

# PSYCHOMETRIC CHARACTERISTICS OF THE CROATIAN VERSION OF THE ZARIT BURDEN INTERVIEW QUESTIONNAIRE AMONG INFORMAL CAREGIVERS OF LONG-TERM MECHANICALLY VENTILATED PATIENTS

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received: 25.7.2021;

revised: 21.12.2021;

accepted: 9.1.2022

## SUMMARY

**Background:** The aim is to evaluate the reliability and validity of the Croatian version of the Zarit Caregiver Burden Interview (ZBI) among the population of informal caregivers of long-term mechanically ventilated patients.

**Subjects and methods:** After a preliminary analysis, 25 participants were selected by using strictly defined criteria and they were asked to complete the Croatian version of the ZBI. The test - retest method was used for reliability assessment while an exploratory strategy of factor analysis was used to identify real-life existent subscales.

**Results:** After reliability and validity assessment, 3 items were removed from the original ZBI so that the Croatian version of the ZBI consists of 19 items. Internal consistency, observed through Cronbach's alpha for extracted subscales and for the whole questionnaire, were identified as high ranged from 0.875 to 0.922. Furthermore, exploratory factor analysis using Guttman-Kaiser criterion identified the 6 subscales for the ZBI.

**Conclusions:** Due to the fact that approximately 30 % of targeted population was included in the study, the Croatian version of the ZBI can be accepted as a reliable and valid tool for measuring burden among informal caregivers of long-term mechanically ventilated patients. Family caregiver's burden level assessment can be crucial to enhance outcomes associated with future caregiving.

**Key words:** long-term ventilation, informal caregiving, burden

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## INTRODUCTION

A person who takes care of a patient and helps him with daily living activities because of restrictions caused by an acute or chronic condition without receiving financial compensation is called an informal caregiver (Collins & Swartz 2011). Informal caregivers are mostly females. Typically they are the patient's wife or daughter aged between 45 and 65, without employment or with part-time employment and of a low educational and socioeconomic level (Carretero et al. 2009). Regarding intensiveness of care provided: informal caregiving is divided into less intensive care (< 20 hours per week) and intensive care (> 20 hours per week) (National Alliance for Caregiving 2015). There is a major concern that caring for a dependent person can generate stress for an informal caregiver, which could have a negative impact on his or her physical and psychological wellbeing, leading to

caregiver burden, a term that was presented in literature for the first time in the 1960's (Zarit 2002, Hoops et al. 2017). It's also defined as a multidimensional biopsychosocial reaction resulting from an imbalance of care demands relative to caregivers' personal time, social roles, physical and emotional states, financial resources, and formal care resources, given the other multiple roles they fulfil (Given et al. 2001, Visser-Meily et al. 2004). Considering demographic change, the fact that the incidence and prevalence of chronic disease are increasing and that individuals prefer being cared for at home, it's expected that the need for informal care will increase (Zwar et al. 2018). There is a special group of patients who require long-term mechanical ventilation (LMV), which is defined as the need for  $\geq 21$  consecutive days of mechanical ventilation for  $\geq 6$  hours per day (MacIntyre et al. 2005). Due to advances in diagnostic and supportive technology, better understanding of the beneficial effects on quality of life and potential cost savings to

health-care systems, long-term mechanically ventilated patients living at home are growing population with special care needs (Rose et al. 2005). Those patients' lives are characterized by long-term immobilization, muscular weakness, dyspnoea, malnutrition, anxiety, depression and the inability to perform daily living activities on their own (Marchioni et al. 2015, Ružman et al. 2017). Due to the severity of their clinical condition, they are completely dependent on someone else's care and assistance, which significantly occupies their caregivers (Pelt et al. 2007). Advances in medicine and supportive technology have resulted in an increase in this particular group of patients (Ambrosino & Vitacca 2018). According to the survey conducted in 2001 that focused on central European countries, the estimated prevalence of HMV in Europe was 6.6 per 100,000 people (Lloyd-Owen et al. 2015). Since then, a substantial increase in the number of patients treated with HMV has been noted. This increase was associated with technological advances and some epidemiological features. Aging of the population (Farrero et al. 2007), rising prevalence of obesity (Sturm 2007), and COPD (GOLD 2019) have resulted in an increased incidence of chronic respiratory failure. For example, Poland reported a 116-fold increase in the number of patients treated from 2000 to 2010 (Nasiłowski et al. 2015).

Since there is no validated questionnaire that could be used for measuring the burden of informal caregivers of long-term mechanically ventilated patients in Croatia, the official Croatian version of the Zarit Caregiver Burden Interview (ZBI) has been used.

Due to the previously stated fact, the aim of this study was to evaluate the reliability and validity of the Croatian version of the ZBI.

## SUBJECTS AND METHODS

### Participants

The study included 25 informal caregivers (23 women, 2 men, aged  $49.13 \pm 7.23$ ) of patients undergoing long-term mechanical ventilation. The study was conducted in the Special Hospital for Lung Diseases, Zagreb, Croatia. During regular monitoring of the underlying disease of patients, their informal caregivers were asked to join the trial. All participants were selected by using inclusion criteria. They had to be over 18 years old, they had to be taking care of long-term mechanically ventilated patients for more than 6 months and had to be living with the patient in the same household, independently if they provided intense or less intense care. 76% of participants provided intensive care (more than 20 hours per week) and 24% of participants provided less intensive care (less than 20 hours per week). All participants were informed of the purpose of the study and participation in the study was entirely voluntary.

### Methods

Due to the nature of the research problem, the study was methodologically descriptive, cross-sectional, measuring the burden of informal caregivers of long-term mechanically ventilated patients by using the Croatian version of the ZBI. Research was conducted completely in accordance with the ethical guidelines of the Declaration of Helsinki and was approved by the local ethical board.

### Instrument

The ZBI questionnaire was used for the purpose of this research (Copyright 1980, 1983, 1990 Steven H Zarit and Judy M Zarit). The ZBI is one of the most widely utilised instruments used to assess the burden on informal caregivers. It was used to assess the caregivers taking care of patients with various diseases (Hebert et al. 2000, Lu et al. 2009, Chattat et al. 2010, Al-Rawashdeh et al. 2016). The questionnaire consists of 22 items regarding the caregiver's health, psychological wellbeing, social life and finances. The answers are rated on a 5-point Likert scale that ranges from 0 (never) to 4 (nearly always) with the sum of scores ranging between 0–88 (Bedard et al. 2001). Higher scores implying greater perceived caregiver's burden. Scores ranging from 61 to 88 identify severe burden, from 41 to 60 moderately severe burden, 22 to 40 moderate burden and less than 21 little or no burden. The ZBI was developed as a unidimensional measure of burden (Harkness & Tramner 2007, Moore 2010). Later research among caregivers, mostly of patients with dementia, have reported a few dimensions such as consequences of caregiving, patient's dependence, exhaustion and uncertainty, guilt or self-criticism, embarrassment/ anger or frustration, psychological burden and emotional reactions, personal strain, and role strain (Hebert et al. 2000, Knight et al. 2000, Flynn Longmire & Knight 2001, Ankri et al. 2005, Springate & Tremont 2014). Originally the ZBI was only in English but later it was adapted to several languages. In this study the official Croatian version of the ZBI was used. Permission was requested and approved by Mapi Research Trust Organization.

### Statistical analysis

The reliability of measurement was examined by using the test-retest method. More precisely, the 25 participants were asked to fill-out the questionnaire again after 3 weeks. As a measure of the reliability coefficient of correlation ( $r$ ) the test and retest was used. A single item was considered reliable if  $r$  appeared to be statistically significant and larger than 0.650. Due to the examination of construct validity, the exploratory strategy of factor analysis was applied together with varimax raw rotation of extracted principal components and Guttman-Kaiser criterion. If a single item was not saturated to factor it was removed from

further analysis and factor analysis was preformed again. Finally, a factor structure matrix was presented together with the amount of variability of items explained by single factor. Extracted latent dimensions were subject to careful researcher interpretation. Furthermore, as a measure of internal consistency, Cronbach's alpha was used, and it was calculated for identified subscales and for the whole questionnaire separately. The type I error was set at  $\alpha=5\%$ . All calculations were performed using the statistical analysis software package Statistica 13.5 (Tibco Software Inc, 2018).

## RESULTS

In order to test the reliability of the Croatian version of the ZBI, testing was performed twice, at 3 weeks interval, on the same sample of 25 subjects. The item-total correlations ranged from 0.744 to 0.923 and were all statistically significant ( $P < 0.001$ ) except item number 7 (concern for the future) ( $p=0.184$ ), which was eliminated from further statistical analysis (Table 1).

Furthermore, in order to test the validity of the questionnaire version in which item number 7 (concern for the future) was eliminated, an exploratory factor analysis was performed and six factors were identified for which the internal consistency coefficients were further measured. The results of the factor structure analysis indicated that the item under number 6 (negative effect on other relationships) and number 12 (suffering of social life) were not associated with any factor and would not be further analysed (Table 2).

As evident in table 3, 6 factors have been identified. The first factor includes items 10, 11, 15 and 22, which represent health, privacy, financial status and the burden of informal caregivers. These items are regarded as general personal and financial burden so Factor 1 was termed „personal/financial burden“. Factor 2 includes items 1, 2 and 14 representing patient's requesting help, caregiver's leisure time and patient's expectations. Factor 2 was termed „patient's dependency“. Factor 3 includes items 4, 5 and 13, consisting of embarrassment, anger and other negative feelings.

This factor was termed „embarrassment/anger“. Factor 4 includes items 20 and 21 representing self-assessment of quality and quantity of care. Factor 4 was termed „self-criticism“. Factor 5 included items 8 and 18 representing assessment of patient's dependency and the wish of passing on care to someone else. Factor 5 was termed „role strain“. Factor 6 included items 3, 9, 16, 17 and 19 represented strain, self-assessment of resources for caregiving in the future, loss of control and self-assessment of skills needed for providing care. This factor was named „psychological strain“. The Cronbach alpha was calculated for all identified factors/subscales and for the whole questionnaire, and it ranged between 0.875 and 0.922.

## DISCUSSION

In this study, the Croatian version of the ZBI was used on a population of informal caregivers of a very severe group of patients. The results provide support for the reliability and validity of the ZBI as a measure of caregiving burden in a group of informal caregivers of long-term invasively, mechanically ventilated patients. All item-total correlations were significantly and positively correlated, with the total score supporting the homogeneity of the scale except item 7 regarding concern for a patient's future.

The low correlation of item 7 can be explained by the fact that the item is future oriented rather than about the current caregiving situation. On the other hand, the analysis of the factor structure identified six factors, which confirms the findings of numerous authors on the multidimensionality of the ZBI questionnaire, regardless of the number of items in the questionnaire and the language into which it was translated. The identified factors in our study partially match the identified factors of other authors, especially: „patient's dependency“, „embarrassment/anger“, „self-criticism“ and „role strain“ (Hebert et al. 2000, Lu et al. 2009, Al-Rawashdeh et al. 2016, Bedard et al. 2001, Bachner & Ayalon 2010, Siegert et al. 2010, Longmire & Knight 2011, Tang et al. 2017). It is important to underline that the ZBI has more versions but it always has a multidimensional structure. For example, by using a 22-item ZBI questionnaire among a population of informal caregivers of patients with dementia in Canada, two factors were identified: „role strain“ and „personal strain“ (Hebert et al. 2000). In a French study among informal caregivers of the same population of patients, three factors were identified: „feeling of guilt“, „influence on the social and personal life“ and „psychological strain“ (Ankri et al. 2005).

Using a 14-item questionnaire, Knight et al. identified three factors among a similar population, namely: „discomfort/anger“, „patient dependency“ and „self-criticism“ (Knight et al. 2000). It is important to note that the Chinese version of the questionnaire has more extracted factors than the English one. The Chinese authors commonly identified five factors, which is more than the results of the studies that used the English version of the questionnaire. Studies in English generally identified two to three factors. In our study the factor analysis extracted six factors: „personal/financial burden“, „patient's dependence“, „embarrassment/anger“, „self-criticism“, „role strain“ and „psychological strain“ which is similar to the results of the Chinese authors. All identified factors are also represented in other studies, but not as a set of all six factors. Given that caregiver burden can be divided into four burden categories: psychological, physical, financial and social, a logical multidimensionality of a questionnaire designed to assess burden is also expected (Tang et al. 2017).

**Table 1:** Test and re-test correlation coefficients for the 22-item questionnaire

No ITEMS	r	P
1 Patient asks for more help than he/she needs	0.837	<0.001
2 Not having enough time for yourself	0.853	<0.001
3 Stressed due to fulfilling different responsibilities	0.874	<0.001
4 Embarrassed of patient behaviour	0.789	<0.001
5 Feel angry around patient	0.869	<0.001
6 Negative effect on other relationships	0.791	<0.001
7 Concern for patient's future	<u>0.282</u>	0.184
8 Patient is too dependent	0.753	<0.001
9 Feel strained around patient	0.744	<0.001
10 Health affected by caregiving	0.825	<0.001
11 Having inadequate privacy	0.842	<0.001
12 Suffering of social life	0.752	<0.001
13 Uncomfortable having friends	0.856	<0.001
14 Patient expects you to be the only caregiver	0.808	<0.001
15 Feel financially stressed	0.821	<0.001
16 Feel unable to take care of the patient much	0.895	<0.001
17 Feel like losing control over life	0.753	<0.001
18 Wish to stop caring for the patient	0.846	<0.001
19 Feel uncertain of what to do	0.784	<0.001
20 Feel like you should be doing more for the patient	0.813	<0.001
21 Feel that you could do better for the patient	0.923	<0.001
22 Feel burdened by providing care	0.834	<0.001

Our study included only informal caregivers of patients performing invasive mechanical ventilation in their home. Validation of ZBI questionnaire was carried out on only 25 informal caregivers, but this sample represents a great proportion of the total number of informal caregivers of the patients on home invasive mechanical ventilation in Croatia. Accurate epidemiological data on the number of patients undergoing home invasive mechanical ventilation are not available for the Croatian population. The most comprehensive survey of home mechanical ventilation (HMV) practice to date has been the Eurovent survey. It was estimated that around 6.6 patients / 100 000 performed mechanical ventilation in Central European countries in the year 2001/2002. 13% of the survey

population had ventilation via a tracheostomy (Lloyd-Owen et al. 2005). Naturally, this data varies from country to country. A study conducted in Hong Kong showed the prevalence of HMV of 2.9 / 100 000 in the year 2002. The predominant mode of HMV was non-invasive ventilation, with only 5.2% tracheotomised patients (Chu et al. 2004). Prospective data from the Swedish HMV Register showed that the treatment prevalence of HMV in 1996 was 6.2/ 100 000 while in 2002 it was 10.5 / 100 000 (Laub et al. 2004). A survey conducted in 2018, in Hungary estimated that the prevalence of HMV was 3.9/100 000. 10.4% of patients received invasive, while 89.6% received non-invasive ventilation (Valko et al. 2018). HMV is the established treatment for chronic respiratory failure and

**Table 2:** Factor structure of the 21-item questionnaire (iteration 1)

No ITEMS	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6
1 Patient asks for more help than he/she needs	-0.093	0.663	0.466	-0.142	-0.113	-0.018
2 Not having enough time for yourself	0.194	0.764	0.013	0.143	-0.075	0.316
3 Stressed due to fulfilling different responsibilities	0.493	0.416	0.019	0.280	-0.347	0.184
4 Embarrassed of patient behaviour	0.204	0.101	0.743	0.051	0.185	0.126
5 Feel angry around patient	0.036	-0.056	0.746	0.105	0.284	0.327
6 Negative effect on other relations	<u>0.277</u>	<u>-0.094</u>	<u>0.296</u>	<u>-0.028</u>	<u>0.443</u>	<u>0.355</u>
8 Patient is too dependent	0.118	0.236	0.066	-0.117	-0.734	0.163
9 Feel strained around patient	0.639	-0.033	0.071	0.032	0.334	0.382
10 Health affected by caregiving	0.230	0.346	0.208	-0.033	0.227	0.685
11 Having inadequate privacy	0.213	0.318	0.081	0.134	0.107	0.617
12 Suffering in social life	<u>0.265</u>	<u>0.639</u>	<u>-0.115</u>	<u>-0.109</u>	<u>-0.166</u>	<u>0.488</u>
13 Uncomfortable having friends	0.156	0.180	0.827	0.093	-0.215	-0.095
14 Patient expects you to be the only caregiver	-0.207	0.762	0.166	-0.013	0.183	0.041
15 Feel financially stressed	0.088	0.079	-0.005	0.229	-0.021	0.881
16 Feel unable to take care of the patient much	0.649	-0.256	0.224	0.091	-0.031	0.444
17 Feel like losing control over life	0.830	0.208	0.113	0.081	-0.066	0.171
18 Wish to stop caring for the patient	0.171	0.319	0.062	-0.068	0.696	0.097
19 Feel uncertain of what to do	0.581	-0.110	0.252	0.381	0.393	0.088
20 Feel like you should be doing more for the patient	0.016	0.083	0.093	0.914	-0.033	0.119
21 Feel that you could do better for the patient	0.172	-0.084	0.023	0.886	0.079	0.189
22 Feel burdened by providing care	0.286	0.135	0.134	0.233	-0.133	0.765
Explained variance	2.626	2.726	2.305	2.062	1.902	3.253
% Explained variance	0.123	0.134	0.113	0.103	0.091	0.154

its prevalence increases steadily over time (Chu et al. 2004, Laub et al. 2004). In Croatia, there is no register of patients undergoing long-term mechanical ventilation. To find out the number of those patients, we contacted distributors of home care ventilators. At the time of the statistical analysis, a total of 83 people in Croatia were performing long-term mechanical ventilation in their home. Accordingly, 25 participants in our study make up 30% of the total target population. Relatively small sample, difference between intensity of care, absence of socioeconomic status of participants

and enrolling of participants in only one hospital are the limitations of this study.

## CONCLUSIONS

Although home mechanically ventilated patients and their informal caregivers appear to represent a small and insignificant group, it is a group of very severe patients that requires great care and ability of their caregivers. It is important to recognize the burden of informal caregivers in a timely manner in order to

**Table 3:** Factor structure of the 19-item questionnaire (iteration 2)

No ITEMS	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6
1 Patient asks for more help than he/she needs	0.023	0.704	0.422	-0.172	-0.121	-0.079
2 Not having enough time for yourself	0.324	0.789	-0.058	0.136	-0.142	0.212
3 Stressed due to fulfilling different responsibilities	0.178	0.405	-0.017	0.294	-0.418	0.573
4 Embarrassed of patient behaviour	0.143	0.106	0.766	0.057	0.186	0.124
5 Feel angry around patient	0.335	-0.010	0.725	0.095	0.264	0.065
8 Patient is too dependent	0.137	0.229	-0.012	-0.10	-0.762	0.086
9 Feel strained around patient	0.380	-0.041	0.078	0.033	0.287	0.657
10 Health affected by caregiving	0.691	0.352	0.163	-0.042	0.179	0.261
11 Having inadequate privacy	0.661	0.263	0.106	0.102	0.116	0.212
13 Uncomfortable having friends	-0.084	0.185	0.841	0.094	-0.211	0.136
14 Patient expects you to be the only caregiver	0.063	0.764	0.150	-0.016	0.175	-0.185
15 Feel financially stressed	0.875	0.035	-0.000	0.228	-0.056	0.082
16 Feel unable to take care of the patient much	0.456	-0.267	0.229	0.071	-0.057	0.647
17 Feel like losing control over life	0.177	0.174	0.124	0.079	-0.105	0.822
18 Wish to stop caring for the patient	0.128	0.336	0.053	-0.072	0.683	0.224
19 Feel uncertain of what to do	0.102	-0.098	0.256	0.373	0.361	0.617
20 Feel like you should be doing more for the patient	0.125	0.079	0.115	0.913	-0.028	0.013
21 Feel that you could do better for the patient	0.187	-0.063	0.014	0.883	0.055	0.185
22 Feel burdened by providing care	0.778	0.123	0.123	0.226	-0.174	0.286
Explained variance	3.009	2.353	2.182	2.030	1.721	2.537
% Explained variance	0.162	0.121	0.112	0.120	0.091	0.138

prevent the negative impacts of their duties on their mental and physical health, and to achieve the highest quality of care provided. The Croatian version of the ZBI can be accepted as reliable and a valid tool for measuring burden among informal caregivers of long-term mechanically ventilated patients. The further researches will be focused to the influence of burden to healthy ageing of informal caregivers. Ethical approval given by the Ethics Committee of Special Hospital for Lung Diseases, Rockefellerova 3, Zagreb, Croatia (02-

267/2019).

**Acknowledgements:** None

**Conflict of interest:** None to declare.

### Contribution of individual authors:

Snježana Benko Meštrović: conceived and designed the study, recruitment and collection of data, literature searches and analyses, drafted the manuscript  
Gordana Pavliša: recruitment and collection of data, drafted the manuscript  
Igor Jelaska: analyzed and interpreted the data, critically revised the manuscript for important intellectual content  
Marinko Artuković: critically revised the manuscript for important intellectual content  
All authors gave approval of the version to be submitted; all authors agree to be accountable for all aspects of the work.

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