

Identification of Problems Faced by Individuals with Epilepsy in Health Communication

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Abstract

Objective: Individuals with epilepsy often face challenges with medication adherence and health monitoring because communication difficulties that hinder self-expression and information exchange, thereby complicating effective disease management. This study aimed to examine the health communication problems experienced by individuals with epilepsy.

Methods: This descriptive, cross-sectional study was conducted among 172 individuals with epilepsy who presented to the neurology outpatient clinic in eastern and northern Türkiye between August 2023 and August 2024. Study data were collected using the descriptive data form and the health communication problems scale. The independent groups t-test, one-way ANOVA, and Tukey test were used to evaluate the data.

Results: On the health communication problems scale, individuals with epilepsy had mean scores of 2.41±0.53 for the effective communication problems sub-dimension, 2.88±0.80 for the social communication problems sub-dimension, and 2.68±0.72 for the communication barriers sub-dimension. No significant differences were detected in the mean scores for health communication problems among individuals with epilepsy by sex, health expenditure, seizure type, or seizure characteristics ($p>0.05$).

Conclusion: The study revealed that individuals with epilepsy experienced moderate difficulty with health communication. Those who were married, had higher educational attainment, were unemployed, had lower income levels, and were receiving polytherapy experienced greater communication challenges with healthcare professionals.

Keywords: Epilepsy, healthcare professionals, communication barriers

INTRODUCTION

Epilepsy is a chronic neurological disorder characterized by recurrent, unprovoked seizures caused by abnormal and excessive electrical discharges in cortical neurons.^{1,2} Epileptic seizures are sudden clinical events marked by spontaneous recurrence and excessive neuronal electrical activity, often accompanied by loss of consciousness.²⁻⁵ Communication is a fundamental process for individuals and society, facilitating relationships and interactions by conveying thoughts, feelings, and information. In this context, health communication is critically important, as individuals' ability to understand medical information, express their needs, and manage their health effectively depends on the quality of communication.⁶⁻¹⁰ Health communication is the exchange of information between individuals or groups regarding health-related issues.¹¹ With advances in healthcare, the importance and application of health communication are increasing across various levels and intensities.^{12,13} Health communication integrates the fields of medical science and communication science.¹⁴ Although it is central to clinical procedures such as diagnosis, treatment, and patient-provider interactions, health communication also encompasses how individuals perceive, interpret, and respond to health-related issues.^{12,14,15} It plays a vital role in developing strategies to manage health problems, understanding symptoms, recognizing risks, and making informed decisions.^{7,16} Moreover, effective health communication contributes to disease prevention, health promotion, and efficient management of medical conditions, producing positive individual, social, institutional, and economic outcomes.¹⁷⁻²⁰ It influences patients' choice of healthcare institutions, their trust in the healthcare system, adherence to treatment, length of hospital stay, and overall quality of care and satisfaction with care.⁷

Epilepsy is a chronic neurological condition that significantly affects the well-being of individuals, families, and societies.²¹ Individuals with epilepsy often experience comorbidities and must carefully manage both their primary condition and associated disorders.^{22,23}

Chronic diseases have profound medical, economic, psychological, and social impacts on individuals, often leading to communication challenges.²⁴ Developing effective self-management strategies for epilepsy requires strong patient-provider communication within a patient-centered approach to care to ensure treatment adherence and to optimize health outcomes.^{22,25}

In managing epilepsy, communication plays an increasingly crucial role. Communication difficulties encountered by individuals during healthcare interactions can hinder self-expression, limit access to adequate information, and compromise disease management. Although previous studies have explored health communication in various populations, no research has specifically addressed the communication problems experienced by individuals with epilepsy. This study aimed to evaluate health communication problems among individuals with epilepsy residing in the northern and eastern regions of Türkiye and to identify factors influencing these problems.

Study Questions

- What are the health communication problems of individuals with epilepsy?
- What are the factors affecting the health communication problems of individuals with epilepsy?

METHODS

This cross-sectional study was conducted in Giresun and Erzurum, located in Northern and Eastern Türkiye, respectively.

Participants

Individuals diagnosed with epilepsy who were followed for at least 6 months at the Neurology Outpatient Clinics of Atatürk University and Giresun University were included in the study. A total of 172 individuals with epilepsy who met the inclusion criteria (being 18 years of age or older, not having cognitive or communication problems, being able to answer the questions in the interview form, and being volunteers for the research) were reached between August 2023 and August 2024 without any sample selection.

Data Collection

The descriptive data form and the health communication problems scale (HCPS) were used to collect the study data.

MAIN POINTS

- Effective health communication is crucial for individuals with epilepsy, as it supports optimal disease management and enhances adherence to treatment. This study explores the communication difficulties encountered by individuals with epilepsy during interactions with healthcare professionals. The findings reveal persistent challenges in understanding medical information, expressing symptoms clearly, and feeling adequately understood by healthcare providers.
- These results underscore the importance of targeted communication training and patient-centered approaches for professionals involved in the care of individuals with epilepsy.
- Enhancing health communication practices may lead to improved clinical outcomes and a higher quality of life for this population.

Descriptive Data Form

The researchers prepared the form, which consisted of 13 questions about age, marital status, sex, education, income, employment status, place of residence, diagnosis period, medication use and number of medications used by individuals with epilepsy, number of seizures in the last year, and seizure types. Loss of consciousness was not evaluated in this study.

Health Communication Problems Scale

The HCPS was developed by Yeşildal et al.²⁶ to identify communication problems experienced by patients in interactions with healthcare personnel. The 5-point Likert-type scale consists of 13 items and three sub-dimensions: effective communication (items 1-6), social communication (items 7-9), and communication barriers (items 10-13). The minimum score that can be obtained on the scale is 13, and the maximum score is 65. Items 1, 2, 4, 5, and 7 of the scale are reverse-coded. As the score on the scale increases, health communication becomes increasingly problematic. The responses on the scale range from 1 (strongly agree) to 5 (strongly disagree). The Cronbach's alpha for the original scale was 0.77,²⁶ and the overall Cronbach's alpha was 0.756 in this study.

Statistical Analysis

The independent groups t-test was used to analyze data from two groups and the one-way ANOVA test was used for three or more groups. Multiple comparisons were made for the results that were significant in the one-way ANOVA, and the Tukey test was used because the data showed homogeneous variances.

Ethical Issues

Written approval was obtained from the Atatürk University Clinical Research Ethics Committee (approval no: 41, date: 26.01.2023). Permission was obtained from the Atatürk University Faculty of Medicine and the Giresun University Department of Neurology. Verbal and written informed consent was obtained from individuals with epilepsy prior to data collection.

RESULTS

Health Communication Problems and Related Factors

Individuals with epilepsy scored 2.41 ± 0.53 on the effective communication problem sub-dimension of the HCPS, 2.88 ± 0.80 on the social communication problems sub-dimension, 2.68 ± 0.72 on the communication barriers sub-dimension, and 2.59 ± 0.51 overall on the HCPS. The effective communication and communication barriers sub-dimensions scored below the obtainable average ($\bar{x}=3.00$), whereas the social communication problem sub-dimension scored close to the obtainable average ($\bar{x}=3.00$) (Table 1).

The mean age of individuals with epilepsy was 37.16 ± 14.83 years, and the mean duration of epilepsy was 14.20 ± 10.64 years. Of the participants, 56.4% were female, 61.6% were married, 45.9% were secondary school graduates, 49.4% lived in the city center, 66.9% were unemployed, 57.6% had income lower than expenses, 33.7% experienced one seizure per year, 50.6% had an undetermined seizure type, and 50% were on polytherapy (Table 2).

Table 1. The distribution of epilepsy patients' scores on the sub-dimensions of the health communication problems scale (n=172)

		Scale and sub-dimensions			
		Effective communication problem	Social communication problem	Communication barriers	Total
Possible scores on the scale	Min-max	1-5	1-5	1-5	1-5
Score received by individuals with epilepsy	Min-max	1.00-3.83	1.00-4.33	1.00-4.50	1.15-3.85
	$\bar{X} \pm SD$	2.41 \pm 0.53	2.88 \pm 0.80	2.68 \pm 0.72	2.59 \pm 0.51

\bar{X} : Mean, SD: Standard deviation, Min: Minimum, Max: Maximum

No significant differences were detected in mean scores for health communication problems among individuals with epilepsy by sex, health expenditure, seizure type, or seizure characteristics ($p > 0.05$). However, the mean scores for effective communication problems ($t = 2.718$, $p < 0.01$) and social communication problems ($t = 3.817$, $p < 0.001$) differed significantly by marital status, with married individuals showing higher scores than single individuals.

By educational status, the mean score for social communication problems differed significantly ($F = 6.848$, $p < 0.001$): primary school graduates had higher scores than illiterate individuals, and primary and secondary school graduates had higher scores than those with a bachelor's degree or higher. No significant differences were observed in effective communication problems or communication barriers across educational levels.

Place of residence showed a significant effect on social communication problems ($F = 3.352$, $p < 0.05$); however, multiple-comparison tests revealed no significant differences between specific groups.

Employment status significantly affected social communication problem scores ($t = 2.229$, $p < 0.05$), with unemployed individuals reporting higher scores than employed individuals.

Perceived income status was significantly associated with effective communication problems ($t = 3.513$, $p < 0.001$), with participants whose income was less than their expenses having higher scores.

Finally, drug use influenced problems with effective communication ($t = -2.288$, $p < 0.05$), such that polytherapy users reported higher scores than monotherapy users (Table 2).

DISCUSSION

Effective communication between individuals with epilepsy, their families, and healthcare professionals is crucial for optimal treatment and care management. Previous studies have emphasized the negative impact of communication problems on treatment outcomes.²⁷ Improving communication is key to enhancing the quality of healthcare for these patients.^{28,29} The results of the present study, which examined healthcare communication problems among individuals with epilepsy, are discussed in the context of existing literature.

This study aimed to investigate the health communication challenges faced by individuals with epilepsy and the factors influencing these difficulties. The main findings revealed that married individuals, individuals with higher levels of education, unemployed individuals, and low-income patients experienced more pronounced communication problems.

Furthermore, patients receiving polytherapy exhibited greater communication difficulties than patients receiving monotherapy. These results highlight the influence of demographic, socioeconomic, and treatment-related factors on patient-provider communication and underscore the need for targeted interventions to improve care quality, patient satisfaction, and overall health outcomes in individuals with epilepsy.

The study found that married individuals experienced more problems with effective and social communication than single individuals.²⁷ However, some studies report contrasting findings, indicating either no significant relationship between marital status and communication problems³⁰ or that single individuals face more social communication challenges.³¹ This discrepancy may reflect differences in study populations, cultural contexts, or social support systems. In our cohort, married individuals may experience reduced social tolerance because of responsibilities, which highlights the importance of individual and contextual factors when interpreting the results.

Notably, the study found that individuals with higher levels of education reported more communication problems in healthcare settings. Consistent with previous research, this may result from increased expectations and attention to detail during healthcare interactions.^{27,30-34} Conversely, patients with lower education levels may prefer sincere and empathetic communication styles, facilitating clearer and more effective interactions with healthcare professionals. Thus, more highly educated individuals may perceive communication challenges more acutely, while individuals with less education may experience fewer problems due to simpler, more direct communication styles. Unemployed individuals with epilepsy experienced more social communication problems than employed individuals with epilepsy. No comparable findings regarding employment status were identified in the literature. This may reflect narrower social circles, psychosocial stress, economic concerns, or social perceptions affecting communication among unemployed patients. Low-income individuals experienced more pronounced communication difficulties, consistent with findings that limited social support can hinder effective health communication.³⁵ The literature shows mixed results; some studies report that higher-income individuals face more social communication problems,³² while others find no relationship between income and communication challenges.^{30,32,36} In our study, low-income patients may hesitate to express their needs due to limited social support networks. Although differences in social communication problems were observed between places of residence, multiple-comparison tests showed that these differences were not statistically significant. This suggests that residence alone does not directly affect social communication, and other individual or socioeconomic factors may play a larger role.³³ Polytherapy users had higher scores for communication problems than monotherapy users, indicating that

Table 2. Comparison of mean scores of epilepsy patients in health communication

		n		Health communication problems scale					
				The problem of effective communication		Social communication problem		Communication barriers	
Personal data		n	%	Mean	SD	Mean	SD	Mean	SD
Sex	Female	97	56.4	2.40	0.51	2.97	0.72	2.66	0.68
	Male	75	43.6	2.41	0.56	2.76	0.88	2.71	0.77
Test and significance				t=-0.116 ^a , p=0.908		t=1.748 ^a , p=0.082		t=-0.444 ^a , p=0.657	
Marital status	Married	106	61.6	2.49	0.55	3.07	0.67	2.70	0.72
	Single	66	38.4	2.27	0.48	2.58	0.89	2.64	0.73
Test and significance				t=2.718 ^a , p= 0.007		t=3.817 ^a , p= 0.001		t=0.552 ^a , p=0.581	
Education get status	Literate or literate	17	9.9	2.35	0.55	2.61	0.75	2.62	0.76
	Primary education	41	23.8	2.59	0.64	3.20	0.71	2.65	0.85
	Secondary education	79	45.9	2.39	0.46	2.96	0.76	2.77	0.60
	Bachelor's degree and above	35	20.3	2.27	0.50	2.47	0.82	2.54	0.80
Test and significance				F=2.643 ^b , p=0.051		F=6.848 ^b , p= 0.001		F=0.891 ^b , p=0.447	
Significant difference				-		1-2, 2-4, 3-4		-	
Residence	City	85	49.4	2.37	0.56	2.74	0.78	2.62	0.73
	District	71	41.3	2.43	0.49	2.97	0.81	2.77	0.68
	Village	16	9.3	2.51	0.58	3.23	0.71	2.58	0.85
Test and significance				F=0.558 ^b , p=0.574		F=3.352 ^b , p= 0.037		F=1.087 ^b , p=0.340	
Significant difference				-		-		-	
Working status	Working	115	66.9	2.36	0.55	2.69	0.88	2.72	0.78
	Not working	57	33.1	2.43	0.53	2.97	0.74	2.66	0.70
Test and significance				t=0.834 ^a , p=0.405		t=2.229 ^a , p= 0.027		t=-0.517 ^a , p=0.606	
Perceived income status	Income less than expenses	99	57.6	2.53	0.51	2.94	0.80	2.71	0.77
	Income equals expenses or exceeds income	73	42.4	2.25	0.52	2.80	0.78	2.64	0.66
Test and significance				t=3.513 ^a , p= 0.001		t=1.144 ^a , p=0.254		t=0.597 ^a , p=0.551	
Seizure frequency	Once in 1-3 months	55	32.0	2.55	0.57	2.95	0.82	2.69	0.73
	Once in 4-6 months	37	21.5	2.40	0.49	2.77	0.88	2.80	0.78
	Once in 7-12 months	17	9.9	2.47	0.32	3.02	0.62	2.97	0.62
	Once in 1-2 year(s)	63	33.7	2.28	0.55	2.84	0.78	2.52	0.68
Test and significance				F=2.618 ^b , p=0.053		F=0.584 ^b , p=0.626		F=2.371 ^b , p=0.072	
Significant difference				-		-		-	
Seizure types	Generalized tonic-clonic	73	42.4	2.47	0.53	3.01	0.77	2.64	0.79
	Partial	12	7.0	2.63	0.55	2.83	0.81	2.69	0.65
	Unidentified	87	50.6	2.32	0.52	2.77	0.81	2.71	0.68
Test and significance				F=2.749 ^b , p=0.067		F=1.843 ^b , p=0.161		F=0.151 ^b , p=0.860	
Significant difference				-		-		-	
Seizure awareness	Yes	37	21.5	2.44	0.57	2.67	0.89	2.51	0.76
	No	135	78.5	2.40	0.53	2.94	0.76	2.72	0.71
Test and significance				t=0.430 ^a , p=0.668		50.6		t=-1.578 ^a , p=0.116	
Medication	Monotherapy	86		2.32	0.58	2.80	0.87	2.68	0.73
	Polytherapy	86		2.50	0.47	2.96	0.71	2.67	0.72
Test and significance				=-2.288 ^a , p= 0.023		t=-1.281 ^a , p=0.202		t=0.079 ^a , p=0.937	

Significant findings are in bold, ^a: Independent groups t-test, ^b: One-way ANOVA test, SD: Standard deviation

multiple medications may contribute to communication difficulties through physical or cognitive impairments, such as confusion.^{37,38} These individuals may seek more guidance from healthcare personnel, highlighting the importance of effective and continuous communication to reduce polypharmacy complications.³⁹ Health communication plays a crucial role in healthcare effectiveness. Health is not only a biomedical concept but also a multidimensional phenomenon encompassing social, psychological, and cultural dimensions.⁴⁰

In the present study, the lowest mean score on the HCPS was 2.41 ± 0.53 in the effective communication sub-dimension, with an overall mean of 2.59 ± 0.51 . Compared with the literature reporting an overall mean of 2.79,³² our cohort experienced relatively fewer communication problems. This may reflect higher treatment adherence, frequent interactions with healthcare personnel, or specific sociodemographic characteristics.

Study Limitations

This study has several limitations. First, it was limited to individuals attending neurology outpatient clinics in the northern and eastern regions of Türkiye, which may limit generalizability. Second, data were self-reported, introducing potential social desirability bias. Third, the cross-sectional design prevents causal inference. Finally, variables such as psychiatric comorbidities, disease duration, and treatment compliance, which may affect communication, were not included. These limitations should be considered when interpreting and generalizing the findings.

CONCLUSION

Individuals with epilepsy experience moderate difficulties in health communication. Marital status, higher education, unemployment, low-income, and polytherapy use were associated with greater communication challenges. Future research should explore strategies to alleviate these problems and support effective communication. Healthcare professionals play a key role in educating patients about communication challenges. Educational programs should be developed to strengthen healthcare providers' communication skills. Clear informational materials and support groups for individuals with epilepsy should be established. Improving patients' communication skills can enhance their understanding of health issues and improve their quality of life and psychosocial well-being. Addressing individual needs and leveraging technology can optimize the benefits of health services for individuals with epilepsy.

Ethics

Ethics Committee Approval: Written approval was obtained from the Atatürk University Clinical Research Ethics Committee (approval no: 41, date: 26.01.2023).

Informed Consent: Verbal and written informed consent was obtained from individuals with epilepsy prior to data collection.

Footnotes

Authorship Contributions

Surgical and Medical Practices: N.B., D.A.C., N.İ.A., Concept: D.A.C., Design: D.A.C., Data Collection or Processing: D.A.C., N.İ.A., Analysis or Interpretation: D.A.C., Literature Search: N.B., D.A.C., Writing: N.B., D.A.C.

Conflict of Interest: No conflict of interest was declared by the authors.

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