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Assessment of Health Care Quality in Chronic Neurological Diseases: Stroke, Multiple Sclerosis and Epilepsy

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Abstract

Objective: The aim of this study is to assess the quality of care in chronic neurological diseases, and to analyze the correlation between patients' dependency and the quality of care.

Methods: The study is designed as a descriptive and cross-sectional one. It was conducted among 184 patients who had visited neurology clinics of Ataturk University, Turkey, from March 2014 to July 2014. Data was collected by using a Self-made questionnaire, PACIC (Patient Assessment of Chronic Illness Care) and Barthell Index (BI). For data evaluation, percentage distribution, mean, independent samples t test, variance analysis and Pears on correlation analysis were utilized.

Results: Overall mean score of PACIC scale was found to be 3.05 ± 0.57. The lowest mean score was obtained in follow-up/coordination subscale (2.73 ± 0.86) among sub-scales of the scale, the highest mean score was found to be in patient activation subscale (3.20 ± 0.74). The mean score for BI was 66.60 ± 38.22. The mean score of PACIC varied significantly according to age, marital status, education, disease diagnosis, co morbid conditions and hospitalization duration and hospital experience.

Conclusion: It was found that the satisfaction of patients in terms of chronic disease is at a moderate level, and the highest score was taken in the patient activation subscale, and the lowest score was taken in the follow-up subscale.

Moreover, the quality of health care perceptions of independent patients was better.

Keywords: Chronic neurological disorders; Dependency; Health care quality; Nursing

Introduction

Many chronic diseases which are related to neurological system are considered as diseases that cause severe disability among individuals [1,2]. Stroke, multiple sclerosis (MS), and epilepsy all have an important place among these diseases. Stroke is one of the leading causes of morbidity and mortality all over the world [3]. According to the data in developed countries; stroke, which is most frequently encountered in neurological diseases, is ranked as the third after heart diseases and cancer as mortality cause and the first as a morbidity cause [4]. One other significant disease that causes functional inadequacy among individuals is MS [5]. This disease is ranked as the first among diseases that cause neurological disability in young adults regardless of trauma [6-8]. On the other hand, epilepsy is a disease that requires the individual to be prepared for physical changes, daily medication use, repeated doctor examinations, and acute medical emergencies which affect quality of life negatively [9].

Today, the purpose of healthcare for individuals with chronic neurological diseases is to increase the capacities of patients and their families to cope with problems, improve self-care, preserve and improve skills, meet information needs, and increase independence and quality of life [10].

The absence of an organized and developed care system may be listed among reasons for individuals with chronic diseases not receiving qualified and adequate care. This compels governments to make changes in health services and create a new chronic care system [11].

A chronic care model was developed by Wagner et al., in order to ensure quality in management of chronic diseases. This model is a model that is most frequently used in the management of chronic diseases and is considered the most effective [12,13], Though the chronic disease management was structured in accordance with the model; it is possible to restrict physiological and psychological effects of the disease, reduce the number of those applying to emergency units and their hospitalization, prevent dependence and increase quality of life [14,15]. With the help of patients consciously participating in their care, the disease is kept under control in a better way and a more effective joint work is maintained among medical team members.

Patient satisfaction constitutes a significant part of the quality in healthcare services. Improvement in results and quality of the care by planning appropriate treatment and follow-up brings the patient satisfaction as a consequence [16].

Expectations of patients from healthcare professionals may vary based on their age, gender, educational level, socio-cultural characteristics, dependence levels, and previous experiences with healthcare institutions [17]. While Glasgow and colleagues could not reveal significant differences in the PACIC scores regarding age, education, and gender [18,19]. Rosemann et al. [20] and Cramm et al. [21] found that younger, more highly educated patients report higher PACIC scores, indicating that their care aligns to a higher degree with the chronic care model.

Evaluation of quality in healthcare services affects the provision of a healthcare service of high quality. Therefore, it is considered necessary to recognize the perceptions of patients' of the given healthcare service and also examine factors affecting these perceptions. The purpose of this study therefore, is to assess chronic disease care in neurological diseases and assess the correlation between patients' dependence and the chronic disease care services.

Methods

Design and sample

The study is designed as a descriptive and cross-sectional one. It was conducted with 200 patients among those who applied to and who were registered in the neurology clinic of Ataturk University Hospital in Erzurum, Turkey between March 2014 to July 2014 these were those who met the research criteria. However, since 16 patients did not participate because they were either busy or unwilling, the study was completed with a total of 184 patients.

The inclusion criteria included (1) being diagnosed with Stroke, MS and Epilepsy six months prior to conducting the study, (2) being stayed at least 3 days to the neurology clinic and (3) being conscious. Patients with communication problems were excluded from the study.

All patients gave informed consent and the study was approved by Atatürk University Ethics Committee.

Measures

A three-part survey was used for data collection. The questionnaires included (1) Personal Information Form, (2) Patient Assessment of Chronic Illness Care (PACIC) scale, and (3) Barthell Index (BI).

Individual information questionnaire

The individual information questionnaire included age, sex, marital status, education, income status, place of residence, disease duration, co morbid conditions, hospital experience, and length of stay in hospital.

Patient assessment of chronic illness care (PACIC)

The initial version of the PACIC questionnaire was developed by Glasgow et al. [18]. Patients' assessed chronic illness care (PACIC) with a 20-item questionnaire comprising of five pre-defined subscales: patient activation (3 questions), delivery-system/practice design (3), goal setting/tailoring (5), problem solving/contextual (4), and follow-up/coordination (5). The five-point response scale ranged from 'almost never' to 'almost always' with higher scores indicating a more frequent presence of the respective aspect of chronic care. The PACIC score was the sum of participants' responses divided by 20. Scores thus ranged from 1 to 5 with higher scores indicating a greater perception of involvement in self-management and receipt of chronic care counseling. Cronbach's alpha of patient activation=0.83, delivery-system/practice design=0.74, goal setting/tailoring=0.79, problem solving/contextual=0.86, follow-up/coordination=0.75. Cronbach's alpha of the overall PACIC scale was 0.93.

The reliability and the validity of the overall PACIC scale for the Turkish population have been demonstrated by Incirkus and Nahcivan [22]. In the original study, the Cronbach alfa value was calculated to be 0.91. In this study, Cronbach alfa parameter for overall PACIC was determined as 0.89.

Barthell index (BI)

The BI is an assessment of a patient's functional level of independence in Activities of Daily Living (ADL) and is scored in increments of 5 points (highest possible total score=100). The values assigned to each item are weighed according to the amount of physical assistance required if the patient could not perform the activity independently. The BI measures 10 personal ADL related to self-care and mobility: control of bowels and bladder, grooming, toilet use, feeding, transfer, mobility, dressing, stairs and bathing. BI score ranges from 0 to 100 and lower scores indicate greater dependency [23].

The reliability and the validity of the BI for the Turkish population have been demonstrated by Kücükdeveciet al. [24]. In the original study, the Cronbach a value was calculated to be 0.93. In this study, total Cronbach a parameter for BI was determined as 0.97.

Data collection

The researcher visited the neurology polyclinic 3 days a week. Patients were assessed to determine whether they matched the inclusion criteria for the study. Data collection forms were applied to patients matching the criteria in face-to-face interview. Literate patients read and filled out the forms by themselves while illiterate patients (n=30) filled out the forms with the help of the researcher who read the forms to them. Completion of data collection forms for each patient took 15–30 min.

Statistical analysis

Coding and statistical analyses of data were done by using the SPSS 18.0 package program. Percentage was used to evaluate the parameters of age, sex, education, marital status, income, place of residence, disease duration, comorbid conditions, hospital experience, length of stay in hospital and dependency level. Variance analysis was applied to examine the difference between the mean score of PACIC according to age, marital status, education level, place of residence and diagnosis of disease. The t test was applied to determine differences between the mean quality of life scores according to gender, income status, comorbid conditions, hospital experience and length of stay in hospital. The Pearson's correlation analysis was applied to determine the relation between PACIC scores and point means of BI. Significance in all statistical analyses was defined as P<0.05.

Results

Overall mean score of PACIC scale was found to be 3.05 ± 0.57. The lowest mean score was obtained in follow-up/coordination subscale (2.73 ± 0.86) among sub-scales of the scale, the highest mean score was found to be in patient activation subscale (3.20 ± 0.74) (Table 1).

Scale	Min-Max	X ± SD
Overall PACIC (0-5)	1.70-4.65	3.05 ± 0.57
PACIC subscales (0-5)		
Patient activation	1.67-5.00	3.20 ± 0.74
Delivery system design/decision support	1.33-4.67	3.15 ± 0.75
Goal setting/tailoring	1.60-4.80	3.13 ± 0.64
Problem solving/contextual	1.50-5.00	3.17 ± 0.61
Follow-up/coordination	1.00-4.60	2.73 ± 0.86

Table 1: Score distribution of the PACIC among patients (n=184). (PACIC-Patient Assessment of Chronic Illness Care; X: Mean; SD: Standard Deviation)

The mean age of patients was 49.41 ± 21.83 years; 45.7% were aged between 18 and 39 years; 52.7% were females, 56.0% were married, 54.3% were primary education, 41.3% lived in the city and 54.3% was income equal to the expenses. 41.8% of patients applying to the neurology clinic had stroke, 70.1% did not have any comorbid disease, 65.2% had hospitalization experiences and 52.2% were staying in the hospital for 10 days and longer.

When mean scores of patients were evaluated according to age, the differences with respect to overall PACIC and all subscales of PACIC were found statistically significant (P<0.05) (Table 2).

Patients who were married and high school and college graduates had higher patient activation and problem-solving mean scores among overall PACIC and the scale's sub-scale scores than the other groups and the difference between them was found to be statistically significant (P<0.05) (Table 2).

The difference between gender, income level, and residence area and overall PACIC mean score was not statistically significant (P>0.05) (Table 2).

Characteristics	n	Patient Activation X ± SS	Delivery System Design X ± SS	Goal Setting X ± SS	Problem Solving X ± SS	Follow Up/ Coordination X ± SS	Overall PACIC X ± SS
Age (years)							
18-39	84	3.50 ± 0.73	3.32 ± 0.71	3.28 ± 0.64	3.44 ± 0.52	2.90 ± 0.99	3.26 ± 0.55
40-59	32	3.02 ± 0.70	3.03 ± 0.90	3.00 ± 0.64	3.11 ± 0.46	2.68 ± 0.74	2.95 ± 0.53
60 and above	68	2.92 ± 0.63	3.00 ± 0.69	2.98 ± 0.62	2.84 ± 0.62	2.55 ± 0.68	2.84 ± 0.54
		F=14.494	F=3.910	F=4.954	F=22.008	F=3.139	F=11.431
P-value		P<0.001	P<0.05	P<0.01	P<0.001	P<0.05	P<0.001
Sex							
Female	97	3.209 ± 0.81	3.11 ± 0.80	3.10 ± 0.62	3.18 ± 0.63	2.78 ± 0.88	3.06 ± 0.59
Male	87	3.206 ± 0.66	3.20 ± 0.70	3.14 ± 0.67	3.1 ± 0.59	2.68 ± 0.83	3.04 ± 0.56
		t=0.025	t=-0.769	t=-0.393	t=0.458	t=0.807	t=0.140
P-value		P>0.05	P>0.05	P>0.05	P>0.05	P>0.05	P>0.05
Marital status							
Married	103	3.31 ± 0.73	3.23 ± 0.73	3.17 ± 0.65	3.25 ± 0.57	2.78 ± 0.88	3.12 ± 0.56
Single	36	3.29 ± 0.82	3.13 ± 0.83	3.13 ± 0.71	3.34 ± 0.63	2.65 ± 1.04	3.10 ± 0.64
Widow	45	2.89 ± 0.62	2.98 ± 0.72	3.00 ± 0.58	2.83 ± 0.57	2.60 ± 0.61	2.85 ± 0.51
		F=5.470	F=1.788	F=1.027	F=9.691	F=0.721	F=3.714
P-value		P<0.01	P>0.05	P>0.05	P<0.001	P>0.05	P>0.05
Education							
Illiterate	30	2.81 ± 0.65	2.83 ± 0.77	2.95 ± 0.54	2.85 ± 0.51	2.57 ± 0.73	2.80 ± 0.52
Primary school	100	3.18 ± 0.73	3.13 ± 0.76	3.13 ± 0.61	3.13 ± 0.60	2.76 ± 0.80	3.04 ± 0.54
High school	54	3.46 ± 0.71	3.37 ± 0.68	3.21 ± 0.74	3.40 ± 0.59	2.77 ± 1.01	3.20 ± 0.63
		F=8.187	F=5.262	F=1.572	F=8.556	F=0.648	F=4.937

P-value		P<0.001	P<0.01	P>0.05	P<0.001	P>0.05	P<0.01
Income level							
Income<expenditure	89	3.12 ± 0.75	3.03 ± 0.75	3.06 ± 0.59	3.10 ± 0.61	2.72 ± 0.81	2.99 ± 0.53
Income=expenditure	95	3.28 ± 0.73	3.27 ± 0.74	3.18 ± 0.69	3.22 ± 0.61	2.74 ± 0.90	3.11 ± 0.61
		t=-1.429	t=-2.233	t=-1.346	t=-1.262	t=-0.203	t=-1.433
P-value		P>0.05	P<0.05	P>0.05	P>0.05	P>0.05	P>0.05
Place of residence							
City	76	3.28 ± 0.80	3.14 ± 0.91	3.08 ± 0.74	3.26 ± 0.60	2.80 ± 0.96	3.09 ± 0.66
Town	71	3.26 ± 0.65	3.24 ± 0.59	3.21 ± 0.58	3.18 ± 0.59	2.76 ± 0.85	3.10 ± 0.53
Village	37	2.94 ± 0.74	3.00 ± 0.68	3.03 ± 0.54	2.93 ± 0.61	2.54 ± 0.61	2.87 ± 0.44
		F=2.940	F=1.237	F=1.175	F=3.847	F=1.255	F=2.291
P-value		P>0.05	P>0.05	P>0.05	P>0.05	P>0.05	P>0.05

Table 2: Comparison of PACIC scores related to socio-demographic characteristics of the patients (n=184). (PACIC: Patient Assessment of Chronic Illness Care; X: Mean; SD: Standard Deviation; p-value, differences between groups established with t Test or Variance analysis).

Mean scores of patients diagnosed with stroke in general PACIC, patient activation, and problem-solving sections were lower than those diagnosed with other neurological diseases and the difference between them was statistically significant (P<0.05) (Table 3).

It was determined that patients with comorbid conditions are lower compared to patients with no comorbid conditions considering general PACIC and goal determining, follow up mean score average for the lower dimensions of the scale which is also statistically significant (P<0.05) (Table 3).

In terms of patients' hospitalization experiences and hospitalization durations, a statistically significant difference was found between overall PACIC and all sub-scale mean scores (P<0.05) (Table 3).

Clinical characteristics		Patient activation	Delivery system design	Goal setting	Problem solving	Follow up/ coordination	Overall PACIC
	n	X ± SD	X ± SD	X ± SD	X ± SD	X ± SD	X ± SD
Disease diagnosis							
Stroke	77	2.99 ± 0.61	3.06 ± 0.68	3.02 ± 0.60	2.89 ± 0.59	2.62 ± 0.66	2.90 ± 0.52
MS	64	3.42 ± 0.79	3.25 ± 0.77	3.24 ± 0.65	3.42 ± 0.52	2.91 ± 0.99	3.22 ± 0.57
epilepsy	43	3.27 ± 0.80	3.18 ± 0.85	3.14 ± 0.70	3.28 ± 0.58	2.66 ± 0.93	3.07 ± 0.61
		F=6.238	F=1.080	F=1.993	F=16.312	F=2.232	F=5.807
P-value		P<0.01	P>0.05	P>0.05	P<0.001	P>0.05	P<0.01
Comorbid conditions							
Yes	55	3.13 ± 0.75	3.00 ± 0.82	2.92 ± 0.66	3.03 ± 0.70	2.48 ± 0.77	2.88 ± 0.61
No	129	3.23 ± 0.74	3.22 ± 0.72	3.21 ± 0.62	3.22 ± 0.56	2.84 ± 0.87	3.12 ± 0.55
		t=-0.818	t=-1.780	t=-2.774	t=-1.919	t=-2.646	t=-2.686
P-value		P>0.05	P>0.05	P<0.01	P>0.05	P<0.01	P<0.01
Hospital experience							
Yes	120	3.09 ± 0.74	3.06 ± 0.80	3.09 ± 0.69	3.16 ± 0.64	2.63 ± 0.90	2.98 ± 0.61
No	64	3.41 ± 0.70	3.33 ± 0.61	3.19 ± 0.56	3.17 ± 0.56	2.93 ± 0.74	3.18 ± 0.49
P-value		t=-2.818	t=-2.393	t=-1.015	t=-0.117	t=-2.333	t=-2.187

		P<0.01	P<0.05	P>0.05	P>0.05	P<0.05	P<0.05
Hospitalization duration							
3- 9 days	88	3.39 ± 0.67	3.43 ± 0.63	3.41 ± 0.60	3.29 ± 0.62	3.15 ± 0.75	3.32 ± 0.56
10 days and over	96	3.04 ± 0.75	2.89 ± 0.77	2.86 ± 0.57	3.05 ± 0.58	2.35 ± 0.77	2.80 ± 0.47
		t=3.246	t=5.149	t=6.240	t=2.732	t=7.090	t=6.760
P-value		P<0.01	P<0.001	P<0.001	P<0.01	P<0.001	P<0.001

Table 3: Comparison of PACIC scores related to clinical variables of the patients (n=184). (PACIC: Patient Assessment of Chronic Illness Care; X: Mean; SD: Standard Deviation; p-value, differences between groups established with t Test or Variance analysis).

The mean score for Barthell Index (BI) was 66.60 ± 38.22. When the distribution of independence levels of patients in their daily life activities was examined according to the BI, 34.2% were independent, 12% were mildly dependent, 15.8% were dependent on a medium level, 17.4% were severely dependent and 20.7% were dependent. There was a positive correlation between the BI and the areas of PACIC such as patient activation ($r=0.439$, $P<0.01$), delivery system design ($r=0.407$, $P<0.01$), goal setting ($r=0.331$, $P<0.01$), problem solving ($r=0.489$, $P<0.01$), follow-up ($r=0.230$, $P<0.01$) and overall PACIC ($r=0.447$, $p<0.01$). This result showed that as independence levels of patients in their daily life activities increased, their healthcare qualities also increased (Table 4).

PACIC Scale	Barthell Index (BI)	
	r	p
Patient activation	0.439	p<0.01
Delivery system design/decision support	0.407	p<0.01
Goal setting/tailoring	0.331	p<0.01
Problem solving/contextual	0.489	p<0.01
Follow up/coordination	0.23	p<0.01
Overall PACIC	0.447	p<0.01

Table 4: Correlation between the PACIC scores with BI. (PACIC: Patient Assessment of Chronic Illness Care; BI: Barthell Index).

Discussion

Chronic conditions are increasingly becoming the primary concern of healthcare systems throughout the world and are soon to be the leading cause of disability [25]. Therefore, evaluation of the care provided for individuals with chronic neurological diseases is getting increasingly important. The results achieved as a result of this study conducted with the purpose of determining the healthcare quality of neurological diseases were discussed in accordance with relevant study results and literature knowledge.

The overall mean score obtained by patients from the PACIC scale within this study was 3.05 ± 0.57. When it is considered that the lowest score to be obtained from the scale is 0 and the highest score is 5; as their scores increase, chronic disease patients' levels of satisfaction from the healthcare services also increase and chronic disease management is adequate, it could be asserted that patients had an above-average level of satisfaction from the healthcare services. Similarly, Gensichen et al. [26] also found the overall PACIC scale mean score as 3.25 ± 0.79. Some studies in the literature have specified that patients have medium and above-medium levels of satisfaction from the healthcare services. The result of this study showed similarity with the results of previously conducted studies [19,22,27,28]. In addition, the lowest mean score among the sub-scales of PACIC scale was obtained in follow-up/coordination subscale (2.73 ± 0.86). This result was compatible with the results of the study conducted by Incirkus et al. [22].

In this study, we could not find any correlation between PACIC scale mean scores of patients in terms of the variables such as, patients' socio-demographic characteristics, gender, income level and residence area. Similarly, previous studies conducted on this subject also indicated that demographic characteristics such as gender, income level and residence area were not effective on healthcare satisfaction and on the adequacy of chronic disease management [18,19,26,29,30].

We found that younger patients reported higher PACIC scores. As compatible with result of this study, Cramm and Nieboer [21] and Rosemannet al. [20] reported that younger patients had higher levels of satisfaction from the care they received as compared to elderly patients.

Higher levels of education were associated with higher scores with regard to overall PACIC, patient activation, and problem solving. Results of the study conducted by Rosemann et al. [20], were compatible with the result of this study and patients with higher educational backgrounds reported better views on healthcare services. This may be due to better coping skills and secured financial and social status of this group of patients. Several studies have shown that higher educational attainment is an important variable significantly associated with compliance with medical care [31,32]. When patients' marital statuses and their levels of satisfaction from healthcare were examined within the scope of this study, it was observed that married patients had higher mean scores in overall PACIC, patient activation and problem-solving sections. Thi et al. [33] also, reported that married patients were more satisfied with hospital services. This result was in parallel with our results. This result may be explained by the fact that married patients had lower care needs depending on the social support they received from their spouses and children and therefore, their levels of expectations from medical professionals reduced.

When healthcare quality was analyzed in terms of patients' disease types; total PACIC, patient activation and problem-solving mean scores of stroke patients were found to be lower. As stroke patients staying in the neurology clinic were more dependent in their daily life

activities, their expectation levels were also considered to be higher. In the study conducted by Mollalogluet al. [34], to evaluate the disability in neurological diseases, they found that stroke patients experienced mobility-related disability in more serious levels.

In this study; general PACIC, objective-setting and follow-up mean scores of patients with co morbid disease were found to be lower. In line with the result of this study, Gensichen et al. [26], found a negative correlation between the number of additional physical conditions and "patient activation" among the PACIC scale's subscales.

We found that patients with no previous hospital experiences had better views on care services. Similar result was also reported in the study of Yilmaz [35]. This result may be interpreted in a way that individuals who were not previously hospitalized did not interact with medical care service providers therefore, their expectations remained limited.

It was found that as patients' hospitalization duration extended, their general PACIC and sub-scale mean scores decreased. As compatible with result of this study, Adams et al. [36], also found the chronic care model components of patients hospitalized for longer periods to be lower.

When the distribution of patients' independence levels was examined in terms of their daily life activities according to the Barthell Index (BI), it was interesting to note that only 34.2% of individuals with chronic neurological diseases were independent in maintaining their daily life activities. It has also been determined in similar previous studies that the majority of patients become dependent on others in maintaining their daily life activities during the course of the disease [34,37]. Many of the chronic diseases related to neurological system are considered diseases that cause severe restrictions and inadequacy for the individual.

We found a positive correlation between all sub-scales of BI and PACIC scale in this study. According to this result, as independence level increased in patients' daily life activities, the healthcare quality also increased. Although several parameters that could affect the quality of the healthcare were evaluated in previously conducted studies; no studies analyzing the correlation between patients' independence level and healthcare satisfaction have been found in the literature. When this result was compared with the findings of studies that examine the burden of care providers and their care quality perceptions according to patients' dependence levels; a positive correlation was reported between patients' dependence levels in their daily life activities and the burden of care [38,39].

Conclusion

According to the result of this study, individuals with neurological disease were found to have a medium level of satisfaction of healthcare. Medical professionals should ensure that they apply chronic disease models on patients effectively, in order to keep the healthcare quality at a desired level among individuals with neurological diseases. In parallel with this apprehension, it is a major necessity to make arrangements that focus on applying chronic care models in order to increase satisfaction among patients in terms of the healthcare services in hospitals.

We also found a positive correlation between the independence levels of patients in their daily life activities and the healthcare quality. This result showed that as patients' independence level increased, the quality of healthcare also increased. Therefore, a dynamic symptom management plan that is suitable with the patient's dependence status should be developed.

Our findings may have important implications towards the care of neurological disease. Further research is needed to confirm our results and assess possible implications for implementing the chronic care model in neurological diseases.

Competing Interests

The authors of this paper have no conflicts of interest to report. All authors have approved the final draft of the article.

Authors' Contributions

DN; conceived, designed and did data collection, did statistical analysis manuscript writing. SZA; editing of manuscript. All authors read and approved the final manuscript.

Disclaimer

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