developed and used for caregivers of patients with Alzheimer, it has also been used for other research groups as well: people with dementia and other mental or psychiatric disorders, patients with stroke, acquired brain injury, muscular dystrophy etc [21].

In Greece little research has been made concerning the burden of the caregivers providing support and care in a person with intellectual disabilities. Therefore, the aims of the current study were to evaluate the psychometric properties of the Greek version of the 22-item Zarit Burden Interview (ZBI) with a sample of carers of persons with intellectual disabilities.

## Material and Methods

### Setting

The present research study was conducted between April 15th to June 10th, 2014, with the assistance of two organizations that host people with intellectual disabilities.

### Participants

In total, 205 questionnaires, in 84 families, were given. From them, 180 were returned completed (response rate: 83.7%) which was the final sample of the study. Initially, there was contact with both organizations in order to explain: a) the purpose of the study and b) the way in which our research would take place. The participants in the study were all informal carers of adults with disabilities, all family members or people who belong to the intimate family context (cousins, uncles, neighbours, professional in-home caregivers, neighbours, etc.). The study was performed in accordance to the Helsinki Declaration and according to European guidelines for good clinical practice. The two organizations ethics committee approved the study, and all the participants signed an informed consent.

The term intellectual disability itself comprises of a wide range of disabilities. In the present study the individuals with intellectual disability, comprised of people with autism, Down syndrome, cerebral palsy, other syndromes (Rett syndrome, Fragile X syndrome, Proteus syndrome etc.). The inclusion criteria for the caregivers were: a) aged  $\geq 18$  years), b) respondents' written informed consent to participate in the study, c) to belong within the family context and to be the main caregivers of the individuals with intellectual disability. Exclusion criteria were: a) impaired cognitive function, b) other dysfunctional behaviors/disorders. Inclusion criteria for the people with intellectual disabilities were: a) aged  $\geq 18$  years, b) intellectual disability.

### Assessment tools

The tools used in our research were the Zarit Burden Interview (ZBI), and the revised 15-item Bakas Caregiving Outcomes Scale (BCOS). A predesigned questionnaire with socio-demographic data was used both for carers and for the people with intellectual disabilities.

### The zarit burden interview

Burden was assessed using the Zarit burden interview (ZBI) consisted of 22 questions. Each question is scored on a five-point Likert scale (higher scores indicate higher degree of burden). The total score ranging from 0-88 (0-21=little or no burden, 21-40=moderate burden, 41-60=severe burden, 61-88=very heavy burden) [20]. Chronbach's alpha was 88. [22] for the total Zarit score. Hassinger and Zarit [23] identified three factors from factor analysis entitled: Caregiver Anger, Patient dependency and Caregiver Lack of Privacy.

### The revised 15-item Bakas Caregiving Outcomes Scale (BCOS)

It is a set of questions relating to possible changes in the life of the respondent from providing care to the patient. For each possible change a number is marked that indicates the degree of change. The numbers indicate the degree of change ranging from -3 "Change for the worse" up to +3 "Change for the better." The number 0 equals 'No change'. Due to the negative rating and for statistical purposes, the process of transcoding was coded, changing the negative sign. The final score is from 1-7, (1: "Change for the worse", 4: "no change, 7: "Change for the better". The internal reliability of the scale is .90 [24].

### Translation

The translation of the Greek version of the ZBI was carried out by two Greek experts, who completed English to Greek translation. It was then back-translated to English by another two independent translators. The final process completed with the matching of these translations.

## Results

### Statistical analysis

The values of variables are presented using the number of participants (N), the means (M) and the standard deviations (SD). In categorical variables the frequencies (n) and percentages (%) were used. The Kolmogorov-Smirnov test and normal probability plot were performed. Exploratory factor analysis (EFA) was explored for the factor structure of the questionnaire [25]. Confirmatory Factor analysis (CFA) conducted to explore the factor structure of the instrument as suggested by the EFA analysis [26]. The retained items were those with loadings  $\geq \pm 0.40$  and eigenvalues  $\geq 1$ . The internal consistency of the Greek-ZBI was assessed using Cronbach's alpha coefficient. Test-retest reliability was determined by calculating Pearson's correlation coefficient between the initial and the second reassessment of the Greek-ZBI where 44 participants were selected randomly to complete the Greek-ZBI 7 days after the initial assessment. The construct validity of the Greek-ZBI questionnaire was evaluated by examining the relationship between the Greek-ZBI and the BCOS GREEK. The known groups validity of the Greek-ZBI questionnaire was examined in terms of the ability of the questionnaire to distinguish between subgroups of the carers and their perceived burden due to the care of the person. . No cases were omitted from the analyses due to missing data. The statistical software SPSS PC for windows (version 12.0).

### Descriptive statistics

Table 1 presented the demographic statistics of the caregivers and their patients. Most of the caregivers were female (n=114). The majority of the carers were parents (62.8%) and other family

members (30.5%). The gender of the person under care was mostly male (n=80%).

### Exploratory factor analysis

Four factors explaining 68.52% of the total variance with Eigen values ranging from 1.17 to 8.49 (Table 2). Items 7, 9 and 22 were excluded.

After rotation the loadings on these four factors were the ones that preserved a high loading. The factors' structure is shown in Table 3. The first factor F1 identified as «Personal strain» consisted of the following items: 1,2,3,8,10,14,15,17. The second factor F2 identified as «Social strain» consisted of 6 items: 4,5,6,11,12,13. The third factor F3 identified as «Uncertainty on providing care» consisted of the following items: 16,18,19 and the fourth factor F4 identified as «Guilty» consisted of items 20 and 21 (Figure 1).

### Confirmatory factor analysis (CFA)

The three-factor model was conducted by confirmatory factor analysis giving unacceptable global fit indices. The resulting global fit indices  $\chi^2=25.13$ ,  $p<0.005$ , chi-square-degrees of freedom (d. f.) ratio=0.06, RMSEA=-0.08, CFI=0.338, NFI=0.244, GFI =7.84, AGFI=7.35, showed that the three factor solution proposed by the author should be rejected.

### Reliability

Internal consistency: The internal consistency of the 22 items of the Greek-ZBI was calculated by the internal consistency coefficient (Cronbach's alpha) and for all four factors was >0.8 which was acceptable (F1=0.88, F2=0.892, F3=0.854, F4=0.852) (table not included).

The means of the Greek-ZBI subscales were the following:

F1=16.91 ± 6.85, F1 reassessment=17.98 ± 6.25, F2= 6.64 ± 5.04, F2 reassessment= 6.68 ± 5.13, F3=6.76 ± 3.99, F3 reassessment=7.16 ± 3.79, F4=3.91 ± 1.99, F4 reassessment=4.27 ± 1.97. The mean of the BCOS Geek was 61.62 ± 15.42 (table not included).

Test-retest reliability: By using the paired samples t-test between the first administration and the follow up (n=44, interval=7 days) there were no statistically significant differences. The ICC coefficient varied to all factors from 0.997 up to 1 ( $p<0.5$ ) showing that the Greek-ZBI total scores were consistent between the two occasions (Table 4).

**Construct validity:** All the loadings from the total score of the BCOS and the factors of the Greek-ZBI were statistically significant ( $p<0.5$ ). The results showed a significant correlation between 'Personal strain' ( $r=-0.627$ ,  $p<0.0005$ ). 'Social strain'( $r=-0.659$ ,  $p<0.005$ ) and BCOS score. For «Uncertainty on providing care» and «Guilty» factor, the loadings are lower ( $r=-0.484$ ,  $r=-0.334$ ) but still statistical significance to the BCOS total score (Table 5).

Known groups validity: The Greek-ZBI examined in terms of its ability to distinguish between subgroups of caregivers' relationship with the person under care. The Greek-ZBI discriminated well between subgroups of carers indicating that there was statistically significant difference among the subgroups of caregivers ( $p<0.005$ , table not included). More specifically, professional caregivers discriminated from the other carers as the mean scores of Greek-ZBI were significantly lower in professional carers than other caregivers (immediate family members) in all four factors.

### Discussion

The aims of the present study were to investigate the psychometric properties of the Greek-ZBI informal caregivers of people with intellectual disabilities.

Table 1: Caregiver and patient's demographic characteristics.

Demographic Characteristics	Variables	N	%
Caregiver's gender	Male	66	36.7
	Female	114	63.3
Education	Primary	38	21.1
	High school	69	38.3
	University	73	40.6
Family income	under 10000 €	75	41.7
	10.000-20.000 €	67	37.2
	Over 20.000 €	38	21.1
Family status	Married	113	62.8
	Unmarried	44	24.4
	Divorced	23	12.8
Working status	Public-private servant	81	45.0
	Freelancer	43	23.9
	Unemployed	24	13.3
	Retired	32	17.8
Relation to the person under care	Parent	103	62.8
	Other Family member	55	30.5
	Professional in-home caregiver	12	6.7
Patient's gender	male	144	80.0
	female	36	20.0
Time of daily care	Under 3 hours	68	37.8
	Over 3 Hours	112	62.2
Intervention in work	Frequent absences or leaves	47	28.5
	Flexible working hours- part time work	118	71.5

**Table 2:** Eigen values and variance explained.

Items	Initial Eigen values			Rotation Sums of Squared Loadings		
	Eigen values	% of Variance	Cumulative %	Eigen values	% of Variance	Cumulative %
1	<b>8.49</b>	<b>44.68</b>	<b>44.68</b>	4.10	21.58	21.58
2	<b>1.93</b>	<b>10.15</b>	<b>54.83</b>	3.85	20.25	41.84
3	<b>1.43</b>	<b>7.53</b>	<b>62.35</b>	3.17	16.66	58.50
4	<b>1.17</b>	<b>6.17</b>	<b>68.52</b>	1.90	10.03	68.52
5	.83	4.36	72.88			
6	.77	4.08	76.96			
7	.64	3.38	80.33			
8	.54	2.84	83.18			
9	.49	2.60	85.78			
10	.48	2.51	88.29			
11	.40	2.09	90.39			
12	.36	1.91	92.30			
13	.32	1.67	93.97			
14	.28	1.45	95.42			
15	.23	1.23	96.65			
16	.20	1.06	97.70			
17	.16	.87	98.57			
18	.15	.77	99.34			
19	.13	.66	100.00			

**Table 3:** Exploratory factor analysis –factor’s loadings.

Items	Personal strain	Social strain	Uncertainty on providing care	Guilty
	Personal Strain	Social Strain		
Item14	<b>0.756</b>			
Item2	<b>0.745</b>			
Item8	<b>0.712</b>			
Item1	<b>0.680</b>			
Item3	<b>0.657</b>			
Item15	<b>0.545</b>			
Item10	<b>0.528</b>			
Item17	<b>0.471</b>			
Item4		<b>0.751</b>		
Item13		<b>0.722</b>		
Item12		<b>0.713</b>		
Item6		<b>0.705</b>		
Item5		<b>0.688</b>		
Item11		<b>0.662</b>		
Item18			<b>0.846</b>	
Item19			<b>0.793</b>	
Item16			<b>0.750</b>	
Item21				<b>0.916</b>
Item20				<b>0.879</b>

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

The burden of a family as a result of a chronic illness of a family member was the subject of research since the mid-1950s. This popular meaning is “concrete”, directly connected with the impact of caring on carers’ [1]. Researchers discovered that the impact of the disability in the family circle was extended and the family’s resilience helped rebound from adversity at the individual and system levels [27,28]. A substantial body of research on families and mental disabilities has examined how caregiving processes were linked to the emotional and general health of the family caregivers [29].

In the current study, the vast majority of the sample were close

family members, parents, siblings and other family members (uncles, cousins, legal guardians) while a 6.7% was professional in-home caregivers. Informal caregivers were mostly females despite the fact that females ended up being the traditional caregivers in many cultures [30]. The mean scores and standard deviations of the items in our research are consistent to those of other validation attempts [18].

The internal consistency for all factors was above 0.8, indicating sufficient validity in both times (baseline and reassessment) [31,32], consistent to previous studies [18,33,34].

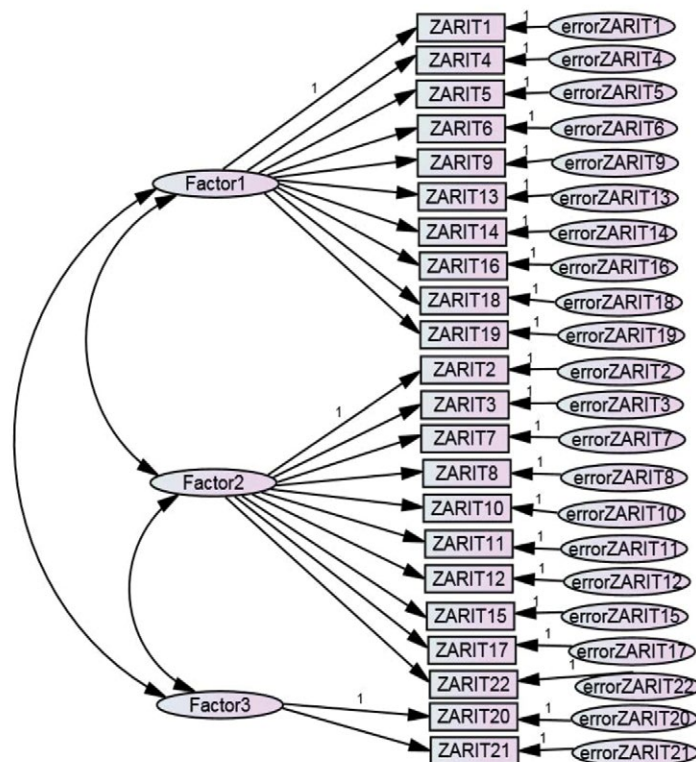


Figure 1: Confirmatory factor analysis of the Greek ZBI.

Table 4: Test-retest reliability.

Variables	ICC ( 95%CI )	Paired samples t-test ( n=44)		
		Initial assessment	Reassessment	p-value
Personal strain	1.00 (0.99-1.00)	17.95 ± 6.25	17.98 ± 6.25	0.323
Social strain	1.00 (0.99-1.00)	6.66 ± 5.10	6.68 ± 5.13	0.325
Uncertainty	1.00 (0.99-1.00)	7.16 ± 3.79	7.16 ± 3.79	1.000
Guilty	0.997(0.995-0.998)	4.29 ± 1.95	4.27 ± 1.97	0.410

Table 5: Construct validity.

Variables	BACAS- Total
Personal strain	-.627*
Social strain	-.659*
Uncertainty on providing care	-.484*
Guilty	-.334*

\* p<.0005

In the exploratory factor analysis, the eigenvalues and the amount of variance in the factor loadings were consistent with Zarit [17] and other validation studies [18,19].

Family burden is a multivariate dimension including various concepts of caregiving burden such as strain, worry, and isolation [35]. In the present study a four factor model was constructed with most of the items used, explaining 62.8% of the total variance. Although in the original article a three factor model was suggested our results are in accordance to other studies that also resulted in a four factor model [35,36]. Besides the factor of ‘Personal strain’ all other three factors (Social strain, Uncertainty on providing care and Guilty) were entitled differently from the original validation study. In the factor ‘Personal strain’ four items were identical to the original validation article

(items 1,8,14,17). Other findings have revealed that carers’ emotional distress was influenced by socioeconomic deprivation and chronic illness may disrupt family relationships or may cause financial and emotional burden on the family members [37]. In addition, social burden seemed to be an important factor in our study. The factor ‘Role strain’ from the original factor structure was similar to our second factor named ‘Social Strain’ with four items matching those of the original (items 6,11,12,13). Feelings of guilt as a factor of burden were also expressed similar to other studies which found that burden associated to uncomfortable feelings that the primary caregivers expressed having a relative with intellectual disabilities [38].

From the current research caregivers of people with intellectual disabilities experienced personal and social strain, guilty and

uncertainty regarding the provision of care, which seemed to compose the burden construct in the current population.

Validity of the Greek-ZBI has been estimated by correlating the total score of all four factors with the total score of the revised 15-item BCOS. The revised 15-item BCOS is a valid and reliable instrument already used in the caregiver research, because it is used to measure changes specifically as a result of providing care and has good psychometric support<sup>14,15</sup>. All of the factors extracted from the Greek-ZBI showed a statistical significance when correlated with the total score of the BCOS. Factors of 'Personal strain' (F1) and 'Social strain' (F2) showed higher loadings ( $rF1=-0.627$ ;  $rF2=-0.659$ ) but all factors were statistically significant for  $p\text{-value}<0.0005$ .

The Greek-ZBI discriminated well between subgroups of carers. In all four factors the professional caregivers are distinguished from parents and other relatives. Even in this case immediate family members (parents, brother-sister etc.) seem to have the greater amount of care of the people with intellectual disabilities while in other studies the results between the subgroups weren't statistical significant [18]. This could be due to the differentiation of the group of persons under care. In the current study all of the people with intellectual disabilities are adults living within the family context. In Greek society even to our days family context seems to be of high value and parents seem to have the most important role in the care of their children, moreover when there is a child with intellectual disabilities.

## Limitations

Our study has also some limitations that need to be mentioned. All of the caregivers that participated in were recruited from two institutions, both set in an urban environment. It would be best in future research to include caregivers from other parts of the country in order our sample to be more representative and to be able to generalize the results.

## Conclusion

In Greece there is not much information about relatives and other informal carers of people living in the community who are intellectually disabled.

The good psychometric properties of the Greek-ZBI revealed its good validity and reliability and can be used among informal caregivers of persons with intellectual disabilities.

Furthermore, studies could use the current burden interview scale to obtain empirical data about the impact of mental disabilities on persons' carers in Greece. The multidimensionality of the ZBI could be of great assist in research and clinical patterns because it can assist health professionals to adopt new and reinforced interventions for people under burden.

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