The Self-Perceived Burden Scale: A Validation Study in Turkish Patients with Spinal Cord Injury

Ümmühan AKTÜRK[1]*, Semra AKTÜRK[2], Behice ERCİ[3]

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ABSTRACT

Aim: The aim of this study was to analyze the psychometric properties of the scale by adapting "Self-Load Perception" into Turkish for patients with spinal cord injury.

Metarials and Methods: The research was carried out on 125 patients with spinal cord injury diagnosis between July 2016 and May 2017. Information form and self-load perception scale were used in the research. Research data were tested with Cronbach's alpha (α), single factor analysis, Bartlett and Kaiser-Meyer-Olkin analysis.

Results and Conclusion: In the present study, the KMO measure of the Self-perceived Burden Scale was determined to be 0.89 and the Bartlett's test of sphericity was found to be 2.919. The Cronbach α reliability coefficient of the SPBS was determined to be 0.96. As a result of these analyses, one factor had an Eigen value of 1 and higher, which explains 60.89% of the total variance found. It has been determined that the single-factor version of the SPBS is a valid and reliable scale for Turkey and can be used to evaluate the self-perceived burden levels of patients who have a spinal cord injury.

Keywords: Spinal cord injury, self-perceived burden scale, nursing, validity

Kendini Yük Algılama Ölçeği: Omurilik Yaralanması Olan Türk Hastalarda Bir Validasyon Çalışması

ÖZET

Amaç: Bu çalışmanın amacı Spinal Kord yaralanması olan hastalarda için "Kendini Yük Algılama Ölçeği"nin Türkçeye uyarlanması ve geçerlilik çalışmasının yapılmaı ile ölçeğin psikometrik özelliklerinin incelenmesi amaçlanmıştır.

Materyal ve Metod: Araştırma Temmuz 2016 - Mayıs 2017 tarihlerinde 125 omirilik yaralanması tanısı olan hasta üzerinde gerçekleştirildi. Araştırmada bilgi formu ve Kendini yük algılama ölçeği kullanıldı. Araştırma verileri Cronbach alfa güvenirlik katsayısı (α), tek faktörlü analiz, Bartlett testi ve Kaiser-Meyer-Olkin (KMO) analizleri kullanılmıştır.

Bulgular ve Sonuç: Bu çalışmada Kendini Yük Algılama Ölçeğinin KMO ölçüsü 0.89, Bartlett'in küresellik testi ise 2.919 olarak bulunmuştur. Kendinden algılanan yük ölçeğinin Cronbach α güvenirlik katsayısı 0.96 olarak belirlenmiştir. Bu analizler sonucunda bir faktörün öz değeri 1 ve üzerinde olup, bulunan toplam varyansın %60.89'unu açıklamaktadır. Kendini Yük Algılama Ölçeğinin tek faktörlü versiyonunun Türkçe geçerli bir ölçek olduğu ve omurilik yaralanması olan hastaların kendi kendine algıladıkları yük düzeylerini değerlendirmek için kullanılabileceği belirlenmiştir.

Anahtar Sözcükler: Omurilik yaralanması, kendi kendine algılanan yük, hemşirelik, geçerlilik

[1] PhD, Department of Public Health Nursing, School of Health, Inonu University, Malatya, Turkey/44280 ORCID: 0000-0003-2203-5223
[2] MD, Physical Therapy and Rehabilitation, Medical School, Inonu University, Malatya, Turkey/44280 ORCID: 0000-0001-9960-6851
[3] PhD, Department of Public Health Nursing, School of Health, Inonu University, Malatya, Turkey/44280 ORCID: 0000-0002-1527-2207
* **Corresponding Author/Sorumlu Yazar:** Ümmühan Aktürk, Assistant Professor, Department of Public Health Nursing, School of Health, Inonu University, Malatya, Turkey/44280, e-mail: ummuhan_akturk@hotmail.com Tel: +90-422-3261569 Fax: +90-422-324 00 51
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INTRODUCTION

Spinal cord injury is an event that causes permanent changes in life due to permanent paralysis and loss of physical function and sensation, as well as the loss of independence of individuals (Lee, Cripps, Fitzharris & Wing, 2014). Many factors such as traffic accidents, severe trauma, heavy work accident, falling from a height, sports injuries, daily life accidents, diving into deep waters, drowning, tumors, infections and bone diseases can cause spinal cord injury (Mayo Clinic, 2014). Spinal cord injury is an injury that negatively affects the patient's family, society and the country's economy, and has severe physical, mental and social consequences (Furlan & Bracken, 2010).

As life expectancy increases in patients with spinal cord injuries, health-related quality of life also increases (Celik, Gultekin, Beydogan & Caglar, 2007; Unalan et al., 2007). In addition, people with spinal cord injuries suffer serious problems due to physical disabilities in their daily living activities, such as health, education, and employment. This causes the patients to continue suffering from the disadvantage of their disabilities. Spinal cord injury has a sudden influence on the lives of affected individuals and many challenges arise, such as self-awareness, setting personal targets, self-fulfillment, autonomy, and coping with social and physical barriers to maintaining a positive life (Cheatham, 2012). Caring for patients with a spinal cord injury (SCI) presents both physical and emotional challenges for nurses. Nurses who choose to work with these patients must be experienced and passionate about the holistic care they provide, especially to these highly physically dependent individuals. As a result, the care provided is crucial as nurses help this person begin the rest of their life now with a different working body. The goal is to help that person and their family, while empowering them to play as productive, independent roles as possible within the limits of their disability. For this purpose, there are centers that provide courses, certificate programs and post-graduate training for nurses. Governments should encourage nurses to gain adequate experience in dealing with spinal cord patients (Khan, Phadke, Singh & Jain, 2017).

The rate of spinal cord disease, which is newly emerging in a year in the world and only due to trauma, can be estimated between 1500-3000 for our country (Worldometers, 2020). In cases of disability induced by a chronic illness such as spinal cord injury, patients inevitably rely on their caregivers to ensure their care, which in turn causes feelings of “being a burden to others” or “self-perceived burden” (Cousineau, McDowell, Steve & Hebert, 2003). Although there are studies on caregivers' burden of care, there are limited studies on patients receiving care seeing themselves as heavy. The dependence of caregivers on their caregivers, their needs and their experiences in this process were not considered important (Arechabala, Catoni, Barrios & Palma, 2012; Cousineau et al., 2003; Leroy, Fournier, Penel & Christophe, 2016; Libert et al., 2017; Ren et al., 2014).

Self-perception burden is an empathic anxiety state that results in distress, stress, guilt and self-loss that occurs in caregivers after the burden occurs due to the patient's care needs being met by others” (Cousineau et al., 2003).

The degree of SPB a patient with spinal cord injury feels may obstruct the interaction with the caregiver, can cause anxiety and depression, and can prevent compliance with treatment. Cousineau et al. (2003), who described SPB as a multi-directional concept, stated that the care recipient experiences frustration and anxiety as a result of feeling dependent on the caregiver. In addition, the feeling of SPB may affect the use of life-prolonging measures and may increase the possibility of committing suicide, namely by demanding euthanasia. We believe that the Self-perceived Burden Scale will provide a multidisciplinary assessment of the needs of patients with a spinal cord injury (Cousineau et al., 2003).

MATERIALS AND METHOD

Objective

This study was conducted to evaluate the adaptation, reliability, and validity of the Self-perceived Burden Scale in Turkish society.

Time and Place of the Study

The methodologically planned study was carried out in the outpatient physical therapy unit of İnönü University Turgut Özal Medical Center and Malatya State Hospital between July 2016 and May 2017.

Population and Sample of the Study

The data of the study were collected in the inpatient and outpatient physical therapy units of Physical Therapy and Rehabilitation Department of Turgut Özal Medical Center and Malatya Training and Research Hospitals. Sample selection has not been made in the research. Completed with 125 patients who were in the clinic and were willing to participate on the dates of the study. Preacher and MacCallum (2002) stated that the minimum sample size should be between 100 and 250. Other opinions give a rate depending on the number of items (Preacher & MacCallum, 2002). According to Tavşancil (2002), the sample size should be variable, i.e. at least five or even ten times the number of items. In this study, the sample size is approximately five times the number of items (Tavşancil, 2002).

Data Collection Tools

A questionnaire was used to obtain information about the demographic characteristics of the patients and spinal cord injury.

Self-perceived Burden Scale

The scale is a self-assessment tool developed by Cousineau et al. to determine a patient's level of SPB. The scale consists of 25 items and uses a 5-item Likert-type scale. In this Likert-type scale, responses vary from "none of the time" to "all of the time." Individuals were asked to think about the person who helped them with their daily routine tasks such as preparing food in the kitchen, shopping for groceries or drugs, and taking them to the hospital for control and to respond accordingly. The survey only covers patients who have unpaid caregivers such as family members, friends or children. Cousineau's (2003) study of SPB in dialysis patients found a Cronbach's α of 0.93, but it was 0.85 in

the brief version.

Language Equivalency and Content Validity

The first step in scale adaptation is translation of the scale. When translating a scale, it is necessary to use the most appropriate sentence structure and phrases in the target language and to change the items that are completely strange for the culture (Savaşir & Şahin, 1994). The most important point in language adaptation is the choice of translators and translation technique. A translator's knowledge and experience greatly affect the success of translation. In the selection of the translator, finding only those who have a good command of both languages is not enough. It is also suggested that the translators know the subject of the scale and have experience in both languages and cultures (Gözüm & Aksayan, 2002; Savaşir & Şahin, 1994). First, the Self-perceived Burden Scale was translated from English into Turkish by the researcher. The subsequent translations of the scale were completed by three people who speak both languages well, one of whom is a native English speaker. After selecting the most suitable expressions at the end of these translations, the back translation of the scale from Turkish to English was conducted by two people who are native Turkish speakers, know both languages, and did not see the English version of the scale before the back translation was compared with the original scale items. Although the back translation method time-consuming, it is the most commonly used method to ensure cultural uniformity of the scale (Gözüm & Aksayan, 2002). The final Turkish form resented to the experts working in the nursing and physiotherapy and rehabilitation departments to obtain their opinions on content validity. Both the original and the translated versions of the scale were given to the experts simultaneously and they were asked to evaluate the suitability of the items of the scale by giving a score between 0 and 5 (0 = completely inappropriate, 5 = completely appropriate). The scale was finalized and was applied to five patients with spinal cord injury in the Physical Therapy and Rehabilitation unit of Malatya Training and Research Hospital. Subsequently, further changes were made in line with the recommendations of the patients. Since there was no negative feedback, the researchers decided the scale could be applied to a sufficiently large sample for validity and reliability studies. The data of the preliminary application group were not included in the scope of the study.

Ethical Principles of the Study

Permission to adapt the scale into Turkish was obtained from the representative of Ian Mcdowell via e-mail (contact: Ian.Mcdowell@uottawa.ca). Ethical approval was obtained from the Malatya Clinical Trials Ethics Committee for the purpose of conducting the study. Before starting the study, written permissions were obtained from Turgut Özal Medical Center and the chief physicians of Malatya Training and Research Hospital. Verbal consents were obtained from the patients before filling out the data collection form. The patients were free to participate or leave at any time.

Data Collection

The data of the research were collected with Self-Perception Burden Scale and questionnaire

form. Filling out the data collection forms took approximately 10-15 minutes.

RESULTS

Table 1 shows the distribution of the descriptive characteristics of the patients included in the study. Of those included, 28.9% were aged 58-80 years, 70.4% were male, 47.2% were primary school graduates, 64% had a moderate level of income, 39.2% had 4-6 children, 74.4% of them expressed that they received care from their children and their spouses, 42.4% of the patients stated they had been diagnosed with a spinal cord injury for 7-12 months, 52.8% worked before the injury, 57.6% were injured due to falls and 64.8% stated that they did not have any information about the disease or treatment.

Table 1. Descriptive Characteristics of the Patients (N=125)

Descriptive Characteristics	N	%
Age		
18-27	13	17.1
28-37	8	10.5
38-47	19	25.0
48-57	14	18.4
58 and +	22	28.9
Gender		
Women	37	29.6
Men	88	70.4
Marital status		
Married	86	68.8
Single	39	31.2
Education level		
Illiterate	15	12.0
< Primary school		12.8
Primary school	16	47.2
High school	59	21.6
University	27	6.4
	8	
Income Status		
Good	6	4.8
Middle	80	64.0
Bad	39	31.2
Number of children		
0	30	24.0
1-3	35	28.0
4-6	49	39.2
7 and +	11	8.8
Provided Care		
Spouse and Children	93	74.4
Parents	32	25.6
Diagnosis Time		
3-6 month	18	14.4
7-12 month	53	42.4
1-3 year	26	20.8
4-6 year	13	10.4
7 and +	15	12.0

Work before injury		
Yes	66	52.8
No	59	47.2
Cause of injury		
Traffic accident	32	25.6
Fall	72	57.6
Work accident	15	12.0
Injury (weapon, knife)	6	4.8
Are you trained about your illness and treatment?		
Yes	44	35.2
No	81	64.8

Table 2 shows the total-item score correlation and factor analysis results, which indicates how much the items forming the scale are related to the overall scale.

Table 2. Results of the Kaiser-Meyer Olkin Measure of Sampling Adequacy and Bartlett's Test of Sphericity

Test		**Results**	
Kaiser-Meyer-Olkin		0.89	
Bartlett's Test	Approx. Chi-Square	2.919	p=0.000
	df	300	
	Sig.	0.000	

The rates of explaining the total variance for the items and factors as a result of principal component analysis conducted to determine the factorial structure of the Self-perceived Burden Scale and the matrix related to the factor burdens arose as a result of applying "varimax" transformation (Table 3). In the present study, total-item score correlation coefficients ranged from 0.518 to 0.833 (Table 3).

Table 3. Total-item score correlation coefficients, factor burdens, alpha coefficient, and explained variance of the self-perceived burden scale

SCALE	**Factor loadings**	**Item- Total Correlation**	**Cronbach's alpha without the item**
SPBS 1	0.761	0.740	0.965
SPBS 2	0.731	0.711	0.966
SPBS 3	0.672	0.643	0.966
SPBS 4	0.506	0.518	0.971
SPBS 5	0.709	0.674	0.965

Table 3. (continued)

SCALE	**Factor loadings**	**Item- Total Correlation**	**Cronbach's alpha without the item**
SPBS 6	0.547	0.527	0.966
SPBS 7	0.726	0.702	0.966
SPBS 8	0.839	0.803	0.964
SPBS 9	0.834	0.805	0.958

SPBS 10	0.862	0.833	0.957
SPBS 11	0.746	0.705	0.959
SPBS 12	0.767	0.730	0.959
SPBS 13	0.676	0.643	0.959
SPBS 14	0.782	0.754	0.958
SPBS 15	0.594	0.574	0.960
SPBS 16	0.647	0.628	0.959
SPBS 17	0.820	0.803	0.958
SPBS 18	0.821	0.797	0.958
SPBS 19	0.855	0.816	0.958
SPBS 20	0.783	0.752	0.958
SPBS 21	0.642	0.627	0.960
SPBS 22	0.801	0.780	0.958
SPBS 23	0.782	0.754	0.958
SPBS 24	0.823	0.797	0.958
SPBS 25	0.827	0.804	0.958
Variance = 60.89%	Cronbach's Alpha=0 .96		

DISCUSSION

In the literature where the 25-item version of the SPB scale was used, two-factor analysis was performed (Arechabala et al., 2012; Cousineau et al., 2003; Oekia, Mogami & Hagino, 2011). Although factor analyzes seem to distinguish different factors, it was seen that it did not fit the conceptual model very well and one general factor weighted dominant. (Cousineau et al., 2003).

Before the factor analysis, it is necessary to perform the KMO measure of sampling adequacy and Bartlett's test to evaluate whether or not the sample number is appropriate. In the literature, it is evaluated as excellent if the KMO value is between .90-1.00, very good between .80-.89, good between .70-.79, moderate between 0.60-0.69, weak between 0.50-0.59, and unacceptable below 0.50 (Akgül, 2003; Tavşancil, 2002). For a good factor analysis, the KMO value should be above .60 (Çimen, 2003). As with the KMO measure, Bartlett's test also measures the relationship power between the variables. In order to be statistically significant, the chi-square values of the Bartlett's test should be less than 0.05 (Şencan, 2005).

The KMO measure of the Self-perceived Burden Scale was determined to be 0.89 and the Bartlett's test result was found to be 2.919. These values showed that both test results were significant at a level of $p < 0.001$ and, thus, the sample data were sufficient to determine the factor.

In the present study, total-item score correlation coefficients ranged from 0.518 to 0.833 (Table 3). While there is no specific standard under which the reliability of the total-item test correlation coefficient is considered inadequate, some studies state that the reliability of items with coefficients below 0.50 is suspect and, according to some other studies, this coefficient should be higher than 0.30 (Esin, 2014). The higher the correlation coefficient, the higher the correlation of that item with the quality being measured. In the interpretation of the total-item correlation, items with a value of 0.30 and higher are accepted as sufficient. When the results of the study were examined, all

items showed correlations with sufficient total scores.

In order to determine the factor structure of the Self-perceived Burden Scale, principal component and varimax transformation analyses were used. In the calculation of the factors, Eigen values were used. Eigen values are the total variance explained by a factor. It is usually appropriate to interpret the number of factors with Eigen values of 1 or higher (Tavşancil, 2002). As a result of the analyses, one factor had an Eigen value of 1 and higher, which explains 60.89% of the total variance found. In the present study, determined that the items were well distributed and there was compatibility between the items and the factors. The higher the variance rates, the higher the factor structure, and the variance rates between 40-60% were considered adequate (Şencan, 2005). The obtained data showed that the internal consistency of the Self-perceived Burden Scale was preserved. In the literature, Cousineau et al. (2003) found first-factor variance to be 44.7% but three-factor variance was only 17.3%. Oekia et al. (2011) determined first-factor variance to be 63.3% and three-factor variance to be 67.3%. Arechabala et al. (2012) determined three-factor variance to be 46%.

In the present study, the mean±SD of the Self-perceived Burden Scale scores was 75.8±13.06 for patients with spinal cord injury (Table 4). In Cousineau et al.'s (2003) study on out-patients undergoing hemodialysis, the mean±SD of the Self-perceived Burden Scale scores was 24.7±18.7. In Arechabala et al.'s (2012) study on patients undergoing chronic hemodialysis, the mean±SD of the Self-perceived Burden Scale scores was 52.8 ±23.9. In Oekia et al.'s (2011) study on patients undergoing chronic hemodialysis, the mean±SD of the Self-perceived Burden Scale (the 18-item version) scores was 41.2 ±18.2.

The Cronbach's α coefficient, which indicates how scale items are correlated to each other and how homogeneous a question group is, is found by calculating the internal correlation of the items with each other (Burns & Grove, 2005; Erefe, 2002). In the literature, Cronbach's α coefficient varies between 0 and 1 and is evaluated as unreliable if it ranges from $0.00 \leq \alpha \leq 0.40$, as having low reliability if it ranges from $0.40 \leq \alpha \leq 0.60$, as being very reliable if it ranges from $0.60 \leq \alpha \leq 0.80$, and as being highly reliable if it ranges from $0.80 \leq \alpha \leq 1.00$ (Şencan, 2005). In the literature, Cousineau et al. (2003) found Cronbach's α coefficient to be 0.93, Arechabala et al. (2012) found Cronbach's α coefficient to be 0.91, Oekia et al. (2011) found Cronbach's α coefficient to be 0.96 (the 18-item version), and Barutçu & Mert (2017) found Cronbach's α coefficient to be 0.88 (the 10-item version). It can be asserted that the scale is quite reliable according to its Cronbach's α coefficients found both abroad and in Turkey.

CONCLUSION AND FUTURE RESEARCH

It was found that the Cronbach α reliability coefficient of the Self-perceived Burden Scale was 0.96. Analysis conducted to determine the factorial structure of the scale resulted in Eigen values higher than 1 and explained 60.89% of the total variance. It was determined that the obtained factors were completely compatible with the original structure.

It has been determined that the single-factor version of the Self-perceived Burden Scale is a valid and reliable scale for Turkey and can be used to evaluate the self-perceived burden levels of patients who have a spinal cord injury. Future research should investigate and evaluate the invariance of the information test of the Self-perceived Burden Scale by applying it to larger groups representing various socio-economic levels.

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