

Validation of the Revised Illness Perception Questionnaire in Turkish epilepsy patients and the effects of earthquake experience on perception of disease

Selda Keskin Güler¹
Sertac Güler²
Bircu Gökçe Çokal¹
Nalan Gunes¹
Mehmet İlker Yon¹
Tahir Kurtulus Yoldas¹

¹Department of Neurology,

²Department of Emergency Medicine,
Ankara Training and Research
Hospital, Ankara, Turkey

Objective: The aims of this study were to investigate the reliability of the Revised Illness Perception Questionnaire (IPQ-R) in Turkish patients with epilepsy (PWE) and to determine the effects of earthquake experience on the perception of disease in patients.

Materials and methods: The sample was composed of 48 PWE, who were affected by the 2011 earthquake (n=21) or who had never had any earthquake experience (n=27). The interview form, IPQ-R, and Beck Depression Scale (BDS) were applied.

Results: The study was carried out on PWE whose mean age was 20.9 years (± 8.1 years) and who had been diagnosed within the last 10 years (± 6.9 years). IPQ-R consisted of three parts: illness identity, attributions concerning the disease, and probable causes. In the part of illness identity, the most frequently met manifestations were fatigue (76.6%) and headache (72.9%). Regarding attributions concerning the disease and probable causes, the test was determined to be reliable (reliability coefficient 0.715–0.814). In terms of personal control, timeline (acute/chronic), emotional representations, illness coherence, consequences, treatment control, and timeline subscales, which were investigated at the dimension about attributions concerning the disease, and psychological causal attributions, risk factors, and immunity subscales, which were investigated at the dimension about probable causes, no significant differences were found between groups ($P > 0.05$). No difference was determined in terms of BDS scores ($z = -0.895$, $P > 0.05$).

Conclusion: The results of this study demonstrated that IPQ-R could be used reliably in the Turkish PWE. A severe life event such as an earthquake did not change IPQ-R scores in PWE.

Keywords: epilepsy, Revised Illness Perception Questionnaire, earthquake

Introduction

Epilepsy is a chronic paroxysmal disease frequently encountered in neurology practice and necessitates adaptation to the disease and its side effects. The indicator of the disease progression is the frequency and severity of seizures. Genetic, environmental, and living conditions, together with emotional status, influence the disease severity and attack frequency. The thought of having a chronic disease, difficulties experienced during treatment, and physical and psychosocial problems disturb the emotional status.

Illness perception is the reflection of individuals' beliefs and expectations related to a disease or manifestations.¹ This concept is based on Leventhal's self-regulatory model.² According to this model, individuals create schemes related to diseases and other life-threatening conditions in their minds within the frame of information they were presented from concrete and abstract sources. These cognitive models, created

Correspondence: Selda Keskin Güler
Department of Neurology, Ankara
Training and Research Hospital, Şükriye
District, Ulucanlar Avenue, No 89, Postal
Code: 06340, Ankara, Altındağ, Turkey
Tel +90 312 596 3000
Fax +90 312 363 3396
Email keskinselda@gmail.com

by the patients, also involve beliefs related to treatment and attitude control.

This cognitive model, consisting of beliefs, interpretations, and emotional and behavioral responses manifested differently in each individual, is the factor that determines the individual's understanding of the disease, the style of coping with the disease, the development of psychiatric disorder, and the quality of life.

Illness Perception Questionnaire (IPQ) was first developed by Weinman et al³ in 1996 and has been revised by Moss-Morris et al⁴ in 2002 (IPQ-R). The development of Turkish version of the scale, together with its validity–reliability study, was performed by Kocaman et al⁵ in 2007. In another study conducted in 2007, the validity–reliability of the scale was evaluated in Turkish cancer patients.⁶

The aims of this study were primarily to evaluate the IPQ in Turkish epilepsy patients, a new patient group, and secondarily to investigate evidence of an effect of earthquake as a serious life event on illness perceptions. Beck Depression Scale (BDS) was used to assess depression.

Materials and methods

Selection of cases

On 23 October 2011, a destructive earthquake of 7.2 magnitude, the epicenter of which was Van Erciș, occurred in the eastern part of Turkey. The earthquake caused significant mortality and morbidity with a large number of homeless and jobless people. According to the official records, 644 people

died and 252 people survived from the wreckage.⁷ This earthquake brought many economic, social, and emotional problems in its wake.

Patients who were admitted consecutively to Van Erciș State Hospital Neurology Outpatient Clinic between February and May 2012 and diagnosed with epilepsy were included in the study as the group that had experienced the earthquake (Group 1). Patients who were living in the province of Mardin, admitted consecutively to the Mardin State Hospital Neurology Outpatient Clinic between May and December 2012, and diagnosed with epilepsy were included in the study as the group that had no earthquake experience (Group 2). This study was approved by the Ankara Training and Research Hospital Institutional Review Board. The participants were selected among volunteers; their written informed consents were obtained. The diagnosis of epilepsy was made by a neurologist, according to the International League Against Epilepsy (ILAE).⁸

Patients who had the diagnosis of epilepsy for at least 1 year, were older than 16 years, who knew the Turkish language, and were educated for at least 5 years were included in the study. Patients who were not present in Erciș during the earthquake, who had an additional psychiatric or chronic disorder, and who encountered seizure in the last week prior to the study were not included in the study.

The study was conducted with the participation of 48 epilepsy patients (15 females [31.3%] and 33 males [68.8%]), with the mean age of 29.5 years (Table 1). The number of

Table 1 Demographic and clinical characteristics of the study population

Characteristics	Whole sample (n=48)	Group 1 (n=21) ^a	Group 2 (n=27) ^b	P-value ^c
Age (in years), mean or median (IR)	29.5 (24–33.8)	31 (22–33.5)	27 (25–35)	0.692
Gender (female/male)	15/33	6/15	9/18	0.487
Marital status (n)				0.446
Single	21	10	11	
Married	27	11	16	
Years of education				0.991
5	15	6	9	
5–8	8	4	4	
8–12	15	6	9	
>12	10	5	5	
Job				0.199
Housewife, n (%)	4 (8.3)	1	3	
Officer, n (%)	8 (16.7)	5	3	
Laborer, n (%)	16 (33.4)	8	8	
Student, n (%)	8 (16.7)	4	4	
Unemployed, n (%)	12 (25.0)	4	8	
Seizure frequency (seizure/year), median (IR)	0 (0–6)	0 (0–5)	1 (0–12)	0.411
Duration of epilepsy (years), median (IR)	7.5 (5–15)	7 (5–15)	8 (5–15)	0.264

Notes: ^aGroup 1 consisted of participants who were living in Erciș and experienced earthquake. ^bGroup 2 consisted of participants who were living in Mardin and did not experience earthquake. ^cIndependent sample t-test for normally distributed variables and Mann–Whitney U test for non-normally distributed variables were performed; statistical tests were performed between Group 1 and Group 2.

Abbreviation: IR, interquartile range.

epilepsy patients with earthquake experience (Group 1) was 21, and the number of epilepsy patients having no earthquake experience (Group 2) was 27 (Table 1).

In all selected patients, by detailed clinical examination, the presence of any associated disorder was excluded. The demographic data, seizure frequency, and duration of the disease were recorded on standard study forms. It was determined that 56.3% of the participants were married, 31.3% were educated for at least 5 years, and 25% were unemployed (Table 1). In epilepsy patients with earthquake experience, the duration of the disease median (range) values were 7 (5–15) years, and seizure frequency median (range) values were 0 (0–5) seizure per year. In epilepsy patients having no earthquake experience, the duration of epilepsy median (range) were 8 (5–15) years and the seizure frequency median (range) values were as 1 (0–12) seizure per year (Table 1).

Collection of data and measurements

The interview form, IPQ, and BDS were applied to the participants.

Interview form

The demographic data, seizure frequency, and the drugs that the participants had been using were similar.

Illness Perception Questionnaire

The scale consists of three dimensions, being illness identity, attributions concerning the disease, and probable causes. The dimension of illness identity questions 14 frequently met disease manifestations, such as pain, nausea, and weight loss. For each one of these, the individual is first asked, “whether it was encountered since the beginning of the disease” and then “whether this manifestation is related to the disease”. This subscale is organized in such a format that both questions can be replied as yes/no. The sum of “yes”-rated replies to the second question forms the evaluation result in terms of illness identity subscale. The dimension of attributions concerning the disease consists of 38 items, and it is a five-level Likert-type scale (ranging from “I strongly agree” to “I strongly disagree”). This dimension involves seven subscales. These are named timeline (acute/chronic), consequences, personal control, treatment control, illness coherence, timeline (cyclical), and emotional representations. The timeline subscale investigates the perceptions of the individual related to the duration of the disease and is grouped as acute, chronic, and cyclical. The consequences subscale investigates the beliefs of the individual about the disease severity and its probable effects on the individual’s physical, social, and psychological

functionality. Personal control investigates the individual’s internal control perception about the duration, progression, and treatment of the disease. Treatment control investigates the beliefs of the patient about the effectiveness of administered treatment. Illness coherence investigates to what extent the individual understands or apprehends the illness. The subscale of emotional representations investigates the individual’s feelings related to the disease. The dimension of illness causes consists of 18 items involving probable causes related to the formation of illnesses. Five-level, Likert-type measurement is used. This dimension investigates the thoughts of the individual about the probable causes of his or her illness and involves four subscales. They are psychological attributions, risk factors, immunity, and accident/chance. For qualitative evaluation, the individual is also required to write down three factors that are considered as the most important causes of the illness, at the end of the scale.

BDS

BDS developed by Beck et al,⁹ Turkish validity and reliability of which was performed by Hisli,¹⁰ was applied.

Statistical analyses

Analyses were conducted by the SPSS package program (version 11.5; SPSS Inc., Chicago, IL, USA). Data were analyzed using frequency distributions for categorical variables and descriptive statistics for the continuous variables, and the results were given as “mean \pm SD”.

The reliability of IPQ-R’s subscales was investigated by calculating Cronbach’s α scores. If the subscales were reliable, the analysis was started. Kolmogorov–Smirnov normality test was used for continuous variables. According to the test results, independent sample *t*-test was chosen for normally distributed variables ($P > 0.05$) and Mann–Whitney *U* test was chosen for non-normally distributed variables ($P < 0.05$) for statistical analysis. Intercorrelations between the subscales of IPQ-R were examined using Spearman’s correlation test.

Results

No statistically significant differences were found between the two groups in terms of age, seizure frequency, and duration of illness ($P > 0.05$; Table 1).

In questioning regarding the dimension of the illness type, the most commonly encountered symptoms were found as fatigue (76.6%) and headache (72.9%) in epilepsy patients (Table 2).

As the result of reliability analysis, performed for dimension about attributions concerning the disease, this dimension

Table 2 The distribution of disease manifestations and their association with the disease

Manifestations	Encountered this manifestation since the beginning of my disease		This manifestation is related to my disease	
	n	%	n	%
Fatigue	36	76.6	27	56.3
Headache	35	72.9	31	64.6
Pain	29	60.4	21	43.8
Dizziness	28	58.3	22	45.8
Loss of strength	27	56.3	21	43.8
Sleep disorders	25	53.2	19	39.6
Burning sensation in the eyes	20	41.7	11	22.9
Stomach complaints	17	35.4	10	20.8
Nausea	17	35.4	9	18.8
Joint stiffness	16	33.3	11	22.9
Difficulty in breathing	15	31.3	8	16.7
Weight loss	13	27.1	7	14.6
Snuffling	12	25.0	8	16.7
Sore throat	11	22.9	2	4.2

was found as consisting of seven factors, the reliability coefficient ranging between 0.779 and 0.874. Regarding the probable causes, the reliability coefficient, consisting of three factors, was determined to range between 0.715 and 0.774 (Table 3).

In the dimension of attributions concerning illness, no significant differences were found between the groups in terms of personal control, timeline (acute/chronic), emotional representations, illness coherence, consequences, treatment control, and timeline (cyclical) subscales (Table 4).

In the dimension of probable causes, no significant differences were found between the two groups in terms of psychological attributes, risk factors, and immunity subscales (Table 4).

Regarding the BDS score, the levels of Group 1 and Group 2 were 16, and no significant difference was found between the groups ($z=-0.895$, $P>0.05$).

When the relationships between the subscales of IPQ were analyzed, it was determined that, as illness coherence increased or negative perception related to illness consequences decreased, the negative beliefs of individuals related to the duration of illness decreased. It was determined that as positive thoughts regarding treatment control increased, the positive control thoughts of individuals regarding their illnesses also increased. Positive relationships were determined between timeline (cyclical) and emotional representations and between timeline (cyclical) and consequences. There was a negative relationship between psychological attributions and illness coherence.

Discussion

The results of our study indicated that IPQ-R could be used as a valid and reliable measurement tool for the evaluation of illness perception in the patient group having the diagnosis of epilepsy. The internal reliabilities of all subscales were high. Cronbach's α values ranged between 0.715 and 0.814. The determination of almost the same mean values of subscales in the group with earthquake experience and the group with no earthquake experience supported the accuracy of the study in terms of both validity and reliability. Although the difficulties related to cultural differences were envisioned prior to the study, it was also observed to be quite suitable for Turkish culture. As the IPQ has not been tested in epilepsy patients in Turkey, this article has potential to contribute to the evidence base.

IPQ has been adapted to many countries and has been in use for many chronic disorders.¹¹⁻¹⁶ In the literature, it has been found that IPQ was used in epilepsy patients in a limited number of studies.¹⁷ To the best of our knowledge, in our country, this was the first study in which IPQ-R was used in epilepsy patients. The results of this study demonstrated that IPQ-R could be used reliably in the Turkish epilepsy patients.

Table 3 The results of the reliability analysis of illness perception scale subscales

Subscale	Number of items	n	Cronbach's α	Level of reliability
Attributions concerning the disease				
Personal control	6	48	0.785	Quite reliable
Timeline (acute/chronic)	6	48	0.779	Quite reliable
Emotional representations	6	48	0.783	Quite reliable
Illness coherence	5	48	0.781	Highly reliable
Consequences	6	48	0.782	Quite reliable
Treatment control	5	48	0.782	Quite reliable
Timeline (cyclical)	4	48	0.874	Quite reliable
Probable causes				
Psychological causal attributions	6	48	0.743	Quite reliable
Risk factors	7	48	0.715	Quite reliable
Immunity	3	48	0.774	Quite reliable

Table 4 The analysis of whether there is a difference in earthquake experience between groups in terms of illness perception and BDS subscales

Subscale	Group	Mean	SD	T	P-value
Attributions concerning the disease					
Personal control	Group 1	3.31	0.647	-0.506	0.615
	Group 2	3.40	0.662		
Timeline (acute/chronic)	Group 1	3.33	0.578	0.713	0.480
	Group 2	3.19	0.751		
Emotional representations	Group 1	3.16	1.019	-1.007	0.319
	Group 2	3.42	0.680		
Illness coherence	Group 1	2.99	1.055	1.168	0.249
	Group 2	2.64	1.029		
Consequences	Group 1	3.16	0.838	-0.276	0.784
	Group 2	3.22	0.672		
Treatment control	Group 1	3.68	0.793	-1.342	0.186
	Group 2	3.98	0.732		
Timeline (cyclical)	Group 1	3.12	0.842	-0.733	0.467
	Group 2	3.31	0.942		
Probable causes					
Psychological causal attributions	Group 1	3.01	0.708	0.951	0.347
	Group 2	2.79	0.899		
Risk factors	Group 1	1.94	0.692	0.568	0.573
	Group 2	2.05	0.666		
Immunity	Group 1	2.37	0.802	1.467	0.149
	Group 2	2.03	0.781		
Beck depression scale	Group	Median (Min-Max)		Z	P-value
BDS score	Group 1	16 (0-42)		0.895	0.371
	Group 2	16 (0-34)			

Abbreviations: BDS, Beck Depression Scale; Min, minimum; Max, maximum.

Owing to the high number of patients and the high morbidity both in Turkey and in the world, together with its socioeconomic burden, epilepsy is a chronic disorder, which has been broadly discussed and tried to be solved in recent years. Failure to reach the treatment goals despite significant improvements in diagnostic, therapeutic, and follow-up methods has led to the investigation of different factors in patients. In patients with the diagnosis of epilepsy, the evaluation of illness perception data and the reflection of these data to the education and treatment plans of the patients may provide additional benefit in achieving seizure control.

The illness perception has been found to determine the quality of life, the compliance with treatment, and the psychosocial response in many diseases.¹⁸⁻²⁴ The studies conducted to determine the relationship of illness perception and the outcome of the diseases other than epilepsy have revealed that the course of the disease was better in individuals having a high perception of internal control.^{25,26} In our study, when the relationships between subscales of IPQ-R were investigated, it was found that in individuals who were able to understand their disorders and who developed positive thoughts about the consequences of the illness, the negative beliefs in terms of disease duration decreased. In addition, it was found that as

positive thoughts regarding treatment control increased, the positive control thoughts of the individuals regarding their illnesses also increased. This result was in correlation with the results of the original study conducted by Moss-Morris et al⁴ in 2002. According to this result, the illness perception should be taken into consideration in order to improve the compliance with treatment in epilepsy patients.

Earthquake, which is an acute severe life event, did not change illness perception in our cohort. This interesting data might be caused by the personal characteristics of perception. The illness perception consists of mental representations of the disease and may be not related to acute life events or stressors. However, our study population was very small. Therefore, this result may not be generalized to all population. The relationship between other severe life events and illness perception in epilepsy patients should be targeted in future studies with larger samples.

It must be emphasized that patients' other severe life events, such as recent bereavement, were not investigated for the cohort for Group 1 and Group 2. This is a limitation for this work. Another limitation is the small sample size. Although it is clear that it is difficult to find many patients with epilepsy having suffered an earthquake experience, the total number of patients is rather scanty.

Conclusion

Illness perception is the cognitive perspective of the illness status. Patients try to explain their illnesses in the light of their personal experiences, knowledge, values, beliefs, and demands.²⁷ Recognition of situations, in which illness perception creates problems, by the physician and taking necessary measure may increase the success rate of treatment.

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Disclosure

The authors report no conflicts of interest in this work.

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