

EPILEPSY Registry Cumulative Surgical Report





EPILEPSY Registry Cumulative Surgical Report 2000-2022

EPILEPSY Registry Cumulative Surgical Report by The Staff of EPILEPSY Registry, Research Centre Biostatistics Epidemiology & Scientific Computing Department

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Disease Registry is not a matter of technology; rather, it is the result of an intellectual attitude aimed at understanding and improving the principles upon which every medical activity should be based.

Therefore, everybody whose work concerns epilepsy can and should contribute to the advancement of Epileptology and the benefit of millions of human beings suffering from epilepsy.

The first milestone towards this goal in the Kingdom of Saudi Arabia was the establishment of the First Comprehensive Epilepsy Program in the kingdom in the year 1998 at King Faisal Specialist Hospital and Research Centre followed by the establishment of the hospital-based Epilepsy Registry. The registry is collecting data on various data items pertaining to the demographic profile of the patient, history, risk factors, medications, diagnostic issues, treatment, and surgical outcome. This year report describes the annual surgical cases variables in detail and report the outcome for the surgical procedures. We do hope that the statistics presented in this document will serve as a baseline both for the researchers and the healthcare.

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Dr. Abdulaziz Al Semari

Principal Investigator, Epilepsy Registry

Heknowledgements

This work would not have been possible without the great cooperation between the Department of Neurosciences and the Research Center represented by the Department of Biostatistics, Epidemiology & Scientific Computing (BESC) and Office of Research Affairs. Therefore, our special thanks to Dr. Edward Culper, Executive Director of the Research Centre, KFSH&RC, for his continued support in provision of resources for this registry.

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Top 10 Epilepsy Statistics for 2022

- Seizure can last up to 30 minutes or longer before risking permanent brain damage.
- Up to 75% of people with active epilepsy don't receive treatment.
- About 50 million people worldwide have epilepsy.
- Every year, nearly 5 million people worldwide are diagnosed with epilepsy.
- 32% of people with epilepsy can't work, as epilepsy statistics in the United States uncover.
- 3 million adults in the United States have epilepsy.
- 56% of people with epilepsy experienced seizures despite taking seizure medicine.
- 70% of people with epilepsy could live seizure-free if diagnosed and treated properly.
- Pediatric epilepsy's causes are unknown in 60%–70% of cases.
- 25% of Americans feel nervous around a person with epilepsy since they may have a seizure.

30 Astonishing Epilepsy Statistics & Facts for 2022 (medalerthelp.org)

Section 1 DEMOGRAPHIC DATA

1.1- Age & Gender

Among the 909 surgical cases of patient 56.8% (n=516) were adult patients and 43.2% (n=393) were pediatrics (<18 years of ae) There has been male predominance noted with 61.4(n=559) while 27.5% (n=355) were female. This is consistent with global studies as it is shown that men more than women have epilepsy in general by a small percentage.

Table 1. Distribution of patients according to gender

Age Group	Male	%	Female	%	Total	%
Pediatric	224	24.6	169	18.6	393	43.2
Adult	335	36.8	181	8.9	516	56.8
Total	559	61.4	350	27.5	909	100

Figure 1. Distribution of patients according to Age

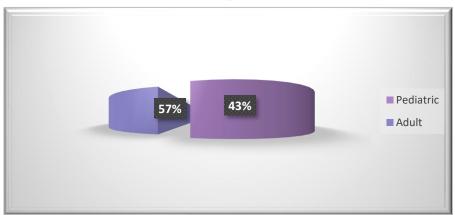
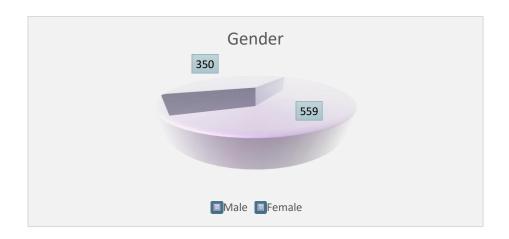


Figure 1.1 Distribution of patients according to gender



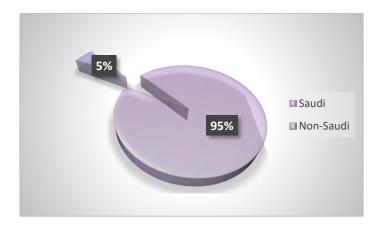
1.2- National

Demonstrates the sociodemographic of the total sample, most of the patients were Saudi (94.6%), and (5.4%) were non-Saudi.

Table 2 Distribution of the Patient's Nationality

Nationality	Male	Female	Total	%
Saudi	530	330	860	94.6
Non-Saudi	29	20	49	5.4
Total	559	350	909	100

Figure 2 Distribution of the Patient's Nationality



1.3- Geographic Region

Geographically, Kingdom of Saudi Arabia is divided into 13 regions and most of the registered cases were residing at the time of registration in Riyadh region 35.7%, (n=320) followed by Asir region (16.7%, n=150), Eastern Province 11.3%, (n=101) and Makkah 10.0%, (n=90).

Table3 Distribution of the Patients Residence

Region	Male	Female	Total	%
Saudi Arabia	550	346	896	98.6
Riyadh	188	132	320	35.7
Asir	98	52	150	16.7
Eastern Province	65	36	101	11.3
Makkah	55	35	90	10
Qasim	43	17	60	6.7
Jizan	16	20	36	4
Madina	17	18	35	3.9
Al Jouf	11	9	20	2.2
Hail	11	8	19	2.1
Tabuk	10	7	17	1.9
Najran	13	3	16	1.8
Baha	9	7	16	1.8
Northern Province	14	2	16	1.8
Outside Saudi Arabia	9	3	12	1.3
Unknown		1	1	0.1
Total	559	350	909	100

Figure 3 Distribution of the Patients Residence

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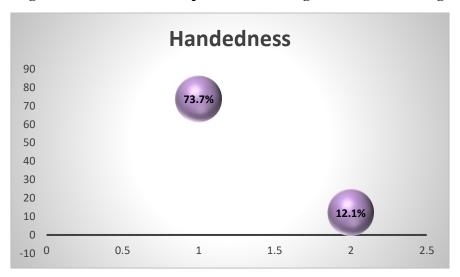
1.4- Handedness

Most of the surgical cases registered were right-handed 73.7 % (n=670) while 12.1% (n=110) have been reported as left-handed.

Table 4 Distribution of patients According to their Handwriting

Handedness	Male	Female	Total	%
Right	411	259	670	73.7
Left	70	40	110	12.1
Ambidextrous	12	7	19	2.1
Not Applicable	19	11	30	3.3
Unknown	47	33	80	8.8
Total	559	350	909	100

Figure 4 Distribution of the patients According to their Handwriting



1.5- Marital Status (Adult Population)

A significant number of adults are never married 51.9%, (n=268) whereas the remaining 211 (40.9%) were married. This may be the effect of social stigma on patients.

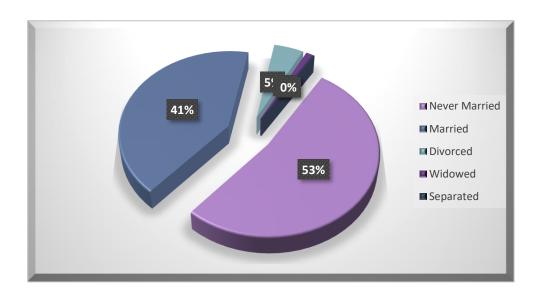


Figure 5 Distribution of the patients Martial Status.

1.6- Living Situation

The majority surgical cases of patient are living with their parents/siblings 75, 1 % (n=683) (Male & Female) this is a normal percentage, because the majority of the patients are not married. Followed by the patients who are living with their Spouse and Children 20. % (n=182).

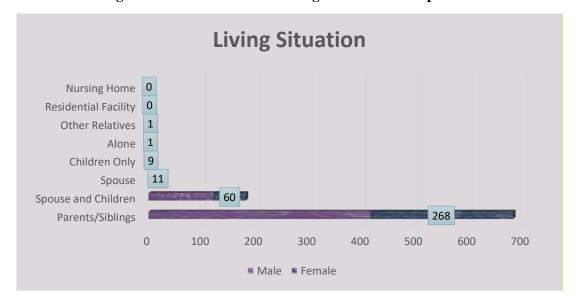


Figure 6 Distribution of the Living situation for the patients

1.7- Education Level

In terms of education the highest percentage of the Registered patients are in primary education 24.8%, (n=225) followed by completion of grade 10-12 19.6 %, (n=178). Also, significant portion of the population either has no education under category (NON) = above 18 years) or (NOT APPLICABLE= under-school age or severely disabled) (21.6% n=196)

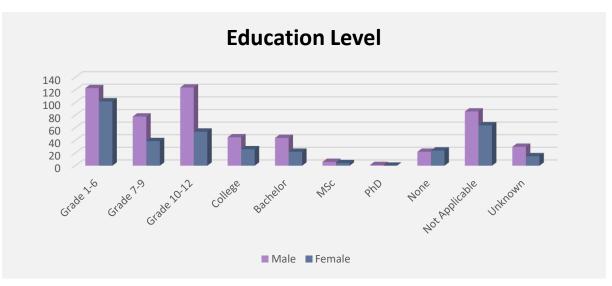


Figure 7 Distribution of the Patients Education level.

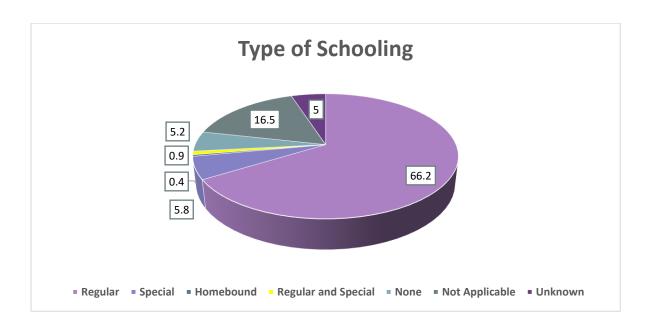
1.8- Type of Schooling

The majority surgical cases of patient are educated (66.8% n=668) are divided into three types of schools:

- Around 66.2% (n=602) of the patients have studied in a regular school
- 5.8% (n=53) studied in a special schooling
- A small percentage moved between Regular and Special schools 0.9% (n=8) **Table8 Distribution of the Schooling type for the patients**

Type of Schooling	Male	Female	Total	%
Regular	383	219	602	66.2
Special	31	22	53	5.8
Homebound	2	2	4	0.4
Regular and Special	5	3	8	0.9
None	23	24	47	5.2
Not Applicable	86	64	150	16.5
Unknown	29	16	45	5
Total	559	350	909	100

Figure8 Distribution of the Schooling type for the patients



1.9- Employment Status (Adult Population)

Regarding the Employment status of patients (n.159) 30.8 %they are employed, or they have been employed either full time or part time.

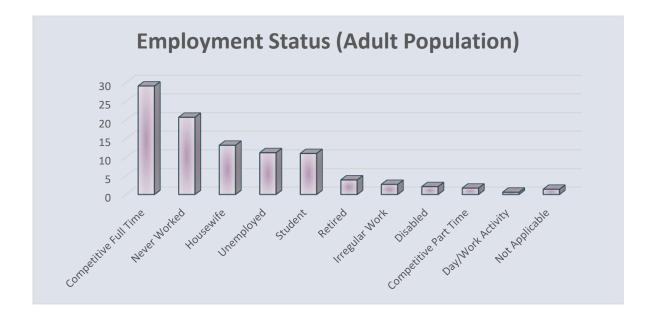
While (n.168) 32.5% surgical epilepsy patients have either never worked or are unemployed) they quit work) and Day/Work Activity and Day/Work Activity.

2.1% n = (11) have a disability that prevents them from working. Around 24.2 n= (125) are students or Housewife

Table9 Distribution of the patient's Employment Status

Employment	Male	Female	Total	%
Competitive Full Time	134	16	150	29.1
Never Worked	49	58	107	20.7
Housewife		68	68	13.2
Unemployed	49	9	58	11.2
Student	37	20	57	11
Retired	20		20	3.9
Irregular Work	14	•	14	2.7
Disabled	10	1	11	2.1
Competitive Part Time	9	٠	9	1.7
Day/Work Activity	3		3	0.6
Not Applicable	3	4	7	1.4
Unknown	7	5	12	2.3
Total	335	181	516	100

Figure 9 Distribution of the patient's Employment Status



1.10- Mental Retardation & Psychiatric History

While 25.8% (n= 234) of cases have been reported to have mental retardation. 14.9% (n=135) surgical cases have been reported to have some kind of psychiatric illness

Table10 Distribution of the patient's Mental Retardation

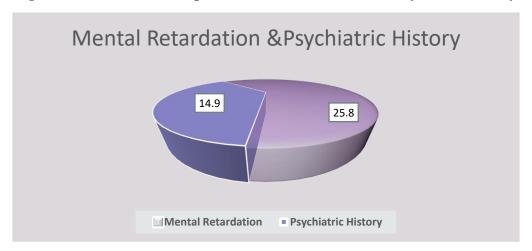
Mental Retardation	Male	Female	Count	Percent
Yes	139	95	234	25.8
No	409	247	656	72.4
Unknown	8	11	19	1.8
Total	556	353	909	100

Psychiatric History

Table11 Distribution of the patient's Psychiatric History

Psychiatric History	Male	Female	Count	Percent
Yes	77	58	135	14.9
No	472	281	753	82.8
Unknown	10	11	21	2.3
Total	559	350	909	100

Figure 10 Distribution of the patient's Mental Retardation & Psychiatric History



Section 2 CLINICAL DATA

2.1- Risk Factors

In terms of positive risk factors, Head Trauma (24.7%, n=190) and Family History (24.7%, n=190) are the highly reported risk factors among others followed by Febrile Convulsion (22.7%, n=175) and Pregnancy/Labor Complications (8.4%, n=65) while the risk of having CNS Infection (7.3%, n=56) and CNS Surgery (4.9%, n=38) before the seizures started is comparatively low.

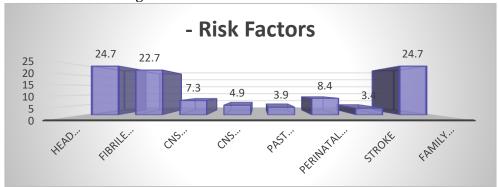
Table12 Distribution of the Risk Factor.

Risk Factors	Male	Female	Total	%
Head Trauma	151	39	190	24.7
Fibrile Convulsions	93	82	175	22.7
CNS Infection	37	19	56	7.3
CNS Surgery	23	15	38	4.9
Past Epilepsy Surgery	16	14	30	3.9
Perinatal/Labour Complications	41	24	65	8.4
Stroke	16	10	26	3.4
Family History	108	82	190	24.7
Total	485	285	770	100

In general, the top three risk factors

- Head Trauma
- Family History
- Fibrile Convulsions

Figure 11 Distribution of the Risk Factor.



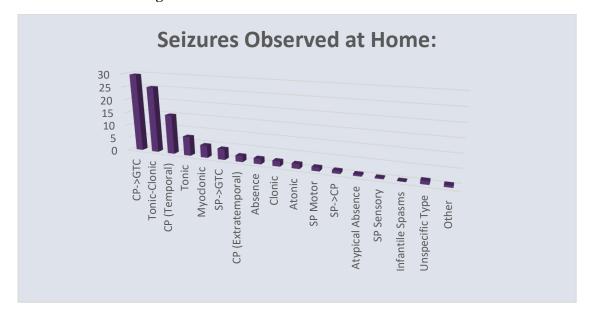
2.2- Seizures Observed at Home:

Majority of the surgical cases of patient reported to experience CP->GTC seizures (29.6 %, n=268) and Tonic-Colonic (25.2%, n=228) at home followed by CP (Temporal) (15.0%, n=136), while (4.7% n=43) cases are reported to have Myoclonic seizures.

Table13 Distribution of the Seizures Observed at Home

Seizure Type (Home)	Male	Female	Total	%
CP->GTC	170	98	268	29.6
Tonic-Clonic	145	83	228	25.2
CP (Temporal)	78	58	136	15
Tonic	39	27	66	7.3
Myoclonic	23	20	43	4.7
SP->GTC	24	13	37	4.1
CP (Extratemporal)	12	9	21	2.3
Absence	12	7	19	2.1
Clonic	13	5	18	2
Atonic	10	6	16	1.8
SP Motor	11	2	13	1.4
SP->CP	6	4	10	1.1
Atypical Absence	4	2	6	0.7
SP Sensory	1	3	4	0.4
Infantile Spasms	2		2	0.2
Unspecific Type	6	8	14	1.3
Other	3	5	8	0.8
Total	559	350	909	100

Figure 12 Distribution of the Seizures Observed at Home



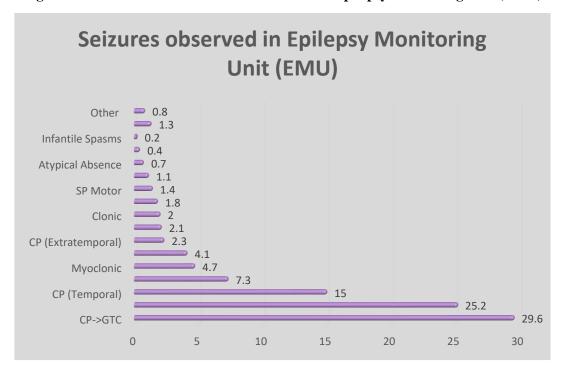
2.3- Seizures observed in Epilepsy Monitoring Unit (EMU)

Following trend has been seen among the 900 patients admitted and observed in the Epilepsy Monitoring Unit (EMU) where 27.7% (n=249) CP->GTC, while 24.6% (n=221) cases have been reported to have Tonic-Colonic seizures followed CP (Temporal) by 17.1 %, (n=154). 6.7 %(n=60) have experienced Tonic, while 0.3% (n=3) have reported to have Non-Epilepsy Seizures Unspecific Type.

Table14 Distribution of the Seizures observed in Epilepsy Monitoring Unit (EMU)

Seizure Type (EMU)	Male	Female	Total	%
CP->GTC	153	96	249	27.7
Tonic-Clonic	140	81	221	24.6
CP (Temporal)	97	57	154	17.1
Tonic	38	22	60	6.7
Myoclonic	28	15	43	4.8
SP->GTC	28	12	40	4.4
CP (Extratemporal)	10	11	21	2.3
Clonic	9	7	16	1.7
Atonic	11	5	16	1.7
SP Motor	8	5	13	1.4
SP->CP	7	6	13	1.4
Atypical Absence	5	4	9	1
Absence	5	4	9	1
SP Sensory	1	4	5	0.6
Infantile Spasms	1	3	4	0.4
Sp Psychic	1		1	0.1
SP Autonomic	•	1	1	0.1
Unspecific Type	6	8	14	1.5
Other	11	9	20	2.2
Total	559	350	909	100



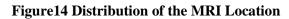


2.4- MRI Location

Most of the Problems that were noted during the MRI are either in the Temporal Lobe 51.2% (n=465) and then in the Frontal Lobe 15.1% (n=137) followed by Hemisphere 10.3% (n=94), 10.0% (n=91) cases were Normal.

Table15 Distribution of the MRI Location

Location	Male	Female	Total	%
Temporal Lobe	295	170	465	51.2
Frontal Lobe	92	45	137	15.1
Hemisphere	50	44	94	10.3
Parietal Lobe	17	17	34	3.7
Occipital Lobe	6	9	15	1.7
Multiple Loops	10	3	13	1.4
Fronto-Temporal	8	1	9	1
Generalized	8	1	9	1
Cerebellum	4	4	8	0.9
Fronto-Parietal	3	4	7	0.8
Basal Ganglia	2	4	6	0.7
Tempero-Parietal	4	1	5	0.6
Insula	3	1	4	0.4
Parieto-Occipital	2	2	4	0.4
Tempero-Occipital	1	2	3	0.3
Intraventricular, Periventricular	2	1	3	0.3
Brain Stem		1	1	0.1
Corpus Collasum		1	1	0.1
Normal	52	39	91	10
Total	559	350	909	100



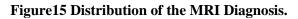


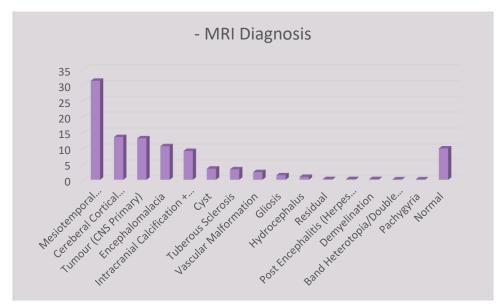
2.5- MRI Diagnosis

MRI diagnosis is reported to be normal for 9.9% (n=89) while 31.3% (n=281) cases have been diagnosed with Mesiotemporal Sclerosis/Atrophy following by Cereberal Cortical Dysgenesis

Table16 Distribution of the MRI Diagnosis.

Diagnosis	Male	Female	Total	%
Mesiotemporal Sclerosis/Atrophy	192	89	281	31.3
Cereberal Cortical Dysgenesis	72	49	121	13.5
Tumour (CNS Primary)	68	50	118	13.1
Encephalomalacia	59	36	95	10.6
Intracranial Calcification + Atrophy	48	34	82	9.1
Cyst	17	14	31	3.5
Tuberous Sclerosis	20	10	30	3.3
Vascular Malformation	11	11	22	2.4
Gliosis	6	7	13	1.4
Hydrocephalus	4	4	8	0.9
Residual	1	1	2	0.2
Post Encephalitis (Herpes Simplix)	1	1	2	0.2
Demyelination	1	1	2	0.2
Band Heterotopia/Double Cortex Synd.	1		1	0.1
Pachygyria	1		1	0.1
Normal	49	40	89	9.9
Total	551	347	898	100





2.6- PET Location

The PET scan also confirmed the results of the MRI, where most of the Problems were present in the Temporal Lobe 43.9% (n=399) Then those problems coming from Frontal Lobe 10.3% (n=71).

Table17 Distribution of the PET Location

Location	Male	Female	Total	%
Temporal Lobe	258	141	399	43.9
Frontal Lobe	56	39	95	10.5
Hemisphere	29	36	65	7.2
Parietal Lobe	18	14	32	3.5
Multiple Loops (>2)	15	10	25	2.8
Ant Temporal Lobe	19	4	23	2.5
Med Temporal Lobe	14	4	18	2
Ocipital Lobe	3	5	8	0.9
Generalized	4	2	6	0.7
Basal Ganglia	1	2	3	0.3
Thalamus	1	1	2	0.2
Cerebellum	2		2	0.2
Lat Temporal Lobe	2		2	0.2
Hypothalamus	1		1	0.1
Not Done	136	92	228	25.1
Total	559	350	909	100

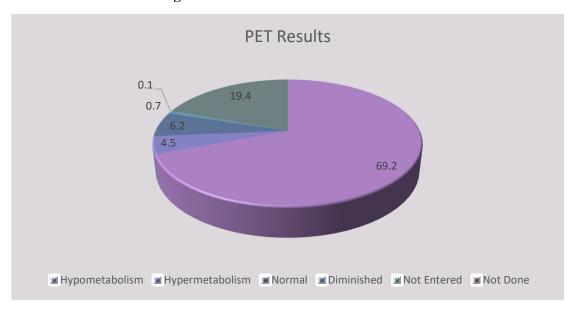
2.7- PET Results:

Among 732 cases that underwent PET investigation, 69.2% (n=629) are found to have Hypometabolism, while Normal results have been noted in 6.5% (n=56) and Hypermetabolism has been seen in 4.5 % (n=41).

Table 18 Distribution of the PET Result.

PET Results	Male	Female	Total	%
Hypometabolism	390	239	629	69.2
Hypermetabolism	27	14	41	4.5
Normal	32	24	56	6.2
Diminished	4	2	6	0.7
Not Entered	1		1	0.1
Not Done	105	71	176	19.4
Total	559	350	909	100

Figure 16 Distribution of the PET Result.



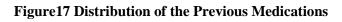
Section 3 TREATMENT

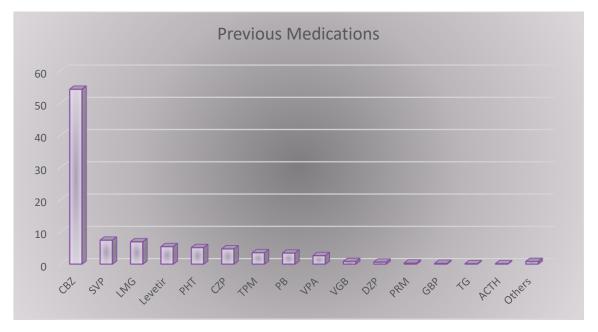
3.1- Previous Medications

Around 54.2% (n=493) cases have been prescribed previously on Carbamazepine followed by Sodium Valproate (7.4%, n=7.4) and Lamotrigine (6.9%, n=63)

Table19 Distribution of the Previous Medications

Medications	Male	Female	Total	%
CBZ	296	197	493	54.2
SVP	35	32	67	7.4
LMG	38	25	63	6.9
Levetir	32	17	49	5.4
PHT	29	17	46	5.1
CZP	31	12	43	4.7
TPM	20	12	32	3.5
РВ	25	6	31	3.4
VPA	16	8	24	2.6
VGB	5	2	7	0.8
DZP	4	1	5	0.6
PRM	2	1	3	0.3
GBP	2		2	0.2
TG		1	1	0.1
ACTH		1	1	0.1
Others	2	5	7	0.8
None	1	7	8	0.9
Unknown	21	6	27	3.0
Total	559	350	909	100.0



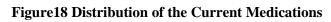


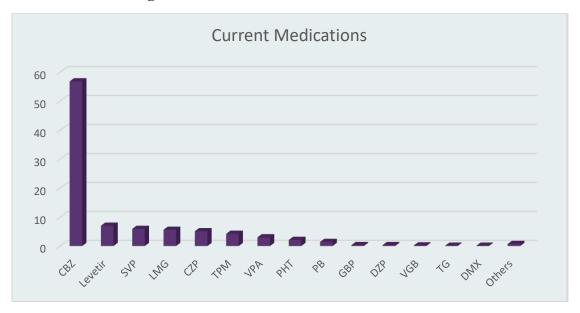
3.2- Current Medications

Almost same trend can be seen in the current medications prescribed to the patients where 56.8% (n=516) cases are on Carbamazepine followed by Levetir (7.0%, n=64) and Sodium Valproate 5.9%, (n=54)

Table20 Distribution of the Current Medications

Medications	Male	Female	Total	%
CBZ	313	203	516	56.8
Levetir	35	29	64	7.0
SVP	36	18	54	5.9
LMG	34	17	51	5.6
CZP	31	15	46	5.1
ТРМ	21	17	38	4.2
VPA	19	8	27	3.0
PHT	12	7	19	2.1
РВ	11	2	13	1.4
GBP	3		3	0.3
DZP	1	2	3	0.3
VGB	2		2	0.2
TG		1	1	0.1
DMX		1	1	0.1
Others	5	1	6	0.7
None	23	18	41	4.5
Unknown	13	11	24	2.6
Total	559	350	909	100.0





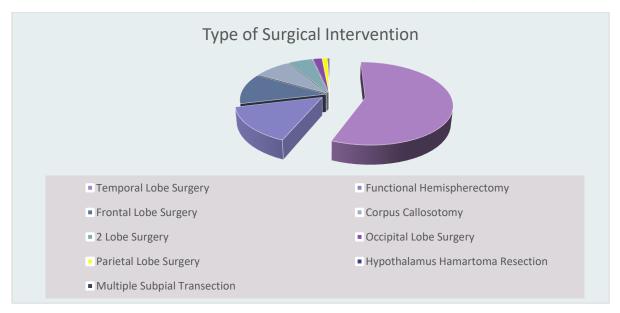
3.3- Type of Surgical Intervention

Among 909 surgical cases 55.9 (n=508) are Temporal Lobe Surgery cases, followed by Functional Hemispherectomy (14.7 %(n=134) Frontal Lobe Surgery was 12 % (n=109)

Table21 Distribution of the Surgical Intervention type

Surgical Procedure	Male	Female	Total	%
Temporal Lobe Surgery	321	187	508	55.9
Functional Hemispherectomy	67	67	134	14.7
Frontal Lobe Surgery	75	34	109	12
Corpus Callosotomy	47	24	71	7.8
2 Lobe Surgery	31	17	48	5.3
Occipital Lobe Surgery	10	7	17	1.9
Parietal Lobe Surgery	2	8	10	1.1
Hypothalamus Hamartoma Resection		2	2	0.2
Multiple Subpial Transection	1	1	2	0.2
Other	5	3	8	0.9
Total	559	350	909	100

Figure 19 Distribution of the Surgical Intervention type



3.4- Primary Pathology

A total of 11cases (n=1.2%) reported a report a normal surgical pathology, while sclerosis / gliosis is reported among 33.9% (n=308) followed by tumor (CNS Primary) 15.7% (n= 143) and , 12.8% (n= 116) Cortical Dysplasia , Heterotopia were 10.3% (n = 94)

Table22 Distribution of the Primary Pathology

Surgical Pathologies	Male	Female	Total	%
Normal	8	3	11	1.2
Sclerosis/Gliosis	198	110	308	33.9
CNS Primary)	87	56	143	15.7
Cortical Dysplasia	73	43	116	12.8
Heterotopia	49	45	94	10.3
Encephalomalacia	15	12	27	3
Chronic inflammation	6	11	17	1.9
Vascular Malformation	8	8	16	1.8
Meningioma	2	3	5	0.6
LEPTOMENINGEAL ANGIOMATOSIS (STURGE-WEBER SYNDROME)	3	1	4	0.4
Post Traumatic Ischaemia, Anoxia	2	1	3	0.3
Glioneuronal Hamartoma	1	2	3	0.3
Ependymoma	2		2	0.2
Hamartoma		1	1	0.1
Others	15	8	23	2.5
No Specific Pathological Change	29	15	44	4.8
None	13	7	20	2.2
Unknown	2	2	4	0.4
Not Done	46	22	68	7
Total	559	350	909	100

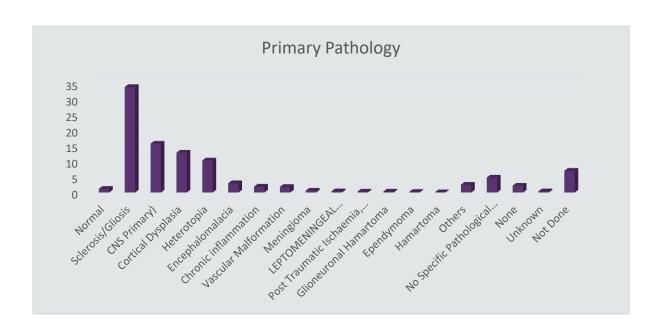


Figure 20 Distribution of the Primary Pathology

3.5- Surgical Outcomes

To measure the outcome of epilepsy surgical we Following International League Against Epilepsy ILEA classification

1= completely seizure free; no auras

2= only auras; no other seizures

3= One to three seizure days per year

Outcome of Epilepsy Surgical Procedures:

3.5.1- First Years Surgical Outcome of Epilepsy Surgical Procedures

The following graph shows excellent surgical outcome of epilepsy surgical procedures in the First Year according to the classification of International League against Epilepsy (ILAE).

Table 23 Distribution of the First Years Surgical Outcome of Epilepsy Surgical Procedures.

Surgical Procedure	Total # of Surgeries	Seizure Free with NO Aura	%	Seizure Free WITH Aura	%	1-3 Seizures	%	Excellent Surgical Outcome	%
Temporal Lobe Surgery	449	267	59.5	20	4.5	52	11.6	339	75.5
Frontal Lobe Surgery	101	51	50.5	1	1	5	5	57	56.4
Parietal Lobe Surgery	8	3	37.5	1	12.5	1	12.5	5	62.5
2 Lobe Surgery	43	21	48.8	2	4.7	5	11.6	28	65.1
Functional Hemispherectomy	121	69	57			5	4.1	74	61.2
Occipital Lobe Surgery	16	5	31.3	1	6.3			6	37.5
Corpus Callosotomy	67	9	13.4			5	7.5	14	20.9
Hypothalamus Hamartoma Resection	2	1	50					1	50
Multiple Subpial Transection	2	2	100					2	100
Other	8	3	37.5				12.5	4	50

Figure 21 Distribution of the First Years Surgical Outcome of Epilepsy Surgical Procedures.



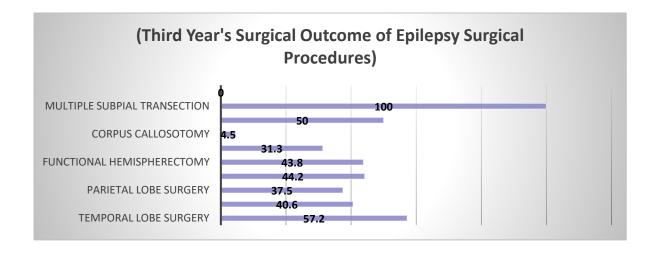
3.5.2- Third Year's Surgical Outcome of Epilepsy Surgical Procedures

The following graph shows excellent surgical outcome of epilepsy surgical procedures in the Third Year according to the classification of International League against Epilepsy (ILAE)

Table24 Distribution of the First Years Surgical Outcome of Epilepsy Surgical Procedures.

Surgical Procedure	Total # of Surgeries	Seizure Free with NO Aura	(%)	Seizure Free with Aura	(%)	1-3 Seizures	(%)	Excellent Surgical Outcome	(%)
Temporal Lobe Surgery	449	210	46.8	13	2.9	34	7.6	257	57.2
Frontal Lobe Surgery	101	34	33.7	1	1	6	5.9	41	40.6
Parietal Lobe Surgery	8	1	12.5	1	12.5	1	12.5	3	37.5
2 Lobe Surgery	43	17	39.5			2	4.7	19	44.2
Functional Hemispherectomy	121	48	39.7	1	0.8	4	3.3	53	43.8
Occipital Lobe Surgery	16	5	31.3					5	31.3
Corpus Callosotomy	67	2	3			1	1.5	3	4.5
Hypothalamus Hamartoma Resection	2	1	50					1	50
Multiple Subpial Transection	2	2	100					2	100
Other	8								

Figure 22 Distribution of the Third Year's Surgical Outcome of Epilepsy Surgical Procedures





THANK YOU

