Archives of Epilepsy

Original Article

The Social and Demographic Characteristics of Neurosurgical Patients With Drug-resistant Temporal Lobe Epilepsy

Galina Odintsova, Natalia Ivanova, Victoria Nezdorovina, Nina Dengina

Almazov Medical Research Centre, Polenov Neurosurgical Research Institute, St. Petersburg, Russia

Galina Odintsova MD

Cite this article as: Odintsova G, Ivanova N, Nezdorovina V, Dengina N. The social and demographic characteristics of neurosurgical patients with drug-resistant temporal lobe epilepsy. *Arch Epilepsy.* [Epub Ahead of Print]

Corresponding Author: Galina Odintsova MD, Almazov Medical Research Centre, Polenov Neurosurgical Research Institute, St. Petersburg, Russia, E-mail: odintsova_gv@almazovcentre.ru

Received: 20.11.2024 **Accepted:** 19.03.2025 **Epub:** 04.06.2025

DOI: 10.4274/ArchEpilepsy.2025.24153

Abstract

Objective: In this study, our objective was to investigate the sociodemographic characteristics of patients with drug-resistant temporal lobe epilepsy (DR-TLE) undergoing neurosurgical management.

Methods: The single-center, non-randomized, retrospective, parallel-group study was conducted in 2022-2023. The subject temporal DR-TLE. The object social and demographic indicators of neurosurgical patients. One hundred patients with DR-TLE after neurosurgical management were classified into two groups according to the type of surgical procedure.

Results: Seventy-eight patients underwent resective surgery in group 1; twenty-two patients underwent destructive surgery in group 2. The mean age of the cohort was 32.3±8.18 years, with 53% of the patients being men and 47% women. The level of education in the cohort was characterised by a predominance of vocational qualifications (41%) compared to secondary education (24%) and tertiary education (34%). In group 1, the majority of patients had secondary vocational education; in group 2, patients with tertiary education predominated. There were twice as many unemployed people as employed people in the cohort, 64% and 31% respectively, indicating a difference between the groups. The percentage of patients with disabilities was 59%, indicating a predominance of patients with disabilities in group 1 and a predominance of patients without disabilities in group 2. The family situation was characterized by a low marital status (38%) and a mean age of 32.3±8.18 years, with no significant differences between the groups. Despite the reproductive age of the patients, the family situation and parental status were characterised by low rates of marriage and a low birth rate of 18%, with no differences between the groups.

Conclusion: The group of neurosurgical patients was socially maladjusted: two-thirds were disabled and unemployed and only a quarter had a university degree. The trend toward late surgical management of drug-resistant temporal epilepsy continues. It is necessary to educate physicians and patients about the current possibilities of epilepsy surgery.

Keywords: Drug-resistant epilepsy, surgery, destructive surgery, resective surgery, social functioning

INTRODUCTION

The current phase of epileptology development is characterized by an increasing interest worldwide in surgical treatments for epilepsy, as well as the updating of basic definitions and classifications.[1] At the 15th European Epilepsy Congress, held in Rome, Italy from 7-11 September 2024, it became evident that numerous sections were devoted to the various aspects of the surgical treatment of epilepsy. The changing stance of the International League Against Epilepsy on terminology to describe management has also contributed to the increasing use of surgical treatment for epilepsy. Experts believe that the term "antiepileptic" is reserved for treatment options that have been shown to have a direct impact on the course of epilepsy, the likelihood of developing epilepsy, or the likelihood of developing more severe epilepsy. Surgical treatments are included in these options.[2] In the history of epilepsy surgery, three main phases are distinguished: the clinical, neurophysiological, and epileptogenic lesion era.[3] The third phase, the era of neuroimaging, has improved the ability to diagnose structural lesions as the cause of epilepsy, which has increased the indications for surgical treatment of epilepsy.[4]

The change in the organizational model of medical care, which is based on the principles of the four Ps: predictive, preventive, personalized, and participatory, requires the use of modern diagnostic technologies.[5] This has led to the development of functional neurosurgery, which uses different types of destruction and stimulation of target brain structures.[6] Minimally invasive surgical techniques expand the possibilities of neurosurgery application and reduce economic losses for the state and disability for patients.[7] Improved diagnostic and treatment methods will enhance patient socialization and minimize disease-related labor losses.[8-10]

The emerging transformation in epilepsy management tactics demands an increase in theoretical and practical research in this area. Indications must be developed, risks of complications must be stratified, and surgical effectiveness must be predicted using new methodologies.[11,12] Choosing an optimal surgical management approach based on the etiology of the disease and predicting outcomes in patients with drug-resistant structural epilepsy, is an important initiative that characterizes the current level of development of the epilepsy surgical management issue.[13-15]

Mesial temporal lobe epilepsy is one of the most frequently surgically treated forms of epilepsy with the highest success rates. However, the structural features and functional importance of the mesial structures also determine the high rate of cognitive complications in surgical treatment, mainly memory impairment.[5] This has led to the development of actively destructive treatment methods in addition to classical resective methods of surgical treatment of mesial temporal epilepsy.[4]

Understanding the problems of epilepsy surgery and developing ways to improve medical care requires an assessment of the social burden of the disease and the demographics of the patients. However, the social and demographic characteristics of neurosurgical patients with drug-resistant epilepsy are poorly studied.

In this study, our purpose was to determine the sociodemographic characteristics of patients with drug-resistant temporal lobe epilepsy (DR-TLE) who underwent neurosurgical treatment.

METHODS

Study Design

The study design was single-center, non-randomized, retrospective, in parallel groups. It was carried out at Polenov Neurosurgical Institute, a branch of Almazov National Research Centre, in 2022-2023.

The study was part of the state assignment commissioned by the Ministry of Health of the Russian Federation (topic no: 123021000127-7: "Development of a New Technology for Neurorehabilitation of Patients After Surgical Management of Drug-resistant Epilepsy").

The subject of the study was DR-TLE. The subject of the study was the social and demographic indicators of neurosurgical patients.

MAIN POINTS

- The development of epileptology is characterised by a growing worldwide interest in surgical treatments for epilepsy.
- Improved epilepsy management will improve the socialisation of patients and minimise sickness-related absence from work.
- Social functioning was assessed on the basis of social activity and family functioning.
- Indicators of social functioning were educational level, employment and degree of disability.
- Family life was assessed on the basis of marital status and the birth index.

Overview of the Groups

The study is based on the results of the examination and treatment of 100 patients, after neurosurgical management of epilepsy, with DR-TLE at Polenov Neurosurgical Institute.

The diagnosis of DR-TLE was based on the definitions and classifications developed and approved by the International League Against Epilepsy: Definition of epilepsy, drug resistance, status epilepticus, classification of epilepsy, and epileptic seizures of 2017.

Inclusion criteria:

1. Signed informed consent.
2. Focal temporal lobe epilepsies.
3. Male and female patients aged 18 to 70 years inclusive at the time of signing the informed consent form.
4. Lesional and non-lesional epilepsy of more than 2 years of duration.
5. Proven diagnosis of drug-resistant epilepsy.
6. Surgical treatment of DR-TLE at Polenov Neurosurgical Institute.
7. Availability of a catamnesis after surgical management.
8. Ability to answer the questionnaire satisfactorily.

Non-inclusion criteria:

1. Type of surgical procedure-neurostimulation, electrode implantation.
2. Extratemporal focal epilepsy.
3. Presence of somatic pathology that aggravates the patient's condition and worsens the overall prognosis.
4. Patients less than 18 years of age.

Exclusion criteria:

1. Generalized forms of epilepsy.
2. Patients who cannot understand the questionnaires.
3. Refusal of any communicative action by the patient, discontinuation of communication.
4. Severe psychiatric comorbidity.

All patients underwent the necessary screening to ensure that they met the inclusion/exclusion criteria. The inclusion/exclusion criteria were chosen to ensure the safety of the patients and the validity of the data obtained.

The patients were divided into 2 groups according to the type of surgical procedure. Group 1 underwent resective surgery, group 2 underwent destructive surgery.

Data on disease onset, disease progression, and treatment were obtained from discharge summaries, from hospitals where the patients had previously been treated, and from history taken from interviews with patients and their relatives. All patients underwent the necessary checks to ensure that they met the inclusion/exclusion criteria. The inclusion/exclusion criteria were chosen to ensure patient safety and validity of the data obtained.

Ethical Aspects

The study was carried out according to the standards of relevant clinical practice and the principles of the Declaration of Helsinki. All patients signed an informed consent form. Approval was obtained from the Ethics Committee of Almazov National Medical Research Centre (date: 18.04.2022, approval no: 2304-22).

Statistical Analysis

Statistical analysis was performed using International Business Machines® Statistical Package for the Social Science® Amos™ 23 (United States of America: Armonk, New York State). For indicators with an approximate normal distribution, the results were presented as the arithmetic mean (M), the standard error of the mean (m), and the sample size (n); in other cases, the results were presented as median and quartiles. The criterion of significance was set at the level of $p<0.05$. Correlations between pairs of quantitative variables were assessed using the non-parametric Spearman criterion. Different types of analysis of variance were used to detect differences between subgroups for single variables, including parametric (ANOVA) and non-parametric (Mann-Whitney U test, Kruskal-Wallis H-test).

RESULTS

The patients were divided into 2 groups according to the type of surgical procedures; group 1 underwent resective surgery, 78 patients (78%). Destructive surgery was performed on group 2-22 patients (22%).

Clinical and Demographic Indicators

The mean age in the cohort was 32.3±8.18 years, with a minimum of 19 years and a maximum of 54 years. Distribution by gender: 53% male, 47% female; male to female ratio 1:1.[13]

The demographic characteristics of the patients are presented in Table 1. Demographic data did not differ between groups.

Clinical Features

The mean duration of epilepsy in the cohort was 20.09±9.24 years, with no differences between the groups (p=0.3).

In the cohort, all patients had mesial temporal lobe epilepsy with proven drug resistance and uncontrolled seizures. The clinical picture of epilepsy is shown in Table 2.

Patients were categorized into four groups depending on how long they had had the disease: three to five years, six to ten years, eleven to twenty years, and more than twenty years of drug-resistant epilepsy (Figure 1).

Social Functioning

Social functioning was assessed based on social activity and family functioning. Indicators of social functioning were educational

Table 1. Social and demographic characteristics in groups and cohort

Baseline characteristics	Group 1 (n=78)		Group 2 (n=22)		Cohort (n=100)		p-value
	Number	Percent	Number	Percent	Number	Percent	
Gender distribution							
Male	44	56	9	41	53	53	0.2
Female	34	44	13	59	47	47	0.18
Age distribution (in years)							
Mean age	32.64±8.19		31.09±8.21		32.3±8.18		0.2
Minimum	19		20		19		
Maximum	54		46		54		-

Table 2. Clinical features of drug-resistant epilepsy in neurosurgical patients

Baseline characteristics	Group 1 (n=78)	Group 2 (n=22)	Cohort (n=100)	p-value
	Years	Years	Years	
Duration of epilepsy				
Mean duration	20.68±8.94	18±10.18	20.09±9.24	0.3
Minimum	4	4	4	-
Maximum	41	42	42	-
Age at the onset of epilepsy				
Mean duration	12.18±8.94	13.09±6.96	12.38±8.52	0.4
Minimum	0.25	4	0.167	-
Maximum	52	27	52	-

background, employment, and disability rates. Family functioning was assessed by marital status and childbirth index. The social characteristics of the patients are shown in Table 3.

The level of education in the cohort was characterized by a predominance of vocational qualifications, 41% compared to secondary education, 24%, and higher education, 34%. In group 1, the majority of patients had vocational secondary education. In group 2, patients with tertiary education prevailed. There were twice as many unemployed as employed in the cohort, 64% and 31% respectively. Additionally, 4.2% were studying. These numbers show a clear distinction between the groups. The number of patients with disabilities was 59%. Patients with disabilities predominate in group 1, while patients without disabilities predominate in group 2. The family situation was characterized by a low marital status (40%). There were no significant differences between the groups, with a mean age of 32.3±8.18 years. Parental status was characterized by a low childbearing rate (18%), with no significant difference between the groups, despite the reproductive age of men and women.

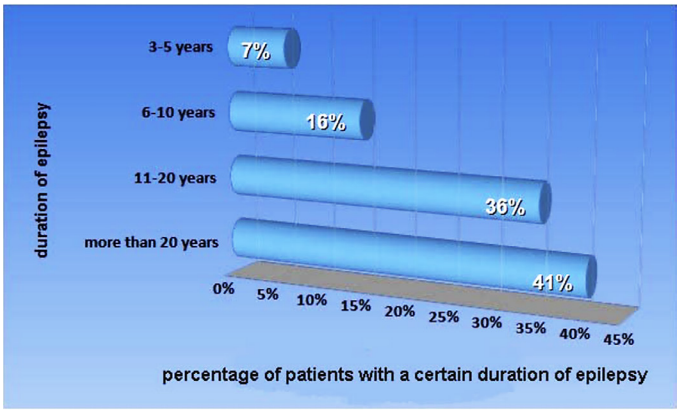

Figure 1. Distribution of patients according to the specific duration of epilepsy

The level of education in the cohort was characterized by a predominance of vocational qualifications (41%), compared to secondary education (24%) and higher education (34%). In group 1, the majority of patients had vocational secondary education; in group 2, patients with tertiary education prevailed. There were twice as many unemployed as employed in the cohort, 64% and 31%, and 4% were studying, showing no difference between the groups. The number of patients with disabilities was 59%, patients with disabilities predominate in group 1, while patients without disabilities predominate in group 2. The family situation was characterized by a low percentage of individuals who were married (39%) and showed no significant differences between the groups; the mean age was 32.3±8.18 years. Parental status was characterized by a low childbearing rate (18%), with no significant difference between the groups despite the reproductive age of men and women.

Disability (p=0.01) or lack thereof (p=0.05), employment status (p=0.01), being married (p=0.03), and childlessness (p=0.01) influenced the decision in favour of surgical treatment of DR-TLE. Educational level and being unmarried were not statistically significant (p=0.2).

The socio-demographic profile of patients who underwent surgery for DR-TLE thus reflects the negative impact of disease duration on social functioning.

Table 3. Social and demographic characteristics in groups and cohort

Variable	Group 1 (n=78)		Group 2 (n=22)		Cohort (n=100)		p-value
	Number	Percent	Number	Percent	Number	Percent	
Disability							
Disabled	49	50	9	9	58	58	0.011*
Not disabled	29	28	13	13	42	42	0.05*
Employment							
Employed	17	24	5	7	22	31	0.011*
Not employed	38	53	8	11	46	64	0.015*
Students	2	3	1	1	3	4	0.1
Seniors	1	1	0	0	1	1	0.15
Level of education							
Secondary education	21	21	3	3	24	24	0.5
Vocational secondary education	33	33	8	8	41	41	0.08
Tertiary education	23	23	11	11	34	34	0.2
Family status							
Single	44	45	12	12	56	58	0.2
Married	30	31	8	8	38	39	0.03*
Living in cohabitation	3	3	0	0	3	3	0.5
Parental status							
Have children	13	17	5	22	18	18	0.5
Have no children	20	26	17	78	37	37	0.01*

DISCUSSION

The sociodemographic characteristics of neurosurgical patients with DR-TLE reflected the social problems of epilepsy: the predominance of young people of working age and the social maladjustment of patients with a long course of disease.[13] The duration of epilepsy before referral to a neurosurgical clinic not only worsened the social functioning of patients with epilepsy, but also inhibited the application of modern surgical treatment methods.[4] The preponderance of patients in group 1 who underwent resective surgery was due to several reasons. In the past, resective techniques were the main surgical management for drug-resistant epilepsy. Destructive techniques are modern methods and have not yet become established in clinical practice. The rate of destructive methods is higher in patients with a short course of epilepsy.

Consequently, destructive surgical techniques have become the methods of choice for the treatment of DR-TLE with a shorter disease duration. The phenomenon of late referral for surgical treatment of epilepsy played a negative role in the development of destructive methods.[3]

The efficacy of destructive techniques was higher in patients with a short duration of epilepsy.[4,5] However, late referral for surgical management reduced efficacy and limited the use of the technique.[3] The duration of the disease contributed to epileptogenesis and the formation of the epileptic system,[12] but also to suicidal behavior in patients.[16]

In the Department of Functional Neurosurgery No. 2 of Polenov Neurosurgical Institute, radiofrequency ablation of the epileptic focus has been used since 2017. Late recourse to neurosurgical management of epilepsy, plays a negative role in the application of destructive methods. The late use of surgical methods reduces efficacy rates and limits their implementation. The lack of significant differences between groups in terms of demographics and disease duration in our study reflected the current state of the problem.

At the same time, our previous studies have shown that the expressed willingness to undergo surgical management was three times higher than the actual willingness.[14] A study of comorbid anxiety and depression in patients with DR-TLE in a neurosurgical clinic found no significant impairment, suggesting a conscious decision.[15]

It is important to consider the impact of disability and unemployment on the decision to surgically manage for DRE. The presence of seizures may play a role in decision making, particularly in relation to employment opportunities for people with vocational training.

Thus, social awareness currently lags behind surgical management options for DR-TLE, negatively impacting the social functioning of people with epilepsy and increasing the social burden of the disease.

Study Limitation

It is a prospective study with a limited sample size.

CONCLUSION

The trend toward late neurosurgical management of drug-resistant epilepsy continues. The group of neurosurgical patients was socially maladjusted: two-thirds were disabled and unemployed, and only a quarter had a university degree.

It is necessary to educate physicians and patients about the current possibilities of epilepsy surgery.

Ethics

Ethics Committee Approval: Approval was obtained from the Ethics Committee of Almazov National Medical Research Centre (date: 18.04.2022, approval no: 2304-22).

Informed Consent: All patients signed an informed consent form.

Footnotes

Authorship Contributions

Surgical and Medical Practices: G.O., N.I., V.N., Concept: G.O., N.I., V.N., N.D., Design: G.O., V.N., N.D., Data Collection or Processing: N.I., N.D., Analysis or Interpretation: G.O., N.I., V.N., N.D., Literature Search: G.O., N.D., Writing: G.O., N.I., V.N., N.D.

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

Financial Disclosure: The authors declared that this study received no financial support.

REFERENCES

1. Legnani M, Bertinat A, Decima R, et al. Applicability and contribution of the new ILAE 2017 classification of epileptic seizures and epilepsies. *Epileptic Disord.* 2019;21(6):549-554. [Crossref]
2. Fisher RS, Acevedo C, Arzimanoglou A, et al. ILAE official report: a practical clinical definition of epilepsy. *Epilepsia.* 2014;55(4):475-482. [Crossref]
3. Krylov VV, Gekht1 AB, Trifonov IS, et al. Outcomes of surgical treatment of patients with pharmacoresistant epilepsy. *Zh Nevrol Psikhiatr Im S S Korsakova.* 2016;116(92):13-18. [Crossref]
4. Sitnikov AR, Skorobogatova VA, Maslova NN. Current neurosurgical approaches to treatment of structural epilepsies. *Annals of Clinical and Experimental Neurology.* 2019;13(1):70–77. (In Russ.) [Crossref]
5. Engel J Jr. Progress in epilepsy: reducing the treatment gap and the promise of biomarkers. *Curr Opin Neurol.* 2008;21(2):150-154. [Crossref]
6. Shlyakhto EV, Vasilievich Yu.I. Outcome-based healthcare. *Translational Medicine.* 2017;4(1):6-10. (In Russ.) [Crossref]
7. Berl MM, Zimmaro LA, Khan OI, et al. Characterization of atypical language activation patterns in focal epilepsy. *Ann Neurol.* 2014;75(1):33-42. [Crossref]
8. Karami M, Mehvari Habibabadi J, Nilipour R, Barekatain M, Gaillard WD, Soltanian-Zadeh H. Presurgical language mapping in patients with intractable epilepsy: a Review study. *Basic Clin Neurosci.* 2021;12(2):163-176. [Crossref]
9. Trimmel K, Caciagli L, Xiao F, et al. Impaired naming performance in temporal lobe epilepsy: language fMRI responses are modulated by disease characteristics. *J Neurol.* 2021;268(1):147-160. [Crossref]
10. Baumgartner C, Koren JP, Britto-Arias M, Zoche L, Pirker S. Presurgical epilepsy evaluation and epilepsy surgery. F1000Res. 2019;8:F1000 Faculty Rev):1818. [Crossref]
11. Baxendale S, Baker GA. Uses and abuses of the neuropsychological assessment in the presurgical evaluation of epilepsy surgery candidates. *Epilepsy Behav Rep.* 2021;18:100507. [Crossref]
12. Kwan P, Arzimanoglou A, Berg AT, et al. Definition of drug resistant epilepsy: consensus proposal by the ad hoc task force of the ILAE

commission on therapeutic strategies. *Epilepsia.* 2010;51(6):1069-1077. **[Crossref]**

13. Odintsova GV, Aleksandrov MV, Ulitin AY, Koloteva AV. Duration of epilepsy and severity of the disease in neurosurgical patients. *Epilepsy and Paroxysmal Conditions.* 2018;10(3):44-51. **[Crossref]**
14. Odintsova G, Dengina NO. Age of readiness for epilepsy surgery. *NJNS.* 2022;19(4)34-38. **[Crossref]**
15. Bannikova VD, Samochernykh KA, Dengina NO, Odintsova GV. Personalised treatment for epilepsy: gender-specific comorbid emotional disturbances in drug-resistant epilepsy in neurosurgical patients. *Russian Journal for Personalized Medicine.* 2022;2(1):63-72. **[Crossref]**
16. Shova NI, Mikhailov VA, Odintsova GV. "Suicidal passport" for epilepsy. *Epilepsy and Paroxysmal Conditions.* 2020;12(4):226-236. **[Crossref]**