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RESEARCH ARTICLE

ADAPTATION OF CAREGIVERS' TASK SCALE FOR MULTIPLE SCLEROSIS TO TURKISH SOCIETY: VALIDITY AND RELIABILITY STUDY

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ABSTRACT

Objectives: This study was planned and carried out methodologically to adapt the Caregiving Tasks in Multiple Sclerosis Scale (CTiMSS) to Turkish society.

Methods: A methodological research. The study was conducted with caregivers of individuals with multiple sclerosis who presented to the neurology clinic of a university hospital between June 2019 and September 2020. The validity and reliability study of the Caregiving Tasks in Multiple Sclerosis Scale (CTiMSS) was performed with a total of 142 individuals, which is more than 5 times the number of items on the scale (24 items).

Results: The validity of the CTiMSS was evaluated with language validity, construct validity (CFA), and content validity. The reliability coefficient of the internal consistency analysis (Cronbach's Alpha) was found to be extremely high (0.97). Item-total correlation of the scale was examined, and accordingly, no items were removed from the scale. The scale was administered to 30 patients at a two-week interval to analyze test-retest reliability and time-dependent invariance.

Conclusion: The CTiMSS, which was adapted to Turkish society to evaluate the tasks of individuals providing care for individuals with multiple sclerosis, is a valid and reliable tool. We recommend that it should be administered to different groups and cultures to increase its evidence value. CTiMSS is an appropriate measurement tool to determine the duties of caregivers of individuals with multiple sclerosis.

Keywords: Multiple sclerosis, caregivers, task, validity, reliability

INTRODUCTION

Multiple sclerosis (MS) is a chronic and autoimmune disease of the central nervous system which is characterized by attacks of demyelination on axons or progressive neurological symptoms. The pathogenesis and physiopathology of MS are not clearly known. It is 2 times more common in women than in men. Symptoms of the disease, which are usually seen between the ages of 15-50, may begin less frequently in childhood or after the age of 50 (1). Patients with MS have a wide variety of care needs and caregivers spend a lot of time on these activities (2,3). Increased care raises increased economic consequences. The cost of professional care required by severely disabled individuals with MS is also increasing (4). The distinctive features of MS shape the quality of care provided by caregivers. The course of the disease is variable, and acute exacerbations may occur unexpectedly. It commonly affects sensory-tactile motor, visual, bladder, sexual, and intestinal functions. The disease deeply affects both the care recipient and the caregiver psychosocially. The demands of providing care for a person with MS are four times the stress-related symptoms of the general population for a caregiver (5). Studies show

that caregivers report a wide variety of problems regarding caregiving (6,7,8,9).

Caregiver burden is known as physical, psychological, emotional, social, and financial difficulties experienced by caregivers (1). There is no consensus on the definition of the caregiver's burden, the concept is broad and vague, and the measurement of the burden is problematic. Several researchers have studied the burden on MS caregivers and stated that the difficulty in conceptualization and measurement of burden stems from these problems. According to Samartkit et al. and Schulz et al., giving care to individuals with chronic diseases has multidimensional effects on caregivers (5,10). In recent years, studies have focused on caregivers of MS patients, as well as informal caregivers of the elderly and patients with dementia (6,7).

Some studies, although few in number, have shown that MS care is associated with a number of problems, such as role change, restrictions on time and freedom, and loss or constraints on employment. Caregiving is evaluated according to the degree of stress, challenge, and control. It has been shown that higher stress tasks in caregiving are associated with more caregiving effects (2,3).

Therefore, this study was planned to determine the caregiver duties of caregivers of individuals with MS.

METHOD

Aim and type of the study

This study was planned and carried out methodologically to adapt the Caregiving Tasks in Multiple Sclerosis Scale (CTiMSS) to Turkish society.

Research question

1. Is the Caregiving Tasks in Multiple Sclerosis Scale a valid and reliable tool for Turkish society?

Study setting

The study was conducted with caregivers of individuals with multiple sclerosis who presented to the neurology clinic of a university hospital between June 2019 and September 2020.

The population and sample of the study

The population of the study consisted of caregivers of individuals with MS who met the sample selection criteria. To conduct the validity and reliability study of the Caregiving Tasks in Multiple Sclerosis Scale (CTiMSS), the sample included 142 patients (n=142), which was more than 5 times the number of items (24 items) on the scale. For test-retest reliability, the scale was administered to 30 patients at a two-week interval.

Inclusion criteria:

Caregivers who

- were giving care to patients who had confirmed diagnosis of multiple sclerosis,
- were first degree family members,
- had no communication disorders,
- volunteered to participate in the study, and
- were aged 18 or over were included in the study.

Exclusion criteria:

Caregivers of individuals with psychological and/or communication disorders were not included in the study.

Data collection tools

The Participant Information Form: This form was developed by the researchers following a review of the literature. It consists of 5 items questioning the personal characteristics of the caregivers (age, sex, marital status, educational status, working status).

The Caregiving Tasks in Multiple Sclerosis Scale (CTiMSS): This scale will be adapted to Turkish and used under the Turkish title “MultiplSkleroz’da Bakım Verenlerin Görev Ölçeği”. The 24-item scale was developed by Pakenham in 2007(6) for the Australian society (Cronbach's alpha = 0.93). The scale consists of 4 subscales (Instrumental Care, Activities of Daily Living Care, Psycho-emotional Care, and Social-practical Care) and has a 5-point Likert type scale with options 0: No help, 1: Little help, 2: Moderate help, 3: Quite a lot of help, and 4: Lots of help.

Evaluation of the scale

The mean score of each subscale is evaluated separately. A minimum of 0 and a maximum of 4 points are obtained from the subscales. Increased mean scores mean increased caregiver tasks. The scale does not contain any reversed items.

Data collection method

The data were collected face to face using the Patient Information Form and the Caregiving Tasks in Multiple Sclerosis Scale.

Table 1. General characteristics of the caregivers

Characteristics	Groups	n	%
Age	≤30	40	28.2
	31-40	41	28.9
	41-50	35	24.6
	≥51	26	18.3
Gender	Female	88	62.0
	Male	54	38.0
Marital status	Married	87	61.3
	Single	44	31.0
	Divorced	11	7.7
Status of education	Literate	5	3.5
	Elementary school	14	9.9
	Middle school	12	8.5
	High school	39	27.5
	University	72	50.7
Working status	Not working	65	45.8
	Working	77	54.2

Data analysis
The construct validity of the scale was conducted with confirmatory factor analysis on the AMOS software package. Test-retest measurements of the scale were tested with the paired samples t-test and correlation analysis. The reliability of the scale was analyzed with Cronbach's alpha, and item analysis was performed for each item.

Ethical aspects of the study
The approval of the ethics committee of a university and the permission of the institution where the study would be conducted were obtained. The permission of the researchers who developed the scale was obtained. Informed consent of the individuals who voluntarily participated in the study was obtained.

Findings
Of the participants giving care to individuals with MS, 28.9% (n=41) were aged between 31 and 40, 62.0% (n=88) were female, 61.3% (n=87) were married, 50.7% (n=72) were university graduates, and %54.2 (n=77) were found to work.

Validity of the CTiMSS
Language validity
The back-translation method was used for the language validity process of the CTiMSS. The scale was translated into Turkish by three people who had a good command of both English and Turkish languages. The appropriateness of each item of the scale translated into Turkish was examined by the researchers. Then, it was translated back into English by a translator. The translated items were compared to the items on the original scale, and inappropriate items were revised. The Turkish version of the translated scale and the English of the original scale were evaluated in terms of meaning, and language validity was achieved.

Content validity
For the content validity index of the CTiMSS (CVI), the scale was submitted to the opinions of eight academicians. To evaluate the consistency of the items and determine their intelligibility, the experts were asked to score each item between 1 and 4 points. In line with the feedback received from the eight experts, necessary corrections were made to the items, and the Turkish form of the scale was finalized. The CVI of the scale was found as 0.933, which is considerably high. The experts reached a consensus on all of the items on the scale.

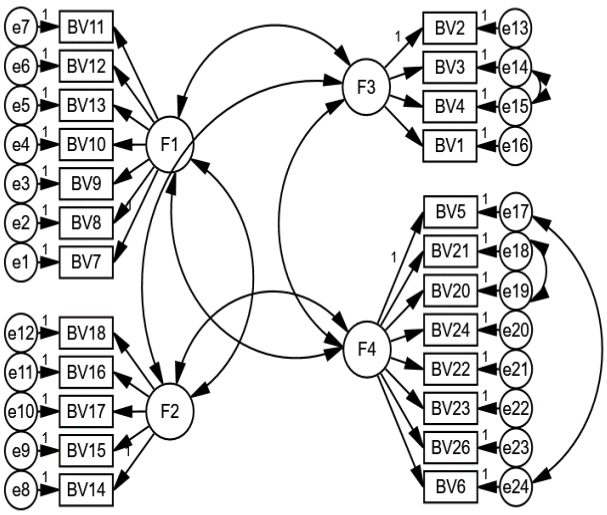

Figure 1. Diagram for Confirmatory Factor Analysis

Table 2. The goodness of fit index values for confirmatory factor analysis

Index	Normal value*	Acceptable range **	Value
χ2/sd	<2	<5	3.62
GFI	>0.95	>0.90	0.90
AGFI	>0.95	>0.90	0.90
CFI	>0.95	>0.90	0.90
RMSEA	<0.05	<0.08	0.08
RMR	<0.05	<0.08	0.06

Construct validity

In the study, the most frequently used goodness of fit indices in studies in the literature was used. The diagram for confirmatory factor analysis is given in Figure 1. The goodness of fit index values for the confirmatory factor analysis are given in Table 2.

The results of the analysis indicated that the fit statistics calculated with the confirmatory factor analysis were consistent with the previously determined factor structure of the scale at an acceptable range. Standardized factor loads, t values and explanatory (R2) values of the items are given (Table 2).

Table 3. Factor loads

Items		Factors	β	Std. β	S. Error	t	p	R^2
BV7	<---	F1	1.000	0.747				0.550
BV8	<---	F1	1.170	0.858	0.107	10.939	p<0.001	0.667
BV9	<---	F1	1.151	0.960	0.092	12.519	p<0.001	0.683
BV10	<---	F1	1.224	0.955	0.098	12.445	p<0.001	0.700
BV13	<---	F1	1.137	0.873	0.102	11.165	p<0.001	0.642
BV12	<---	F1	1.085	0.909	0.093	11.724	p<0.001	0.630
BV11	<---	F1	1.185	0.963	0.094	12.570	p<0.001	0.617
BV14	<---	F2	1.000	0.846				0.464
BV15	<---	F2	0.974	0.851	0.074	13.101	p<0.001	0.829
BV17	<---	F2	1.040	0.902	0.071	14.571	p<0.001	0.598
BV16	<---	F2	1.093	0.923	0.072	15.243	p<0.001	0.670
BV18	<---	F2	1.075	0.912	0.072	14.880	p<0.001	0.777
BV2	<---	F3	1.000	0.882				0.831
BV3	<---	F3	0.915	0.818	0.072	12.746	p<0.001	0.852
BV4	<---	F3	0.878	0.774	0.076	11.532	p<0.001	0.813
BV1	<---	F3	0.925	0.911	0.059	15.675	p<0.001	0.724
BV5	<---	F4	1.000	0.681				0.715
BV20	<---	F4	1.115	0.785	0.129	8.668	p<0.001	0.928
BV19	<---	F4	1.125	0.793	0.129	8.749	p<0.001	0.827
BV23	<---	F4	0.969	0.801	0.110	8.827	p<0.001	0.762
BV21	<---	F4	1.086	0.836	0.118	9.177	p<0.001	0.913
BV22	<---	F4	1.076	0.826	0.119	9.076	p<0.001	0.922
BV24	<---	F4	1.048	0.817	0.117	8.984	p<0.001	0.736
BV6	<---	F4	1.043	0.741	0.087	11.972	p<0.001	0.557

Table 4. Item analysis

	Scale score when the item is deleted	Variance when the item is deleted	Item-total correlation	Cronbach's alpha when the item is deleted
BV1	31.930	790.775	.852	.973
BV2	31.732	788.878	.779	.974
BV3	31.444	790.759	.770	.974
BV4	31.746	792.304	.740	.974
BV5	31.535	793.399	.698	.974
BV6	31.535	789.570	.775	.974
BV7	32.310	798.045	.745	.974
BV8	32.465	795.697	.758	.974
BV9	32.486	797.599	.844	.973
BV10	32.472	795.698	.811	.973
BV11	32.592	798.116	.815	.973
BV12	32.627	803.101	.773	.974
BV13	32.430	797.254	.777	.974
BV14	31.627	787.455	.840	.973
BV15	31.803	796.188	.763	.974
BV16	31.577	791.480	.791	.974
BV17	31.711	796.519	.753	.974
BV18	31.775	790.616	.805	.973
BV19	31.444	791.298	.749	.974
BV20	31.528	791.187	.748	.974
BV21	31.958	791.516	.819	.973
BV22	31.768	795.641	.767	.974
BV23	31.613	801.884	.748	.974
BV24	31.697	797.957	.751	.974

When the standardized coefficients were examined, it was determined that the factor loads were high, the standard error values were low, and that the t values were significant. These results confirmed the construct validity relating to the previously determined factor structure (Table 3).

The reliability of the CTiMSS

Reliability

The reliability analysis of the scale was performed and the Cronbach's alpha coefficient was found to be 0.97. The item analysis regarding the effect of items on internal consistency is presented in Table 4.

Item-total correlation

Item-total correlation values of the items on the scale ranged between 0.69 and 0.85. The internal consistency coefficients (Cronbach's Alpha) obtained when the items were deleted one by one were around 0.97, and these values did not show much deviation from the overall internal consistency value of 0.97. As a result of the analysis of the items, no items were removed from Test-retest reliability the scale table 4. In the study, the scale was administered to 30 individuals at a two-week interval to examine the inter-rater consistency. Test-retest reliability of the scale items was tested with paired samples t-test and correlation analysis. According to the results obtained, it was determined that the retest measurements did not show a significant difference and indicated a high correlation. According to this finding, the items on the scale showed internal consistency according to the responses received (Table 5).

Table 5. Test-retest

	Mean difference	S.D.	t	p	r	p
BV1 - T1	0.000	0.263	0.000	1.000	0.988	0.000
BV2 - T2	0.000	0.263	0.000	1.000	0.989	0.000
BV3 - T3	0.033	0.320	0.571	0.573	0.978	0.000
BV4 - T4	0.000	0.263	0.000	1.000	0.989	0.000
BV5 - T5	0.000	0.263	0.000	1.000	0.990	0.000
BV6 – T6	-0.033	0.183	-1.000	0.326	0.994	0.000
BV7 - T7	0.000	0.263	0.000	1.000	0.990	0.000
BV8 - T8	0.033	0.183	1.000	0.326	0.995	0.000
BV9 - T9	0.000	0.263	0.000	1.000	0.989	0.000
BV10 - T10	0.000	0.263	0.000	1.000	0.989	0.000
BV11 - T11	0.000	0.263	0.000	1.000	0.989	0.000
BV12 - T12	-0.033	0.183	-1.000	0.326	0.995	0.000
BV13 - T13	-0.033	0.320	-0.571	0.573	0.985	0.000
BV14 - T14	-0.033	0.183	-1.000	0.326	0.995	0.000
BV15 - T15	-0.067	0.254	-1.439	0.161	0.989	0.000
BV16 - T16	-0.033	0.183	-1.000	0.326	0.994	0.000
BV17 - T17	-0.033	0.183	-1.000	0.326	0.994	0.000
BV18 - T18	-0.033	0.183	-1.000	0.326	0.994	0.000
BV19– T19	-0.033	0.183	-1.000	0.326	0.994	0.000
BV20 - T20	-0.033	0.183	-1.000	0.326	0.995	0.000
BV21 - T21	-0.033	0.183	-1.000	0.326	0.995	0.000
BV22 - T22	0.033	0.183	1.000	0.326	0.994	0.000
BV23 - T23	0.100	0.548	1.000	0.326	0.936	0.000
BV24 - T24	0.067	0.583	0.626	0.536	0.929	0.000

t: paired samples t-test, r: correlation analysis, $p<0.01$

DISCUSSION

In this section, the findings of the study are discussed with the literature.

Content validity means that a measurement tool is free from the effects of factors. It is carried out to evaluate whether the overall scale and sub-dimensions measure the intended domains and express different concepts. Expert opinion is consulted to calculate the content validity (11). The qualifications and number of experts (between 5 and 40) are of great importance in obtaining objective results in content validity calculations (12). The feedback of 8 academicians was received for the content validity index of the CTiMSS (CVI). CVI was calculated by dividing the number of experts who gave 3 or 4 points to each item on the scale by the total number of experts, and it was decided that the content of the Turkish form of the scale was appropriate. The CVI of the scale was found to be 0.92, which is higher than the generally accepted standard level (0.80 and above) (11). The experts reached a consensus on all items on the scale.

Confirmatory factor analysis (CFA) was employed to evaluate the construct validity of CTiMSS. CFA is a type of structural equation model (SEM) that can measure the relationship between observed and latent variables (13). It explains the result obtained from the scale and what this result is related to (14). It is about how accurately the scale items measure the determined properties. In scale adaptation studies, the factor structure of the scale is compared with the factor structure of the original scale, and similarities and differences are evaluated. In adapting a scale to another language, it is expected that the

factor structure of the scale does not change much. CFA allows the evaluation of fit indices showing model and data fit (11, 15). In our study, the most frequently used goodness of fit indices in studies in the literature were used. Goodness of fit indexes are given in Table 2. In the present study, the factor structure of the scale evaluated as a result of CFA was found to be similar to the original scale with 4 subscales (Figure 1). The fit index values obtained showed that the data obtained from the sample and the model had a fairly good fit (Table 2).

Reliability analysis was conducted to determine the internal consistency of the scale. The reliability analysis shows whether the items on the scale are consistent with each other and with the overall scale. It also determines whether individuals understand the expressions on the scale in the same way. Reliability is the consistency between participants' responses to scale items (16). In the literature, the reliability (internal consistency) of a scale is often determined with the Cronbach's alpha coefficient. The evaluation criteria for the Cronbach's alpha value showing the reliability is as follows: $0.00 \leq \alpha < 0.40$, not reliable; $0.40 \leq \alpha < 0.60$, poor reliability; $0.60 \leq \alpha < 0.80$, quite reliable; $0.80 \leq \alpha < 1.00$, highly reliable (17). In our study, the reliability analysis of the scale was conducted, and Cronbach's Alpha coefficient was found to be 0.97, showing the scale is highly reliable. The item-total correlation is used to examine the relationship between each item on the scale and the total score. Item-total correlation explains the relationship between the scores obtained from the test items and the score obtained from the overall test (18). Responses to the items are expected to have a positive correlation with items and the overall scale. This shows that the participants understand the propositions correctly and give objective answers. When the correlation coefficient of an item on a scale with the item-total is 0.3 or above, this indicates a high discriminating power (16). The high correlation of each item with the overall scale score shows the consistency of the measuring tool. The correlation coefficient is determined by "r", and its values vary between 0 and 1. The closer the correlation value approaches 1 (± 1.00), the higher the reliability is (15,19). As a result of the evaluation of the item analysis, no items were removed from the scale (Table 4).

Test-retest reliability is conducted to evaluate the time-dependent invariance of the test. In other words, the process of administering a test to the same group after a certain period of time is a method used to determine the reliability of the related test (18). To administer the retest, there must be at least two and at most four weeks between the first and second measurements. Test-retest reliability is recommended to be administered to at least 30 people (15). In our study, the scale was administered to 30 individuals at a 2-week interval to examine inter-rater consistency. Test-retest reliability of scale items was tested with paired samples t-test and correlation analysis. According to the results obtained, it was determined that the retest measurements did not show a significant difference and that retest results had a high correlation. Accordingly, the items on the scale showed internal consistency according to the responses received (Table 5).

CONCLUSION

The CTiMSS, which is originally in English and was adapted to Turkish society, was consistent with its original form in terms of having 24 items and 4 subscales. This scale is a highly valid and reliable tool in evaluating the tasks of individuals providing care for individuals with multiple sclerosis in Turkish society. We recommend that it should be applied in different cultures and groups to increase its value of evidence.

Limitations of the research: Due to the pandemic, there have been problems in reaching caregivers of individuals with MS.

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Author contributions: The project was constructed by N.E., A.T.T., designed, N.E. performed experiments and analyzed the data, N.E were responsible for data collection and processing, N.E. wrote the manuscript, and N.E., A.T.T., edited the manuscript.

Conflict of Interest: No conflict of interest has been declared by the authors.

Ethical Approval: Ethics committee approval was obtained from Marmara University, Faculty of Health Sciences, Non-Interventional Ethics Committee (24.04.2019/60) and the permission of the institution where the study would be conducted.

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