



ARAŞTIRMA / RESEARCH

Patient Health Engagement Scale (PHE-s): Validity and reliability for Turkish patients with chronic diseases

Hasta Katılımı Ölçeği: Kronik hastalığı olan hastalarda Türkçe geçerlik ve güvenilirlik çalışması

Dilara Usta¹, Fatoş Korkmaz¹, İmatullah Akyar², Andrea Bonanomi³

¹Hacettepe University, Faculty of Nursing, Department of Fundamentals of Nursing, ²Department of Internal Medicine Nursing, Ankara, Turkey

³Università Cattolica del Sacro Cuore, Department of Statistical Sciences, Milan, Italy

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Abstract

Purpose: Engaging patients in their health care management journey has emerged as the requirement of the patient-centered care. Considering as an evidence-based measure, The Patient Health Engagement Scale was developed to evaluate patients' emotional, behavioral, and cognitive competences during their care. This study aimed to assess the psychometric properties of PHE-s in Turkish patients with chronic diseases.

Materials and Methods: In this methodological study, one hundred and fourteen inpatients with chronic diseases were recruited in June 2018 in a university hospital. Content validity and reliability analysis were conducted. The original scale was translated into Turkish and back into English.

Results: The Ordinal alpha was found 0.80, which refers to a good internal consistency. The Rasch analysis demonstrated that the scale is unidimensional. The inter-item polychoric correlation coefficient was equal to 0.61 and every factor loadings in the Categorical Principal Component Analysis were higher than 0.74.

Conclusion: Taking into consideration, The Turkish version of the Patient Health Engagement Scale has good psychometric properties for evaluating the patient engagement phases and can be used by the Turkish-speaking community.

Keywords: chronic disease, nursing, patient engagement, psychometric properties

Öz

Amaç: Hastaları sağlık bakım yönetimine dahil etmek, hasta merkezli bakımın bir gerekliliği olarak ortaya çıkmıştır. Hasta Katılımı Ölçeği, hastaların bakımları süresince duygusal, davranışsal ve bilişsel yeterliliklerini değerlendirmek üzere geliştirilmiştir. Bu çalışmanın amacı, kronik hastalığı olan bireylerde, Hasta Katılımı Ölçeği'nin Türkçe formunun psikometrik özelliklerini belirlemektir.

Gereç ve Yöntem: Bu metodolojik çalışma, bir üniversite hastanesinde yatmakta olan ve kronik hastalığa sahip 114 hasta ile, 2018 yılı haziran ayı içinde yürütülmüştür. Kapsam geçerliliği ve güvenilirlik analizi sağlanmıştır. Orijinal ölçeğin Türkçe dil geçerliliği yapılmıştır.

Bulgular: Ordinal alfa değeri 0.80 olarak hesaplanmıştır, bu değer iç tutarlılığın yüksek olduğunu işaret etmektedir. Rasch analizi, ölçeğin tek boyutlu olduğunu göstermektedir. Maddeler arası polikorik korelasyon katsayısı 0.61'dir ve Kategorik Temel Bileşen Analizi'ne göre her faktör yükü 0.74'ten yüksektir.

Sonuç: Sonuç olarak, Hasta Katılımı Ölçeği'nin Türkçe uyarlamasının hasta katılımı fazlarını değerlendirmede yeterli psikometrik özelliklere sahip olduğu söylenebilir.

Anahtar kelimeler: kronik hastalık, hemşirelik, hasta katılımı, psikometrik özellikler

INTRODUCTION

Engaging patients in chronic care is recognized as a vital element of high-quality healthcare services,

specifically when chronic disease management is taken into account^{1,2}. Since the nature of the chronic diseases requires change in life styles and needs an

Yazışma Adresi/Address for Correspondence: Dr. Dilara Usta, Hacettepe University, Faculty of Nursing, Department of Fundamentals of Nursing, Ankara, Turkey E-mail: dilarausta6@gmail.com

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organized, proactive multicomponent, patient-centered approach, patients must be included as main actors of care process. Patient engagement is described as a patient-centered care model, in which healthcare professionals engage patients as peers to make decisions about their care, based on clinical evidence and patients' care expectations³.

Patients' emotional, cognitive, and conative dynamics affect their attitudes and meaning-making skills during care^{3,4}. This process is featured in four sequential phases: blackout, arousal, adhesion, and eudaimonic project^{4,5}. *Blackout* phase, starting with a diagnose, patients describe their situation as unexpected and out of their control⁶ which causes emotional confusion^{3, 5}. Within the following phase, *arousal*, patients are highly aware of their every clinical symptoms which are perceived as an "alarm bell" leading permanent anxiety and negative feelings⁴. When patients have enough knowledge about their disease and behavioral skills to adhere medical treatment, the *adhesion* phase emerges³. When patients completely adjust their condition and have a better psychological position is regarded as *eudaimonic project* phase⁵.

Understanding patients' position in the engagement process provides clinicians and healthcare services to better adapt to enhance patients' role in their chronic care management⁴. Identifying the engagement phase allows clinicians to determine the approach to the patient. i.e. [1] stimulating patients in managing their care and playing an active role in treatment process, [2] providing the reliable information and support to strengthen their health literacy, [3] empowering patient's autonomy in decision making, [4] enabling the involvement of family in the caring process, and [5] reinforcing the team work among healthcare providers⁷⁻⁹. In blackout phase, clinicians are perceived as an information source and expected to act as supportive figures. In the arousal phase, patients generally express their need for clinician support and anticipate psychological help. Patients in the adhesion phase need to be supported both at the emotional and practical level. Finally in the eudaimonic project phase, the clinician is required to assist patients in chronic disease management strategies and help patients in making life plans³.

Patient engagement in chronic disease management is positively related to life satisfaction^{10,11}, higher quality of life¹², better clinical outcomes¹³, better patient self-management¹⁴, perceiving a higher quality of life and enhanced health status¹⁵⁻¹⁷, effective

medication adherence and improved medication safety^{14,17-20}, and reduction in healthcare costs^{21, 22}.

Since the effective improvements in adapting methods of patient engagement are needed, it is critical to assess the phase of patient engagement with a validated tool to meet patients' needs and expectations more efficiently²³. The PHE-s is first developed and validated by Graffigna et al.⁴ to evaluate the psychosocial experience in patients with chronic disease. Additionally, the adaptations of the PHE-s in Chinese²⁴ and Spanish²⁵ languages are completed. In Turkey, there is no study to evaluate the patient engagement process. Therefore, in this study, it is aimed to conduct the Turkish validity and reliability study of the PHE-s in patients with chronic diseases.

MATERIALS AND METHODS

This methodological research was conducted to analyze the validity and reliability of the PHE-s in Turkish. It was conducted at the clinics of general internal medicine in a university hospital in June 2018. Patients with chronic diseases were recruited from among inpatients of general internal medicine department based on the following inclusion criteria: Patients [a] older than 18 years old, [b] literate, [c] diagnosed with chronic diseases, [d] following a medical treatment for the chronic disease/s and [e] not having a major psychiatric disease.

Written permissions were obtained from the authors who conducted the original scale development study. Our research was found acceptable by a university's ethics committee (GO 17/827) in Ankara, Turkey. The written permission of the institution has been taken from the relevant departments to conduct the research. Each patient received information about the study with an informed consent and was asked to give written permission. In addition, participants were notified about their right to withdraw and anonymity.

The sample size was estimated by multiplying the total number of items by ten. The 5-10 participants for per variable is commonly accepted in the literature^{26, 27}, yet Jöreskog and Sörbom²⁸ suggested that having 10 participants per parameter is sufficient. Therefore, for the PHE scale with 5 items, there should be at least 50 survey participants. The study was completed with 114 inpatients.

Patients were included in the study with simple

random sampling method. First, each participant was visited in patient room, given information about the study and were invited to the research. Then, the forms were distributed them and the structure of the PHE-s was clarified. It took about 10-12 minutes for each patient to fill in the forms.

Instruments

In data collection phase, the Sociodemographic Form prepared based on the literature by the authors and the PHE-s was used^{4, 24, 25}.

The Sociodemographic Form

In this form, there are a total of seven questions about the age, gender, marital status, education status, working status, type of chronic disease and when the patient was diagnosed.

Patient Health Engagement Scale

The scale was first developed and validated by Graffigna et al.⁴ in Italy in 2015. The PHE-s was developed based on a 4-stage model of patient

engagement which reflects a dynamic and complex process (blackout, arousal, adhesion and eudaimonic project)⁴. The PHE-s has an ordinal structure, consisted of five items with seven responses that potentially indicates the stages of engagement experience lived by the patients (See Table 1). Patients were asked to respond by positioning themselves between one and seven points in relation to their experience. The PHE-s allows patients to assess their engagement stage in intermediate positions (e.g. between arousal and adhesion). Thus, intermediate positions are referred to the former engagement phase, for example, a score of four points out the patient locates him/herself in the second phase of engagement meanwhile a point seven means a position in the fourth phase⁴. Figure 1 demonstrates the instruction form to be presented to the patients before filling in the scale. In course of calculating the final PHE-s score, the median value is regarded more substantial and reliable accordingly the scale's ordinal nature²⁹. Procedure of calculating the PHE-s level is given in figure 2.

Table 1. Items of the PHE-s: Turkish version

Items						
Hastalığım hakkında düşündüğümde						
1	Tamamen karanlıkta kalmış gibi hissedirim.	Telaşlanıyorum.	Durumumun farkındayım.			Olumlu hissediyorum.
2	Şaşkın hissediyorum.	Zor durumdayım.	Hastalığımın bilincindeyim.			Rahat/sakin hissediyorum.
3	Duyularla bunalmış hissediyorum.	Her yeni belirti ortaya çıktığında kaygılanıyorum.	Hastalığıma alıştım.			Hastalığıma rağmen hayatımı uyum ve devamlılık içinde hissediyorum.
4	Hastalığım yüzünden çok bezginim.	Hastalıkla baş etmeye çalıştığım zaman endişe hissediyorum.	Hastalığıma uyum sağladığımı hissediyorum.			Sağlık durumum ve geleceğimden genel olarak umutluyum.
5	Hastalığım nedeniyle büyük bir baskı altında hissediyorum.	Yeni bir belirti ortaya çıktığında üzülüyorum.	Hastalığıma kabullendiğimi düşünüyorum			Hastalığıma rağmen hayata anlam verebiliyorum.

Figure 1. Instruction form of introducing the PHE-s to the patients (Graffigna et al. 2015b)⁴⁰

Aşağıda sizin hastalığınıza uyumunuzu ve bakımınıza katılma durumunuzu belirlemek üzere hazırlanmış olan Hasta Katılımı Ölçeği' nin maddeleri yer almaktadır. Ölçek toplamda 5 satırdan oluşmaktadır. Her bir satırda 4 adet ifade ve 7 adet işaret seçeneği bulunmaktadır. Her bir satırda size uygun bulduğunuz "bir" seçeneği işaretleyiniz. Eğer yan yana bulunan iki ifadenin arasında kalmışsanız, ikisinin arasındaki seçeneği işaretleyiniz.

Soruları yanıtlamanıza yardımcı olacak bir örnek

Örnek 1

Hastalığım hakkında düşündüğümde...

Duyularla bunalmış hissediyorum.	Her yeni belirti ortaya çıktığında kaygılanıyorum.	Hastalığıma alıştım.	Hastalığıma rağmen hayatımı uyum ve devamlılık içinde hissediyorum.
<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Eğer hastalığınızın size hissettirdiği duygulardan bunalmış hissediyorsanız, ilk seçeneği işaretleyiniz.

Örnek 2

Hastalığım hakkında düşündüğümde...

Duyularla bunalmış hissediyorum.	Her yeni belirti ortaya çıktığında kaygılanıyorum.	Hastalığıma alıştım.	Hastalığıma rağmen hayatımı uyum ve devamlılık içinde hissediyorum.
<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>

Eğer hastalığınızın size hissettirdiği duygulardan bunalmış hissediyor ve aynı zamanda ortaya çıkan her yeni belirtiden dolayı kaygı duymaya başladığınız, ikinci seçeneği işaretleyiniz.

Translation process

The method of the translation process^{30, 31} followed these steps: [a] The PHE-s was first translated from English into Turkish by three academicians with competent English language skills from the faculty of nursing who are working in the relevant field. [b] The obtained translations were combined and turned into a single instrument by an assistant professor. [c] The

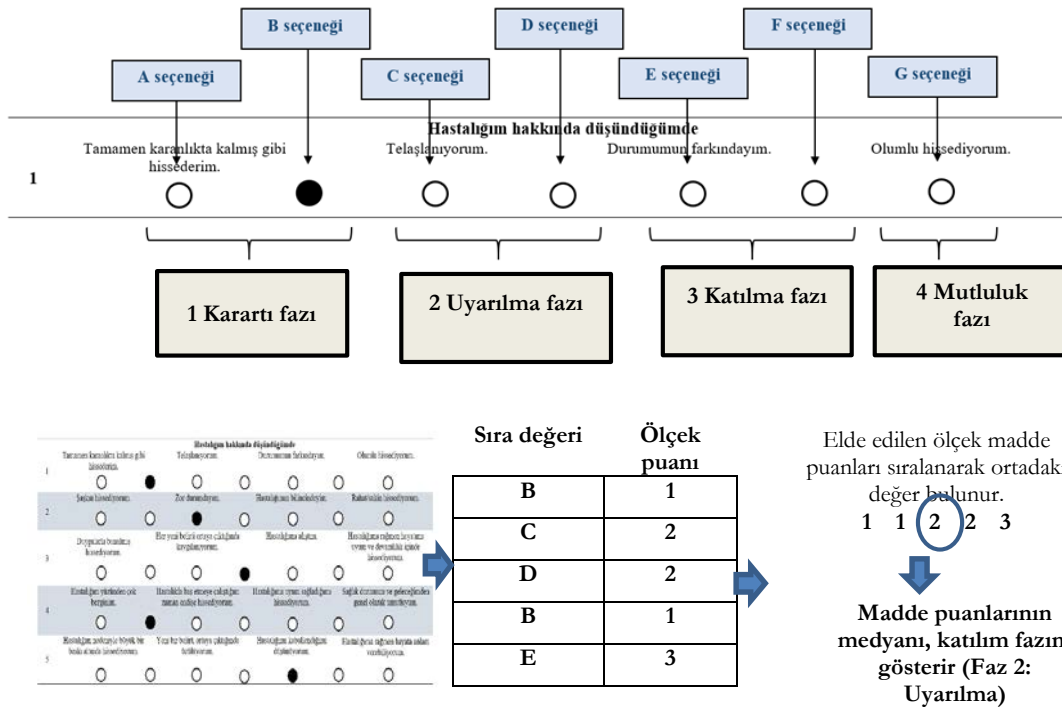
congruity of the combined scale to Turkish was assessed by the Turkish Language and Literature specialist and arranged according to the recommendations. [d] Then the PHE-s, finalized in Turkish, was retranslated into English by three academicians who were experts in the area and proficient in English. [e] The final translation and the original format was compared by the author who developed the scale and was found compatible.

Content validity

The constituted Turkish version of the scale and the evaluation form³² were submitted to 8 experts, including specialists of nursing services

administration, obstetrics and gynecology, internal medicine, public health, and psychiatric nursing. These experts confirmed the first Turkish version of the PHE-s to assess its content validity with Turkish language.

Figure 2. Procedure to calculate the PHE-s level (Graffigna and Barello, 2016)



Assessing reliability and data analysis

The data were examined with IBM SPSS 24.0, and R 3.2.4 software packages. The content validity was estimated using the content validity index (CVI), Scale-level Index Average (S-CVI/Ave), and the item-level (I-CVI)³³.

The psychometric properties of an ordinal scale

As the process of testing the psychometric properties

of an ordinal scale, The Categorical Principal Component Analysis – one factor solution (CATPCA) was performed in exploratory analysis. Infit-Outfit mean square standardized (MNSQ), logits, Chi-Square, and p-value were estimated. In addition, the Rasch Model (RM) was carried out to additional investigation if the PHE-s was unidimensional. If the data suited the RM, the MNSQ values should be between 0.6-1.4 and all of the thresholds should be below the limit of 4.0 logit³⁴. Moreover, the Person Separation Index (PSI) was used to evaluate the reliability of the RM. Finally, the

internal consistency was calculated with Ordinal Alpha via Empirical Copula Index. The item-item polychoric correlation was shown which is considered as a subtype of internal consistency reliability^{35, 36}. A reliability index which is more than 0.7, 0.8, or 0.9 can be defined as “acceptable, good, or excellent”, respectively³⁷.

RESULTS

Participants (n=114) in the study were 50.9% male, aged between 18 and 82 (M=55.9, SD=14.5) (27.2% of the patients are older than 65), and 71.9% of them were married. Most of the patients (38.6%) were graduated from elementary school, and 43% were unemployed. The patients’ average hospitalization period for current stay was 9.7 ± 12.2 days and the average duration from the first diagnosis was 8.2 ± 9.0 years. Chronic diseases of the patients can be seen in Table 2.

As content validity analysis, the CVI was performed. It was found that the I-CVI values varied 0.87-1.00, and the S-CVI/Ave was 0.98 in the PHE-s. In Table 3 these are reported, for each item, descriptive statistics (minimum, maximum, and range, median as tendency central index and Shannon Entropy as dispersion index, due by the ordinal nature of the data).

Exploratory analysis

The exploratory analysis conducted by a CATPCA suggested only one factor (eigenvalue equal to 3.2),

Table 2. Chronic diseases of patients

Chronic disease*	n (%)
Diabetes mellitus	38 (33.3)
Hypertension	33 (28.9)
Cancer**	25 (21.9)
Cardiovascular disorder	21 (18.4)
Chronic renal failure	15 (13.2)
Rheumatologic disorders	11 (9.7)
Chronic obstructive pulmonary disease	9 (7.9)
Anemia	5 (4.4)
Cushing syndrome, Hypothyroidism, Goiter	5 (4.4)
Asthma, Chronic bronchitis	4 (3.5)
Chronic liver failure, Celiac disease, Chronic pancreatitis, Cystic fibrosis	4 (3.5)
Systemic lupus erythematosus	4 (3.5)
Hyperlipidemia	3 (2.6)
Osteoporosis	1 (0.9)

*Multiple data; **Patients with leukemia, lymphoma, multiple myeloma, lung, breast, and thymus cancers

explaining 62.8% of the total variability. The factor loadings had a value superior to 0.70. The unidimensionality of the scale is confirmed (Table 4).

Internal consistency

The internal consistency was measured by the average inter-item polychoric correlation index, obtained by the average of all polychoric correlation coefficients. The polychoric correlation coefficient is a correlation measure, suitable for ordinal data. Every polychoric correlation coefficient was higher than 0.5. The average inter-item polychoric correlation is equal to 0.61, which indicates a high correlation between items (Table 5).

The internal consistency is also measured by the Ordinal Alpha via Empirical Copula, equal to 0.80. So PHE scale showed a good internal consistency. In Table 6, the Ordinal Alpha was evaluated after deleting individual items. Since deleting every item the value of Ordinal alpha decreases, then each item contributed significantly to the PHE scale score. Overall, the study of the internal consistency of the PHE-s was satisfactory.

RASCH analysis

The item analysis was conducted by Infit and Outfit statistics. Their value ranged from 0.721 – 0.881, all within the acceptable range. The reliability in the Rasch Model was evaluated by the Person Separation Index (PSI = 0.848) (Table 7).

Table 3. Item-level descriptive statistics for ranks on the PHE.

PHE Item	Rank Range	Minimum	Maximum	Median	Shannon Entropy
Item 1	1-4	1	4	3	0.82
Item 2	1-4	1	4	3	0.81
Item 3	1-4	1	4	3	0.89
Item 4	1-4	1	4	3	0.76
Item 5	1-4	1	4	3	0.77

Table 4. Factor loadings from Categorical Principal Component Analysis (CATPCA) – One factor solution

PHE Item	One factor solution
Item 1	0.748
Item 2	0.804
Item 3	0.831
Item 4	0.785
Item 5	0.793

Table 5. Item-item polychoric correlation matrix for ranks on the PHE

PHE Item	Item 1	Item 2	Item 3	Item 4	Item 5
Item 1	-	0.61	0.61	0.58	0.52
Item 2		-	0.67	0.56	0.57
Item 3			-	0.57	0.63
Item 4				-	0.70
Item 5					-

Table 6. Ordinal alpha via empirical copula if item deleted

Item	Ordinal Alpha if item deleted
Item 1	0.77
Item 2	0.75
Item 3	0.74
Item 4	0.76
Item 5	0.76

Table 7. PHE Scale – Rasch Analysis

PHE Item	Measure (logits)	Infit MNSQ	Outfit MNSQ	Chi-Square (df)	p-value
Item 1	0.75	0.881	0.831	90.54 (108)	0.89
Item 2	0.20	0.813	0.756	82.40 (108)	0.97
Item 3	0.63	0.721	0.741	80.81 (108)	0.98
Item 4	-0.78	0.834	0.822	89.58 (108)	0.90
Item 5	-0.73	0.844	0.804	87.64 (108)	0.93

DISCUSSION

In this research, we conducted the validity-reliability study of the PHE-s into Turkish and examined the psychometric properties in patients with chronic diseases. For the content validity of the PHE-s, the CVI was used which was obtained from the expert evaluations. It is stated that the content validity indexes of the items should be above 0.80 in order to

be sufficient³⁸. In this study, the I-CVI values ranged between 0.87-1.00 and the S-CVI/Ave was 0.98, which presented a very high validity. The exploratory analysis (CATPCA) confirmed that all factors had a very high value (ranging from 0.74 to 0.83), that means the CATPCA suggests the PHE-s fit in with a single-factor and unidimensional construct. The CATPCA was performed through the ordinal nature of the items of the PHE-s⁴.

The average inter-item polychoric correlation (0.61) showed a high correlation between items as in the original version of the PHE-s (0.68). In this study, the Ordinal Alpha via Empirical Copula was calculated, since this version prevents the assumption by the researcher about the dependency type for hidden variables underlying the ordinal indicators⁴. The data obtained from the PHE-s indicated a good internal consistency for patients with chronic diseases by Ordinal Alpha ($\alpha=0.80$). In the Italian, Chinese, and Spanish versions, the Ordinal Alpha values were found 0.85, 0.89, and 0.85, respectively^{4, 24, 25}.

The Rasch analysis was performed to investigate if the PHE-s was unidimensional and the items fit the model sufficiently⁴. The analysis demonstrated a good series of infit values (ranged 0.721 – 0.881) for each items of the PHE-s, which was acceptable. If the data fitted the Rasch model, the statistics could be between 0.6 and 1.4³⁴. In the original version of the scale, the Rasch analysis varied 0.62 to 1.14⁴.

In conclusion, our study showed the evidence that the PHE-s in Turkish population has a satisfactory psychometric properties in patients with chronic diseases. Thanks to its ordinal and short structure, it can be easily implemented into the health care which allows the professionals to sustain patient-centered care experiences. It is known that engaging patients in their healthcare experience has a positive impact on their adherence in treatment and health care management³⁹. For that reason, it is recommended that implementing the PHE-s in health care settings to better understand the engagement levels of patients with chronic diseases.

Yazar Katkıları: Çalışma konsepti/Tasarımı: DU, FK, İA; Veri toplama: DU; Veri analizi ve yorumlama: DU, FK, İA, AB; Yazı taslağı: DU, FK, İA, AB; İçeriğin eleştirel incelenmesi: DU, FK, İA, AB; Son onay ve sorumluluk: DU, FK, İA, AB; Teknik ve malzeme desteği: DU; Süpervizyon: DU, İA, FK; Fon sağlama (mevcut ise): yok.

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