

Validation of Zarit Care Giver Burden Scale among Primary Care Givers of persons with Dementia in Bengali: Study from a Tertiary Care Hospital of Eastern India

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Abstract: Dementia is an important disorder of public health importance. Memory Loss in dementia necessitates caregiver care. Thus caregiver burden assessment is thus also very important part in dementia. Zarit Care Giver Burden Scale is widely used scale for assessment of caregiver burden assessment in persons with dementia. Thus Bengali validation of this scale in Bengali is also very important for the caregivers of persons with dementia who can understand only Bengali but not English. In this context the present study was planned with the following objectives : of to validate the English version of Zarit caregiver burden in Bengali and to establish the reliability of the Bengali version of the Zarit caregiver burden scale among primary care givers of persons with Dementia The study was carried out at the Dementia Clinic, Department of Psychiatry, RG Kar Medical College. The scale to be validated into Bengali, the Zarit Care Giver Burden Scale is a 22 item scale. According to the rule of validation the minimum sample size required for the validation study come to be $22 \times 10 = 220$.These 220 study participants were selected from the Dementia Clinic, RG Kar Medical College. A sampling frame of all the primary caregivers of the patients attending the Dementia Clinic of RG Kar Medical College was prepared of which 220 primary caregivers of the patients who fulfilled the inclusion and exclusion criteria of the study were selected by simple random sampling. Consent was obtained from all study participants. Bengali translation of Zarit Care Giver Burden Scale used the sequence of steps suggested by World Health Organization. The steps were- : Establishment of a bilingual group of experts, Examination of the conceptual structure of the instrument under study by the experts, Translation, Examination of the translation by the experts, Examination of the translation by a monolingual group, Blind back translation, Examination of the blind back-translation by the experts. Data was compiled and analysed by SPSS 20.0. In the present study the validated Zarit Care Giver Burden Scale was found to be reliable and valid .The mean Kappa value was found to be 0.961. Reliability of the validated Zarit Care Giver Burden Scale measured by Cronbach Alpha was found to be 0.646. Component Matrix revealed that 7 factors could explain 94 % of the variance .

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I. Introduction

Globally average life expectancy of populations of many countries increasing . This translates into a better percentage of the world's population falling above the age of 65. The global population aged 60 years or over are more than 962 million in 2017, more than twice as in 1980 when there were 382 million older persons globally. The number of older persons is likely to double again by the year 2050, when it is estimated to reach nearly 2.1 billion.^{1,2}

The older population of the developing regions is also growing fastly than in the developed countries.¹ Consequently, the developing countries are home to a growing share of the world's older population. In 1980, the developing regions were home to 56 per cent of persons aged 60 years or over. In 2017, over two thirds of the world's older persons lived in the developing regions. Between 2017 and 2050, the number of persons aged 60 years or over in the developing regions is expected to increase more than twofold, from 652 million to 1.7 billion, whereas the more developed countries are projected to see a 38 percent increase in the number of older persons over that period, from 310 million persons aged 60 years or over in 2017 to 427 million

in 2050. Projections indicate that in 2050, 79 per cent of the world's population aged 60 or over will be living in the developing countries.

In the process to be diagnosed with dementia, one must experience a decline in mental ability hamper with daily life. Whereas symptoms of dementia can vary deeply, the most common indicators are memory related problems, language and communication destruction, and the loss of ability to focus and pay attention. Symptoms of dementia frequently lean to start out slowly and then progress gradually over the time. Most of the types of dementia continue to aggravate and are generally irreversible. Apparently signs of dementia may include: asking the same questions frequently, becoming misplaced in familiar locations, unable to track simple directions, getting confused about time, people and places, and a loss in attention for personal health and hygiene. Diagnosing dementia requires vigilant medical evaluation, including a thorough past medical history and different neurological exams and tests. Whereas physicians can almost always decide if a person has dementia, it may be difficult to find out the exact cause.^{2,3,4}

There are different types of dementia, of which Alzheimer's is the most common disease. Some people may have a combination of different types of dementia. Each person will practice their dementia in their own unique way.^{5,6}

In 2015, dementia affected more than 47 million people worldwide. By 2030, it is estimated that more than 75 million people will be living with dementia, and the number is expected to triple by 2050. This is one of the major health challenges for our time. In one Australian study, it was estimated that around 10% of the expected increase in health-care costs during the next 20 years would come from demand for care for this condition alone.⁷

In dementia there is memory loss which may be distressing in many cases. Caring a person with dementia involves great stress. The public health interventions for dementia should include interventions for reduction of caregiver burden of dementia. Thus assessment for caregiver burden in persons with dementia is an important area of public health research. Zarit Caregiver Burden Scale is an instrument to study the caregiver burden scale of dementia. Thus validation of the Bengali version of Zarit Care Giver Burden Assessment Scale is needed for Bengali population. In this background the study was done with the following Objectives :

II. Aims And Objectives

To establish the validity and reliability of the Bengali version of the Zarit Care Giver Burden Scale among primary care givers of persons with Dementia in Bengali

Design and Development: The study was carried out at the Dementia Clinic, Department of Psychiatry, RG Kar Medical College.

Inclusion Criteria for validation Study

Willingness to participate in the study;
Ability to understand both Bengali and English

Sample Size and Sampling Technique

Administration of Zarit Care giver burden scale

The primary caregivers of these persons with dementia were assessed for burden by validated Zarit Caregiver burden scale. Zarit care giver burden scale is a 22 item scale so taking up minimum of 10 study subjects for each item as per the rules of validation the sample size came to be 220. A sampling frame of all the primary caregivers of the patients attending the Dementia Clinic of RG Kar Medical College was prepared of which 220 primary caregivers of the patients who fulfilled the inclusion and exclusion criteria of the study were selected by simple random sampling.

The steps followed in the validation process are as follows:

- a) Establishment of a bilingual group of experts,
- b) Examination of the conceptual structure of the instrument under study by the experts,
- c) Translation,
Examination of the translation by the experts,
- e) Examination of the translation by a monolingual group,
- f) Blind back translation
- g) Examination of the blind back-translation by the experts

In the present study the above steps were followed for the development of an appropriate Bengali version of the Zarit Care Giver Burden Scale –

1. Establishment of a bilingual group of experts:- A bilingual local expert committee was formed at the beginning of the study. The committee comprised of one public health expert, one psychologist, two psychiatrists, two educated laypersons from the community.

2. Examination of the conceptual structure of the instruments by the experts

The experts examined the conceptual structure of the instrument.

3. Translation: Zarit Care Giver Burden Scale was translated from English to Bengali. This preliminary translated Bengali version was then available to a local expert committee for discussion.

4. Examination of the Translation by the experts: The committee sat over several meetings and worked extensively on the preliminary Bengali version of Zarit Care Giver Burden Scale.

Repeated searches were made from an English-to-Bengali dictionary for appropriate wording whilst equal attention was given to retaining the connotative meaning of the word to ensure that the Zarit Care Giver Burden Scale was easily understandable by all classes of people in West Bengal.

5. Examination of the translation by a monolingual group:

The expert group examined the translation group

6. Blind back translation: This intermediate Bengali version was back translated from the target language to its source by language expert who was unaware of the project and had no knowledge about the Zarit Care Giver Burden Scale. The back translated version was then reviewed by two native English speaking health professionals to check for congruence with the original English version

7. Examination of the blind back translation by the experts. During evaluation the experts were requested to compare each translated item with original in terms of the various forms of equivalence as suggested by Flaherty et al¹⁰

1. Content equivalence. The content of each item of the instrument is relevant to the phenomena of each culture being studied.

2. Semantic equivalence-The meaning of each item is the same in each culture after translation into the language and idiom (written or oral) of each culture (both denotative and connotative meaning was taken into consideration).

3. Technical equivalence. The method of assessment (e.g. pencil and paper, interview) is comparable in each culture with respect to the data that it yields.

4. Criterion equivalence. The interpretation of the measurement of the variable remains the same when compared with the norm of each culture studied.

5. Conceptual equivalence. The instrument is measuring the same theoretical construct in each culture.

a) Apart from these issues the experts were requested to keep in mind issues pertaining to translated items being comprehensible, acceptable, and relevant and complete.

Pilot testing: Pilot testing was carried out on three states as follows: a) self-administration of the Zarit Care Giver Burden Scale b) interview and self-administration of the Zarit Care Giver Burden Scale and c) interviews only with the Zarit Care Giver Burden Scale. These three stages of piloting of Zarit Care Giver Burden Scale were undertaken sequentially to make the scale comprehensible, culturally acceptable and usable for the Bengali knowing women in West Bengal. A convenience sampling strategy was adopted for each of the stages, as described in more detail below.

Self-administration of the Zarit Caregiver Burden Scale : Envelopes containing the Zarit Care Giver Burden Scale were serially numbered from 1-22.

The Bengali version of the Zarit Care Giver Burden Scale thus prepared was pilot tested among 15 volunteers to understand the comprehensibility of the scale.

The scale to be validated into Bengali, the Zarit Care Giver Burden Scale is a 22 item scale.

Interviews and self-administration of the Zarit Care Giver Burden Scale:

The scale to be validated into Bengali, the Zarit Care Giver Burden Scale is a 22 item scale. According to the rule of validation the minimum sample size required for the validation study come to be $22 \times 10 = 220$. These 220 patients were selected from the Dementia Clinic, RG Kar Medical College. A sampling frame of all the primary caregivers of the patients attending the Dementia Clinic of RG Kar Medical College was prepared of which 220 primary caregivers of the patients who fulfilled the inclusion and exclusion criteria of the study were selected by simple random sampling.

Data was compiled and analysed by SPSS 20.0.

The results obtained are as follows :

In the Bengali Zarit Care Giver Burden Scale

: The mean Kappa value was found to be 0.961. Reliability of the validated Zarit Care Giver Burden Scale

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measured by Cronbach Alpha was found to be 0.646. Component Matrix revealed that 7 factors could explain 94 % of the variance . Details of the result is as follows :

Table1: Inter rater agreement of the Validated Bengali Zarit caregiver burden scale

Sl. No	Item of the scale	Kappa Value	Significance
1	1	0.965	<0.001
2	2	0.961	<0.001
3	3	0.816	<0.001
4	4	0.968	<0.001
5	5	0.961	<0.001
6	6	0.957	<0.001
7	7	0.971	<0.001
8	8	0.901	<0.001
9	9	0.961	<0.001
10	10	0.953	<0.001
11	11	0.957	<0.001
12	12	0.965	<0.001
13	13	0.968	<0.001
14	14	0.959	<0.001
15	15	0.967	<0.001
16	16	0.961	<0.001
17	17	0.961	<0.001
18	18	0.972	<0.001
19	19	0.950	<0.001
20	20	0.967	<0.001
21	21	0.957	<0.001
22	22	0.961	<0.001

Table 2 : Average Kappa value of the Zarit caregiver burden scale instrument
KAPPA

N	Mean
22	0.961

III. Discussion

In the present study the validated Zarit Caregiver Burden Scale was found to be reliable and valid. The mean Kappa value was found to be 0.961. Reliability of the validated Zarit Caregiver burden Scale measured by Cronbach's α was found to be 0.646. Component Matrix revealed that 7 factors are significant. These 7 factors could explain 94 % of the variance.

In the study by Boon Kheng Seng et al found that the validated Zarit care giver instrument had a intra class correlation of 0.89 and Cronbach's α of 0.93.⁸

In the study by O.O. Ojifinni and O.C. Uchendu found that the validated Zarit care giver instrument had a intra class correlation of 0.84 and Cronbach's α of 0.90.⁹

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