ORIGINAL RESEARCH

Positive Aspects of Caregiving Questionnaire for Family Caregivers of People with Dementia: Psychometric Properties of the Turkish Version

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Abstract

Objective: Negative and positive aspects of caregiving (PAC) coexist. Ignoring the PAC limits the overall understanding of caregiving adaptation and thus undermines the development of initiatives. This study aimed to translate the PAC Questionnaire (PACQ) into Turkish and assess its psychometric properties of the Turkish version of the positive aspects of caregiving questionnaire (T-PACQ).

Materials and Methods: This study used a descriptive and methodological approach. After linguistic validity, we conducted a convenience sample of 222 family caregivers of people living with dementia, all home dwellings, using a socio-demographic form, Beck depression inventory, and T-PACQ. Factor analysis [exploratory factor analyses and confirmatory factor analyses (CFA)], analyses of discriminant validity, internal consistency (using Cronbach's alpha), item-total and item-sub-dimensions correlations, ceiling and floor effects, and Hotelling's t-squared test were conducted.

Results: The linguistic validity of the instrument was satisfactory. The total explained variance of the instrument consisting of two domains and 10 items was determined to be 48.40%. According to CFA, model fit indices were ≥0.90. The value of Cronbach's alpha was found to be 0.80. No response bias or ceiling-floor effects were observed.

Conclusion: This instrument is a short and robust measurement tool for assessing family caregivers' perceptions of the PAC. It could be used to engage in appropriate initiatives for family caregivers and assess their effectiveness.

Keywords: Caregivers, caregiving, dementia, psychometrics

Introduction

Dementia is a concern for public health around the world, according to the World Health Organization. More than 55 million people have dementia, with the majority (over 60%) residing in low- and middle-income countries such as Turkey, and over 10 million new cases are diagnosed annually (1). There were approximately 800,000 people living with dementia (PwD) in Turkey in 2019, and the number is projected to rise to 3 million by the year 2050 (2). With a 277% increase expected between 2019 and 2050, the demand for PwD caregivers will rise in the Turkish society.

Dementia is one of the leading causes of disability and dependence in people aged 65 years and older worldwide. PwDs,

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their caregivers, families, and society as a whole have to deal with the financial, social, psychological, and physical effects of this condition. The main source of informal care and a key factor in supporting dementia care in the community is family caregiving. In 2019, informal caregivers (most commonly family members and friends) provided an average of 5 h of daily care to PwD (1). Maintaining this valuable source of informal care for PwD requires a significant focus on encouraging caregivers to successfully adapt to this process. Research in the caregiving of PwD places great emphasis on negative aspects and decreases the burden and associated health consequences, but little attention has been given to the positive aspects (3). However, the process of caring for someone includes both negative and positive aspects. Therefore, disregarding the positive aspects of caregiving (PAC) would hinder understanding of the entirety of the process that family caregivers go through while coping with PwD (4). Strengthening caregiver adaptation includes going beyond reducing the caregiver burden to enhancing PAC (3). PAC is thought to be a protective factor for caregivers' quality of life (4) and can reduce the negative effects on health outcomes (5).

In sum, PAC is a positive appraisal response that results from effective coping with a difficult caregiving situation. Recognizing and promoting PAC can help lessen the effect of negative experiences and feelings that arise while caring for someone (6). To assess family caregivers' perceptions of PAC, valid and reliable measurement tools are required. There is only one valid and reliable scale in Turkish (7), but using the 42-item scale takes time. The PAC questionnaire (PACQ) is a short (10 item) and robust tool based on the stress-coping model (8). Some aspects of the spiritual or moral dimensions of caregiving have been neglected in previously developed instruments. The PACQ also addresses this aspect. The PACQ consists of 10 items structured into two 5-point Likert subdimensions: patient-caregiver relationship and caregiver's psychological well-being. Exploratory factor analysis (EFA) revealed that the factor loadings were suitable (min: 0.531 to max: 0.875). Internal consistency was high for the overall questionnaire (0.785). Because of its usefulness, ease of use and understanding, quick implementation time, and good psychometric values, it will likely be implemented in clinical practice.

Materials and Methods

Aim

The research adapted the PACQ into the Turkish language and to test the psychometric properties of the Turkish version of the positive aspects of caregiving questionnaire (T-PACQ) among family caregivers of PwD.

Design

Using a descriptive, methodological, and cross-sectional research design, the psychometric properties of the T-PACQ were examined. The study followed standard reporting guidelines for the development and validation of scales in the fields of health, social science, and behavioral research (9). The PACQ was translated into Turkish and back-translated from Turkish into English, and linguistic validation tests were performed. Subsequently, construct validation and reliability assessment were examined for T-PACQ.

Linguistic Validation

First, Dr. İbrahim Abdollahpour, the original developer of the questionnaire, granted permission to translate the PACQ and evaluate T-PACQ psychometric properties. The questionnaire was originally written in English, and the research team independently translated it into Turkish. The meaningfulness, linguistic accuracy, and conceptual equivalence of each item were then evaluated by the researchers. A bilingual professional translator with no prior familiarity with the questionnaire translated the items from Turkish to English (10). During the last step of adaptation, the team met online to discuss questionnaire translations. The researchers compared the English translation to the original. Dr. İbrahim Abdollahpour confirmed the back-translation via e-mail, and no changes were made to the questionnaire items.

The items of T-PACQ relevance and meaningfulness to the target population were evaluated using face validity. At this stage, 14 family caregivers of PwD participated. The researchers designed an anonymous form that included the following questions: what general comments do you have about the questionnaire? Is the number of questions appropriate? Do you think the question order makes sense? Did you have any difficulty understanding or responding to any question? What opinions do you have regarding each statement? Was the questionnaire overall simple and easy to understand? Have you had any challenges with the statement rating? Do you have any recommendations?

The content validity was examined by seven experts, including two nursing academicians (one an expert in psychometric research and the other in geriatric nursing), two clinic nurses (one with eight years of clinical experience in geriatrics and over five years of clinical experience in neurology), and three physicians (one neurologist and two geriatricians). Experts rated each item on a four-point scale, ranging from inappropriate (1) to appropriate (4).

Construct Validation and Reliability Assessment

Setting and Sample

Sample sizes of 10 participants per survey question and/or 200-300 observations are recommended for use in scale development and validation studies (9). To conduct EFA and confirmatory factor analyses (CFA), it was necessary to collect data from at least 200 individuals, which would mean 20 responses per scale item (10 items in total). The study was

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conducted between May and September 2022 in a neurology and geriatrics outpatient clinic in Turkey. A total of 222 family caregivers of PwD who were all home-dwelling were recruited. Samples were chosen using convenience sampling with non-probability. To be included in the study, caregivers needed to meet the following criteria: they had to be the primary family caregiver for a PwD, be responsible for his/her daily activities, have cared for a PwD for at least six months, have lived in the same house, have voluntarily agreed to participate in the study, be literate in Turkish, and be at least 18 years old. The following were the requirements for caregiver exclusion: people having difficulty hearing or speaking, and people with any psychological illness (self-reported).

Data Collection

A socio-demographic form of PwD and their caregivers, the Beck depression inventory (BDI), and the T-PACQ were used to collect the study data.

Socio-demographic Data: The form was designed to collect socio-demographic data about PwD and their caregivers, including age, sex, years of formal education, duration of disease (years), and marital status.

BDI: Twenty one items were responded to in four options, measuring depression-related attitudes and symptoms. The total score is determined by summing together the points awarded to the right of each question that was answered. The range of the score that can be obtained from the inventory is 0-63 (0-16 points for normal or mild mood disorder, 17 points and above for depressed). Higher scores indicate greater depressive symptoms in individuals (11). Both the total scale and sub-dimension Cronbach's alpha for the Turkish population were quite high (12). The Beck depression scale was used in this study for discriminant validity assessment.

PACQ: On a Likert-type questionnaire, 10 questions were answered with a response ranging from strongly disagree (0) to strongly agree (4). The questionnaire includes two sub-dimensions: patient and caregiver relationship (item 1 + item 2 + item 3 + item 4) and caregiver's psychological well-being (item 5 + item 6 + item 7 + item 8 + item 9 + item 10). The two subdimensions are added together to obtain the total score (min: 0, max: 40). Higher scores indicate positive satisfaction with the caregiving process. Cronbach's alpha scores for both the questionnaire and its sub-dimensions were found to be in the higher ranges (8).

Each caregiver contacted a researcher face to face before the survey began to obtain information about the study and provide written consent.

Ethics

The first author of the original questionnaire provided written permission for the psychometric testing of the T-PACQ. The Dokuz Eylül University Non-Invasive Research Ethics Committee approved the study (decision number: 2022/15-13, date: 20.04.2022). Each caregiver provided their informed consent to participate in the study after being provided with information regarding the purpose and methodology of the research being conducted.

Statistics

Analysis of Moment Structures (AMOS) 25.0 and (SPSS) 24.0 were used in the analysis. We used a confidence interval of 95% ($p<0.05$).

For face validity, the responses were analyzed descriptively. The item content validity index (I-CVI) and scale levels (S-CVI) were evaluated for expert opinions (13-16). The level of expert agreement was tested using Kendall's W analysis.

Construct validity was evaluated using EFA, CFA, and discriminant validity. Using participant entry codes, the study sample was divided at random. EFA was used on one of these halves to examine the measurement model, and CFA was used on the other half to confirm the model. Both the Kaiser-Meyer-Olkin (KMO) coefficient and the Barlett sphericity test were used to determine whether or not the data were suitable for factor analysis. For testing the necessary EFA assumptions, the KMO was used to be greater than 0.60, and the Bartlett test for sphericity was used to have a significance level of less than 0.05. To investigate domain identification, the principal components EFA with a Varimax rotation was employed. The data's assumed normality was tested using the skewness and kurtosis indices. If the eigenvalue was at least 1 and the factor loadings were at least 0.30, it was thought that the factors and items were being kept well. The following variables were analyzed for CFA: Pearson chi-square (χ^2), degree of freedom (df), root mean square error of approximation (RMSEA), goodness-of-fit index (GFI), and comparative fit index (CFI) (13,17,18).

The reliability of the questionnaire was calculated using Cronbach's alpha (18-20), item-total correlation, ceiling and floor effects, and Hotelling's t-squared test for response bias (16,20). Cronbach's coefficient was used to conduct the reliability analysis, and a value of 0.60 or higher was regarded as satisfactory (13,15).

Results

Linguistic Validation

Items were remarkably similar to the originals after translation and back translation and did not require alteration (Supplementary Material 1).

Face validity testing was performed on 14 family caregivers of PwD aged (mean) 59.21±8.30 years (range: 41-71), 78.6% of

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whom were female, 85.7% of whom were retired or unemployed, 42.9% of whom were bachelor graduates, 71.4% of whom were children of PwD, and more than 57.1% of caregivers stated that their income was the same as their expenses. The quantity and order of items were considered appropriate by all caregivers, and they had no difficulties with the statement ratings. The T-PACQ was deemed relevant and understandable by most respondents. No changes were made to the questionnaire items. I-CVI for ten items ranged from 0.90 to 1, and the S-CVI was 0.98. The ratings for each item were similar, with no statistically significant differences (Kendall W: 0.18, p=0.23). As a result, all items were retained in the questionnaire.

Construct Validation and Reliability Tests

The mean age of caregivers (n=222) was 54.72±12.07 years (range: 19-84), 76.6% (n=170) were female, 72.5% (n=161) were married, 58.6% (n=130) stated that their income was the same as their expenses, and 38.3% (n=84) had a bachelor's degree. Most caregivers (67.6%, n=150) were children of PwD, and their patients had Alzheimer's type dementia (57.7%, n=128) (Table 1).

The KMO coefficient was found to be 0.74 and a Bartlett sphericity test χ^2 of 300.64 (p<0.001), indicating that the data were appropriate for factor analysis. Within the EFA, two factors were identified: the first explained 34.13% of the total variance and the second explained 14.27%. These factors explained 48.40% of the total variance. Factor loadings for factor 1 (patient and caregiver relationship) ranged from 0.36 to 0.93, and factor 2 (caregiver's psychological well-being) ranged from 0.40 to 0.74 (Table 2).

The CFA applied to the two-factor solution showed that this model was suitable. CFI: 0.94, GFI: 0.91, χ^2/df: 1.47, p<0.001, and RMSEA: 0.06 were the model fit indices that were determined (Figure 1). There was a moderately positive correlation between patient and caregiver relationships and the caregiver's psychological well-being subscales using Pearson product-moment correlation (r=0.469, p<0.001). The discriminant validity test found a statistically significant difference between the two groups (t=2.369, p=0.01). Non-depressed participants had higher T-PACQ scores (25.51±8.54) than depressed participants (22.26±8.92).

The overall Cronbach's alpha was 0.80 (patient and caregiver relationship: 0.72, caregiver's psychological well-being: 0.71). Hotelling's t-squared test was 284.06, p<0.001, suggesting no response bias. No floor or ceiling effects were determined (=0.01%). All of the item-total correlations were satisfactory, with values ranging from 0.39 to 0.68 from 0.64 to 0.81 for the patient and caregiver relationship, and from 0.43 to 0.75 for the caregiver's psychological well-being (Table 3).

Table 1. Descriptive characteristics of the sample (n=222)		
Caregivers	**n**	**%**
Sex		
Female	170	76.6
Male	52	23.4
Income status		
Income less than expenditure	44	19.8
Income equal to expenditure	130	58.6
Income more than expenditure	48	21.6
Working status		
Working	63	28.4
Not working	159	71.6
Marital status		
Married	161	72.5
Single	61	27.5
Educational status		
Literate/elementary school	59	26.5
High school	57	25.7
University	85	38.3
Postgraduate	21	9.5
Relationship with the patient		
Spouse	53	23.9
Children	150	67.6
Other family member	19	8.5
	X	**SD**
Age (years)	54.72	12.07
Caregiving period (months)	39.57	30.52
Patients		
Age (years)	77.92	9.42
Diagnosis (years)	42.13	31.31
	n	**%**
Sex		
Female	137	61.7
Male	85	38.3
Marital status		
Married	144	64.9
Single	78	35.1
Educational status		
Illiterate	34	15.3
Literate/elementary school	112	50.5
High school	41	18.5
University	28	12.6
Postgraduate	7	3.1
Types of dementia		
Alzheimer's disease	128	57.7
Frontotemporal dementia	13	5.9
Vascular dementia	19	8.6
Lewy body dementia	25	11.3
Parkinson's disease dementia	10	4.6
Unknown	27	12.1
X: Mean, SD: Standard deviation		

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Discussion

The PACQ was initially developed in English and then translated into Turkish. Its psychometric qualities were then examined in Turkish family caregivers of PwD. To demonstrate that the T-PACQ provides valid and reliable PAC process scores among Turkish family carers of PwD, we used face and content validity assessments, EFA, CFA, discriminant validity, and reliability testing. The best psychometric performance was produced by retaining the original version's 10 item, two-factor structure.

This study is the first to examine PACQ's reliability and validity in a different language and context (8); therefore, we lack any variables to compare. Findings showed that the questionnaire

was easily completed by the intended sample because all questions were easily understood and considered relevant. The T-PACQ seems to measure the concept it is supposed to measure, as the content validity scores were all above the minimally needed levels (19). This suggests that the experts could reach a satisfactory compromise.

Similar to the initial study, the T-PACQ was found to have a two-factor structure (8), with the items strongly correlating with each factor. This indicated that both factors in a strong factor structure measured the intended concept. Because all of the factor loadings and fit indices obtained from the CFA were within the ranges stated in the literature, it was concluded that the factor structure of the instrument gave the best feasible fit (21,22). The initial study (8) did not include CFA, so we did not have any variables to compare. Discriminant validity is used to examine whether the concept being measured is different from other concepts (9). Scores on the T-PACQ were expected to be statistically different between the depressed and nondepressed groups. Similarly, caregivers' self-rated health was significantly associated with PACQ scores in the initial study (8). These construct validity results suggest that the questionnaire can provide valid data on PAC for family caregivers of PwD.

The T-PACQ was found to provide highly reliable results. Cronbach's α was approximately the same as that found in the initial study (total α: 0.78, patient and caregiver relationship: 0.71, and caregiver's psychological well-being: 0.70) (8). Additionally, there was no potential for significant response bias according to the Hotelling t-square test results, which showed that people answered questions based on their opinions, not outside factors (16,23). The floor and ceiling effect was 0.01%,
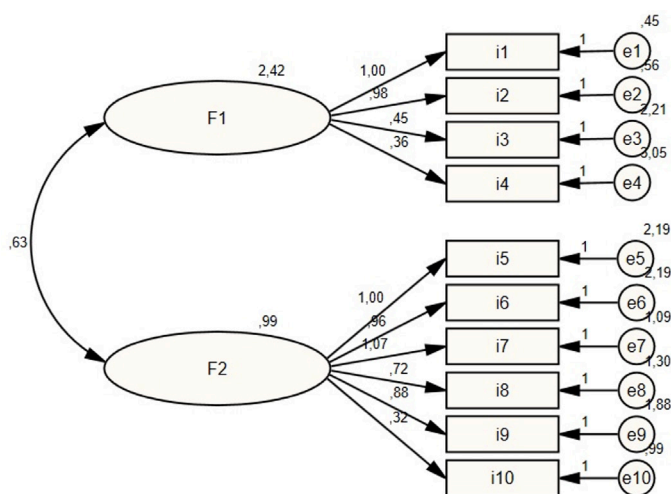

Figure 1. Confirmatory factor analysis of T-PACQ

T-PACQ: Turkish version of the positive aspects of caregiving questionnaire

Table 2. Factor loadings, exploratory factor analysis (n=111)		
Items*	**Factor 1: patient and caregiver relationship**	**Factor 2: caregiver's psychological well-being**
1. Do you feel that, caring your patient has resulted in more dependency feeling to him/her?	0.92	
2. Do you feel that, comparing to the past, you have become closer to your patient?	0.93	
3. Do you feel that, due to caring your patient, your life has become more meaningful?	0.46	
4. Do you believe that caring your patient, due to providing a compensation opportunity for appreciate him/her, donates a satisfaction feeling to you?	0.36	
5. Did you believe that, as a result of caring your patient, you have become a better human comparing to your past?		0.58
6. Do you believe that collaboration in caring your patient has brought your family members closer together?		0.68
7. Do you think that your faith, in the time of caring your patient, has provided a source of power and peace for you?		0.74
8. Did you believe that, during caring your patient, you have learned many useful things?		0.61
9. Do you believe that caring your patient has spiritual/moral remuneration?		0.59
10. Do you believe that caring your patient has been beneficial for your patient?		0.40
Explained variance (%)	34.13	14.27
*Turkish version of instrument was administered to the caregivers		

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Table 3. Item-total and item-sub-dimensions' correlation scores (n=222)

Sub-dimensions	Item	Item-total correlation (r)*	Item-subdimension correlation (r)*
Patient and caregiver relationship	Item 1	0.65	0.81
	Item 2	0.63	0.81
	Item 3	0.68	0.68
	Item 4	0.56	0.64
Caregiver's psychological well-being	Item 5	0.64	0.67
	Item 6	0.55	0.64
	Item 7	0.65	0.75
	Item 8	0.55	0.61
	Item 9	0.62	0.69
	Item 10	0.39	0.43
*p<0.001			

which is much less than the 20% limit and shows that this bias did not exist (16,23).

Study Limitations

Participants in the survey were family members of PwD who received routine care at a neurology and geriatrics outpatient clinic in Turkey. Common generalizations are limited by the use of a non-random sample approach because bias may exist. Reliability, and especially validity, is an increasing and never-ending process. Therefore, a larger population can be used to evaluate the questionnaire's validity and reliability. Assessment of the time variation of the questionnaire was not performed. These should be considered in future studies.

Conclusion

The results show that the T-PACQ is a strong two-factor structure that provides valid and reliable results about PAC for family caregivers of PwD. Using T-PACQ will demonstrate value for assessing caregivers' perceptions of the PAC and engage in appropriate interventions for caregivers as the number of people with dementia rises in Turkey and worldwide. Because of its practicality, simplicity, and short application time, it is expected to be a measurement tool preferred by health professionals.

Ethics

Ethics Committee Approval: The first author of the original questionnaire provided written permission for the psychometric testing of the T-PACQ. The Dokuz Eylül University Non-Invasive Research Ethics Committee approved the study (decision number: 2022/15-13, date: 20.04.2022).

Informed Consent: Informed consent was obtained.

Authorship Contributions

Concept: M.A.A., B.A.S., Ö.K., P.S., B.Ö.S., B.G., İ.S.E., D.Ö., Design: M.A.A., B.A.S., Ö.K., P.S., B.Ö.S., B.G., İ.S.E., D.Ö., Data Collection or Processing: M.A.A., P.S., B.Ö.S., B.G., İ.S.E., Analysis or Interpretation: M.A.A., B.A.S., Literature Search: M.A.A., B.A.S., Ö.K., P.S., B.Ö.S., B.G., İ.S.E., D.Ö., Writing: M.A.A., B.A.S., Ö.K.

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Supplementary Material 1. Turkish version of the positive aspects of caregiving questionnaire (T-PACQ)

Bakım Vermenin Olumlu Yönleri Ölçeği	Kesinlikle katılmıyorum	Katılmıyorum	Kararsızım	Kararsızım	Kesinlikle katılıyorum
1. Hastanıza bakım verdiğiniz için onunla aranızda daha fazla bağlılık oluştuğunu hissediyor musunuz?					
2. Geçmişe kıyasla hastanızla daha yakın olduğunuzu düşünüyor musunuz?					
3. Hastanıza bakım verdiğiniz için hayatınızın daha anlamlı hale geldiğini düşünüyor musunuz?					
4. Bakım vermenin hastanıza borcunuzu ödeme fırsatı verdiği için memnuniyet duymanızı sağladığını düşünüyor musunuz?					
5. Hastanıza bakım vermenin bir sonucu olarak, geçmişinize kıyasla daha iyi bir insan olduğunuza inanıyor musunuz?					
6. Hastanızın bakımında yaptığınız işbirliğinin aile üyelerini birbirlerine daha yakınlaştırdığına inanıyor musunuz?					
7. Hastanıza bakım verirken inancınızın size güç ve huzur kaynağı olduğunu düşünüyor musunuz?					
8. Hastanıza bakım verirken birçok yararlı şey öğrendiğinize inanıyor musunuz?					
9. Hastanıza bakım vermenin manevi mükâfatı olduğuna inanıyor musunuz?					
10. Verdiğiniz bakımın hastanız için yararlı olduğuna inanıyor musunuz?					