

A STUDY TO ASSESS THE QUALITY OF LIFE AMONG EPILEPSY PATIENTS AT AIIMS, JODHPUR WITH A VIEW TO DEVELOP AN INFORMATION BOOKLET

A Thesis submitted to the

All India Institute of Medical Sciences, Jodhpur

In partial fulfilment of the requirement for the degree

Master of Science in Nursing

(Medical Surgical Nursing-Neuroscience Nursing)

By

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[2021]

DECLARATION BY THE CANDIDATE

I hereby declare that the thesis entitled —A study to assess the quality of life among epilepsy patients at AIIMS, Jodhpur with a view to develop an information booklet is a bonafide work carried out by me under the guidance of Dr. Ashok Kumar, Associate Professor, College of Nursing, All India Institute of Medical Sciences (AIIMS), Jodhpur (Rajasthan). No part of this thesis has formed the basis for the award of any degree previously.

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CERTIFICATE BY THE GUIDE

This is to certify that the thesis entitled —A study to assess the quality of life among epilepsy patients at AIIMS, Jodhpur with a view to develop an information booklet—, is a bonafide work done by Ms. Shweta Sharma in partial fulfilment of requirement for the award of M.Sc. (Nursing) degree of the All India Institute of Medical Sciences, Jodhpur under the guidance of undersigned. She has carried out the work at College of Nursing, All India Institute of Medical Sciences, Jodhpur.

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LIST OF ABBREVIATIONS USED

df- Degree of freedom

f- Frequency

SD- Standard Deviation

χ^2 - Chi square test

N- Number

%- Percentage

QOLIE -31- Quality of Life in Epilepsy -31

ABSTRACT

INTRODUCTION- Epilepsy is a neurological disorder and has negative effect on quality of life among epilepsy patients and their relatives. Quality of life (QOL) is impaired among epilepsy patients on many aspects in addition to complications due to seizure episodes and having a poor health condition, associated stigma, and being socially isolated.

OBJECTIVES- To assess the quality of life among epilepsy patients and determine the association of quality of life among epilepsy patients with selected socio-demographic and clinical variables of epilepsy.

METHOD- A non-experimental descriptive research design with quantitative approach was conducted on a sample of 250 epilepsy patients. Data was collected through face to face and telephonic interview on patients taking treatment in AIIMS Jodhpur and having epilepsy for at least 1 year or more.

RESULTS- 70.8% patients had good quality of life, 24.8% had fair quality of life whereas 4.4% had poor quality of life. The mean quality of life score was 56.88 with standard deviation of 11.46. This shows good quality of life among epilepsy patients at AIIMS, Jodhpur. The highest mean was for social functioning, 82.4 (22.04) followed by cognitive functioning, 78.93 (23.48) and lowest was for seizure worry, 58.82 (25.75) followed by energy/fatigue, 65.78 (23.11). Education, income per month, triggering factor, presence of seizure in past 4 weeks were found to be associated with overall quality of life score at $p < 0.05$ level of significance.

CONCLUSION- The study findings showed that social functioning is least affected for epilepsy patients as compared to worry about seizure and low energy which are more affected. Results of the study suggest that there is statistically significant association between the overall quality of life score and the selected socio-demographic and clinical variables of the study as per chi-square analysis.

KEYWORDS- Quality of life; Epilepsy patients; Information booklet.

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CHAPTER I

INTRODUCTION

CHAPTER I: INTRODUCTION

Background of the study:

Epilepsy is a non-communicable chronic neurological disorder that can affect any individual irrespective of age and gender. The word -epilepsyll means to be taken, seized or attacked.¹

As per the International League Against Epilepsy, epilepsy can be described as at least two or more unprovoked seizures that occur at least 24 hours apart or a single unprovoked seizure with a recurrence risk of at least 60% over the next 10 years or an identifiable epileptic syndrome.¹

Many diseases can be responsible for epilepsy, but the exact cause is still not known in about half of the cases worldwide. The etiology of epilepsy can be categorized into: structural, infectious, genetic, metabolic, idiopathic and immune-mediated.²

Every year, International Epilepsy Day is celebrated on the second Monday of February to encourage epilepsy patients to live their life to the fullest possible way. It provides a chance for epilepsy patients to share their experiences with a global audience. It is celebrated to increase awareness and educate the general population on the true facts about epilepsy and the importance of improved treatment, better care of persons with epilepsy, and greater investment in research.³

Seizure is sometimes also called a fit or convulsion. A seizure is a result of abnormal and excessive electrical discharges from the neural tissue. It results in a sudden and abnormal functioning of the body, often associated with loss of consciousness, loss or excess of muscular activity, or an abnormal sensation.⁴

The excessive nerve-cell discharges or excitation may remain in a small or local area of the brain (a localized lesion or focus) which gives rise to partial (focal) seizures, or

begin immediately in the whole brain or spread from the small area or focus to the whole brain and spinal cord leading to generalized seizures. These discharges can vary in site, severity and extent.⁴

Two main categories of seizure are: **Idiopathic, or cryptogenic** in which the cause of seizure episode is not known and **symptomatic** in which the cause of seizure episode is known.⁵

Depending upon the area of the brain causing the seizures, there are two seizure classifications— partial and generalized seizures.

A **partial seizure** takes place when the abnormal electrical discharge takes place in one area of the brain. Two sub-types of partial seizure are **simple partial seizure** during which the patient is having consciousness and, mostly, is also aware about the environment. The other is **complex partial seizure** in which the patient becomes unconscious and most of the time does not remember that the seizure attack has taken place. If, however remembered, the memory of seizure episode will be vague.⁵

A generalized seizure episode occurs when the abnormal electrical discharge occurs in both hemispheres of the brain and the patient becomes unconscious during the seizure episode.

Tonic-clonic seizures (grand mal seizures) cause the person to lose consciousness, shaking and stiffness of body. **Absence seizures**, also known as **petit mal seizures**, cause short periods of interruption in consciousness where the patient stares towards the sky for a few seconds. In **tonic seizures**, the muscles of the body become stiff that can put a person at risk of fall whereas in atonic seizures, losing the tone of muscles can cause the patient to fall suddenly. **Clonic seizures** involve movements of arms and legs and sometimes face also in a rhythmic and

jerking manner. **Myoclonic seizures** result from involuntary twitching of muscles usually in the upper body parts.⁵

About 10% of the worldwide load of neurological diseases is due to epilepsy.⁶ About 50 million people are affected with epilepsy all over world.² 7.6 / 1000 population have epilepsy during their lifetime. The impact of epilepsy is large and is often ignored among public health issues. The approximate proportion of the epilepsy patients among the general population at a given period of time is about 4 - 10 / 1000 people.⁷

More than 80% of epilepsy patients are from low or middle socio-economic background which puts them at risk for poor quality of life. Also, more than half of the epilepsy patients can live without having any seizure episode if timely diagnosed and properly treated. Epilepsy patients are having thrice more risk for premature death as compared to healthy people.²

Divyani Garg (2020) reported that nearly 10–12 million people with epilepsy are living in India, which contributes to almost one-sixth of the disease burden. The incidence of epilepsy in India is 0.2 - 0.6/1000/year and prevalence range from 3.0 - 11.9/1000 population. A large proportion of epilepsy patients do not receive appropriate treatment, which leads to a large treatment gap. The article showed that poor awareness of antiepileptic drugs, cultural practices, social stigma regarding epilepsy, lack of accessibility to healthcare services, and a severe shortage of medical professionals trained in the management of epilepsy are major contributors for the treatment gap.¹

Epilepsy has various and adverse effects on the subjective or overall quality of life among epilepsy patients.⁸ It is also having serious physical, social and psychological

problems associated with it.⁹ Some of the epilepsy patients can have co-existing physical or mental conditions.⁴

Epilepsy patient's quality of life is thought to be poor particularly when seizure attack and number of seizure episodes are not in proper control and is further deteriorated by the presence of psychological disturbances. The aim of curing epilepsy should not necessarily be seizure eradication but also obtaining maximum improvement in quality of life.¹⁰

Health related-quality of life refers to the impact of long-term illness on patient's individual experience in physical, social, emotional and psychological domains.¹⁰

Epilepsy patients as well as their families are having stigma and discrimination related to epilepsy all over the world. Many parents don't send their children with epilepsy to school and adults are refused to give work, to drive and to marry.⁷

The violation of human rights encountered by epilepsy patients all over the world are irrelevant and not acceptable. Improvement of knowledge and raising awareness about epilepsy are needed to decrease the stigma.⁷

Several aspects of epilepsy, including duration of disease, age at onset, severity of seizure attack and frequency of seizures, are thought to affect the quality of life among epilepsy patients. However, seizure frequency is a consistent predictor of quality of life among epilepsy patients.¹¹

Patients whose epilepsy is not under control often have a feeling that they are a burden for others, because their activities of daily living are affected due to epilepsy. Moreover, epilepsy patients have more chances to get some mental illness or psychological stress, and reporting physical problems.¹¹

Epilepsy patients are more at risk for reduced quality of life due to its effect on physical as well as psycho-social dimensions that affect the overall quality of life.¹²

Dr. Ashis Datta (2020) in an article reported that persons with epilepsy have challenging quality of life as epilepsy has impact on different parts of life. They may have poor self-esteem, high anxiety levels and depression. Most of them are unemployed with low marriage rate and more socially isolated. Moreover, despite advances in education, people are having many misconceptions and stigma related to epilepsy which also directly or indirectly affects the quality of life.¹³

Epilepsy can be treated with the help of anti-epileptic drugs and surgery. Anti-epileptic drugs are the most commonly used treatment for epilepsy patients. They help to control seizure episodes in around 7/10 of people. But there are associated side effects also which need to be identified and managed to prevent poor quality of life.¹⁴

Need of the study:

Epilepsy has negative effect on quality of life among epilepsy patients and their families. QOL is impaired among epilepsy patients on many aspects in addition to complications due to seizure episodes and having a chronic disease condition, associated stigma, and being socially isolated. It also affects the physical, psychological and emotional aspects of a person's life.¹⁰

Almost 20% of the patients coming in the neurology OPD of AIIMS, Jodhpur are of epilepsy. 6 out of 1000 people are suffering from epilepsy. Around 2500 people come to AIIMS OPD for taking treatment of epilepsy every year.¹⁵

News reported in Times of India revealed that the anxiety level in patients with epilepsy in the COVID -19 pandemic period went up causing an increase in number

of seizure episodes during lockdown. An epilepsy patient, resident of Rajasthan consulted his doctor telling about fear and anxiety of getting infected with corona virus. The anxiety alone was the reason for frequent seizure episodes.¹⁶

Also, it was found that there were some other epilepsy patients also who reported the same symptoms. This anxiety can cause sleep disturbances and changes in activities of daily living which make a person more prone to depression, anxiety and seizure episodes.¹⁶

Epilepsy patients often experience changes in their quality of life like less mobility, as well as the impact of epilepsy on learning, academic performance, job, relationships, and social interactions. Patients living with epilepsy also suffer from major depression and dysthymia. Some patients experience mild types of depression that can affect their quality of life and also treatment response.¹⁷

Data shows that unemployment, use of combination therapy and lower socio-economic class were having negative effect on quality of life among epilepsy patients.²¹

Though various studies are there in India which assessed the quality of life among epilepsy patients but from Rajasthan are very few and the number of epilepsy patients are increasing day by day due to various false practices and inadequate knowledge.¹⁸

Majority of the epilepsy patients and their caregivers are not having enough and proper knowledge about triggers of seizure attack, care during and after seizure attack, anti-epileptic drug therapies, adverse effects of medicines, follow-up, etc. which affects the quality of life among epilepsy patients.

Thus, researcher conducted the present study in order to assess the quality of life among epilepsy patients at AIIMS, Jodhpur and develop an information booklet to improve the quality of life among epilepsy patients.

Aim- To assess the quality of life among epilepsy patients at AIIMS, Jodhpur and develop an information booklet.

Problem Statement- A study to assess the quality of life among epilepsy patients at AIIMS, Jodhpur with a view to develop an information booklet.

Objectives-

The objectives of the study are: -

1. To assess the quality of life among epilepsy patients at AIIMS, Jodhpur.
2. To determine the association of quality of life among epilepsy patients with selected socio-demographic and clinical variables of epilepsy.

Rationale-

The present study was carried out to assess the quality of life among epilepsy patients and develop an information booklet. According to a news published in a leading Hindu newspaper Dainik Bhaskar (Nov 22, 2019), around 2500 epilepsy patients are coming to AIIMS, Jodhpur every year for their treatment and 20% of the total patients coming to neurology OPD of AIIMS, Jodhpur are of epilepsy.¹⁵ According to a data published in INDIAN EPILEPSY ASSOCIATION (2013), Western parts of Rajasthan have more number of epilepsy patients. Ignoring the disease condition, practice of getting treated through non-professional health workers, stigma and high treatment gaps are leading to increasing number of epilepsy cases.¹⁸ Therefore, to fill the gap of knowledge about epilepsy and its treatment, the researcher felt a need to assess the quality of life among epilepsy patients and

develop an information booklet with a view to improve the quality of life among epilepsy patients.

Hypothesis-

Hypothesis is tested at a significance level of 0.05.

Null hypothesis (H_0)-

- There is no significant association of overall quality of life score of epilepsy patients with selected socio-demographic variables.
- There is no significant association of overall quality of life score of epilepsy patients with clinical variables of epilepsy.

Research hypothesis (H_1)-

- There is a significant association of overall quality of life score of epilepsy patients with selected socio-demographic variables.
- There is a significant association of overall quality of life score of epilepsy patients with clinical variables of epilepsy.

Operational definitions-

Quality of life- 'Quality of life' stands for the standard of health, comfort, and ability to participate in or enjoy life events among epilepsy patients.

Epilepsy patient – It refers to a patient who is having two or more unprovoked seizure episodes.

Information Booklet- It refers to a small, thin book of 4-5 pages giving information about epilepsy.

Delimitations-

Study was delimited to epilepsy patients in the age group of 18 to 60 years having partial or generalized epilepsy from at least one year or before at All India Institute of Medical Sciences, Jodhpur.

Summary:

This chapter deals with the introduction, need of study, statement of problem, objectives of study, operational definitions and delimitations of the study.

CHAPTER II

REVIEW OF LITERATURE

CHAPTER II: REVIEW OF LITERATURE

Literature review is an important step of any research study. Review of literature is a broad, comprehensive study, systematic and critical review of educational publications, unpublished materials and audio-visual materials.

The literature review also gives a proper background for a particular research study. The literature review keeps the researcher updated with the research findings of a particular field. The objectives of the review are to discover certain aspects that need to be included into the study to confirm or refuse earlier findings, to find certain data that may be available in interpreting the conclusion of the study. It was also necessary to ascertain, what has already been done in the field of study and what more needs to be done.

Muche EA, et al (2020) carried out a study on 354 patients to determine the quality of life and factors affecting quality of life in epilepsy patients. The average QOLIE-10 score was 19.85. Good quality of life was found in 54.8 % participants. Illiteracy, unemployment and presence of co-morbidities were associated with poor quality of life. The study found that half of the patients had poor quality of life. Patients having some co-morbidity, illiteracy and unemployment should be given more focus to improve their quality of life.¹⁹

Addis B, et al (2020) conducted a research study to measure quality of life among 370 epilepsy patients using QOLIE-31. 55.81 was the mean overall HRQOL score. The score of energy sub scale was the lowest among the seven scales. Significant positive association was found for social support whereas seizure frequency, depression, perceived stigma, anxiety and adverse drug reaction were negatively

associated with quality of life. The study concluded that the quality of life among epilepsy patients was low and mostly affected by emotional and energy aspects.²⁰

Jauhari R, et al (2019) conducted a research on 65 epilepsy patients to assess their quality of life using QOLIE-31. 30.6% of the participants were on monotherapy and 69.0% were on polytherapy. 39.12 was the mean total QOLIE-31 score. The study concluded that epilepsy patients had poor quality of life with low total QOLIE-31 score. Unemployment, use of combination therapy and lower socio-economic class were having association with lower quality of life among epilepsy patients.²¹

Kaddumukasa M, et al (2019) carried out a study on 48 epilepsy patients to find the association between severity of seizure and quality of life in Uganda using QOLIE-31. The mean of QOLIE-31 score was 62.5. An inverse relationship was seen between severity of seizure and the total QOLIE-31 score, and seizure worry. The study concluded that seizure severity directly impacts the life of epilepsy patients.²²

Nagarathnam M, et al (2017) conducted a prospective study to assess the role of demographic, socioeconomic, clinical factors and stigma in quality of life among 170 epilepsy patients using QOLIE-31 and stigma questionnaire. 60.29 was the mean total quality of life score and 22.21 was the mean stigma score. Majority of epilepsy patients had mild stigma. Stigma as well as polytherapy were the important factors affecting quality of life. The study concluded that in addition to seizure control, use of monotherapy and destigmatization programs may help to improve the quality of life among epilepsy patients.²³

Sureka RK, et al (2017) assessed the quality of life among 70 epilepsy patients using QOLIE-31 questionnaire. The mean of QOLIE-31 score was 60.46. A major difference was seen in the total QOLIE-31 score between the groups taking

monotherapy and polytherapy. The study concluded that patients taking monotherapy had a much better quality of life than the patients on polytherapy.²⁴

Singh P, Pandey AK (2016) carried out a study on 101 epilepsy patients to assess the quality of life at a tertiary care hospital using QOLIE-9. 65 patients were having partial seizures and 36 patients were having generalized seizures. Seizure frequency per month had positive correlation with total QOLIE-9 scores and had high statistical significance. The study concluded that seizure frequency, low educational qualification and single status were having negative effect on quality of life among epilepsy patients.²⁵

Gholami A et al (2016) performed a study on 52 epilepsy patients in Neyshabur to determine the quality of life compared to healthy persons. Each patient was compared to two healthy persons. Both groups were similar for age, gender and social background. The mean total score of SF- 36 were 55.88 and 68.52 in patient and healthy group respectively which was significant. The study concluded that epilepsy affects the quality of life among epilepsy patients to a large extent.²⁶

Mutluay FK et al (2016) determined the quality of life among 124 epilepsy patients and see the association of demographic and clinical variables. All SF-36 average scores were lower for women as compared to men. The study concluded that epilepsy patients were not aware of impaired health status. Moreover, the mental health of patients appears to be poor, especially in women. Therefore, mental health requires to be more focussed in epilepsy patients.²⁷

Anu M, et al (2016) assessed the quality of life among epilepsy patients attending outpatient departments of a hospital on 98 subjects. 53.9 was the mean total quality of life score. People having low educational qualification and poor control of seizures

had significantly lower mean total quality of life score. The study concluded that treatment of epilepsy, demographic and clinical variables affect the quality of life among patients in various aspects of life.²⁸

Pimpalkhute SA et al (2015) assessed the quality of life among epilepsy patients in a tertiary care teaching hospital on 60 patients using QOLIE-31. 64.61 was the mean total QOLIE-31 score. Scores of cognitive functioning and medication effects were better in group taking carbamazepine than on valproate. The study concluded that patients taking monotherapy had a better quality of life as compared to polytherapy.²⁹

Mehta S, et al (2014) evaluated the clinical factors affecting quality of life among 31 epilepsy patients using QOLIE-31. Only frequency of seizures was found to have significant correlation with seizure worry, emotional well-being and social functioning subscales of QOLIE-31. The study concluded that the care of epilepsy patients should be aimed at prevention of seizures as well as treating depression which alone can affect the quality of life among epilepsy patients to a large extent.³⁰

Ranjana G, et al (2014) conducted a research study on 451 epilepsy patients to evaluate effect of socio-demographic, clinical and pharmacotherapy aspects on quality of life among adult epilepsy patients using modified QOLIE-10. The mean quality of life score was 64.1. The study concluded that patients taking monotherapy had better quality of life and those having low income, focal epilepsy and receiving anti-epileptic drugs had poor quality of life. Increased frequency of seizures and adverse drug reactions were found to be significant predictors of quality of life among epilepsy patients.³¹

Norsa'adah B, et al (2013) determined the quality of life and its association with presence of seizures in 106 epilepsy patients using QOLIE-31. 68.9 was the mean total QOLIE-31 score. Patients having presence of seizures in the last four weeks were found to have lower mean quality of life score than those who had no seizure. The study concluded that worrying about seizure was the main factor contributing to quality of life, while medication effect was the least.³²

Ashwin M, et al (2013) evaluated the quality of life among 100 epilepsy patients using WHOQOL-BREF questionnaire. The mean quality of life score was 51.49. The study concluded that quality of life among epilepsy patients was low in the psychological domain, patients having age more than 30 years and female gender.³³

Romy Mahrer-Imhof, et al (2012) conducted a cross-sectional study to determine the factors influencing quality of life among hospitalized adult epilepsy patients and their relatives at a hospital in Switzerland among 104 patients using QOLIED-36. The quality of life among relatives was affected by the patients' knowledge of the disease but patient's quality of life scores had no effect on quality of life of relatives. It showed that both epilepsy patients as well as their relatives should be taken care of well-being and coping abilities.³⁴

Shakir M, Al-Asadi JN (2012) compared the quality of life among 116 epilepsy patients and 116 healthy persons in Iraq using SF-36. Epilepsy patients were having low quality of life as compared to healthy persons. The study concluded that age, educational qualification, monthly income, duration of illness and frequency of seizures were significant determinants of quality of life among epilepsy patients.³⁵

Shetty PH, et al (2011) conducted a study on 60 epilepsy patients in Belgaum, India to assess the quality of life and to evaluate various factors affecting the quality of life

in them using QOLIE-89 instrument. The study concluded that quality of life was affected in epilepsy patients with more effect in women, aged patients, patients having simple partial seizures, increased duration of epilepsy and those with recent seizures.³⁶

Gordon-Perue G, et al (2011) explored the quality of life among 109 epilepsy patients in Jamaica and see the effect of socio-demographic variables using QOLIE-31 questionnaire. The study concluded that polytherapy, duration of epilepsy and social functioning were the significant factors affecting quality of life among epilepsy patients in Jamaica.³⁷

Zhao Y et al (2011) evaluated the quality of life among 303 adult epilepsy patients in north China using the QOLIE-89. Seizure worry and medication effects mostly affected the quality of life as compared to other subscales. The study concluded that quality of life among adult epilepsy patients reduces with old age, course of disease, and high frequency of seizures. More educational qualification and high socio-economic status affected the quality of life positively.³⁸

CHAPTER III

METHODOLOGY

CHAPTER III: METHODOLOGY

The methodology of any research study is of vital importance. It is a description of the methods applied in a particular research study. Foundations of research are built and conducted over a structure called methodology and a valid study will always adapt encouraging research methodology.

In this chapter, the researcher explains research methodology including research study approach, research study design, study setting, study sample and sampling technique. This chapter also includes the development and description of tool, validity of content, reliability of tool, pilot study, data collection, plan of data analysis and plan for information booklet development.

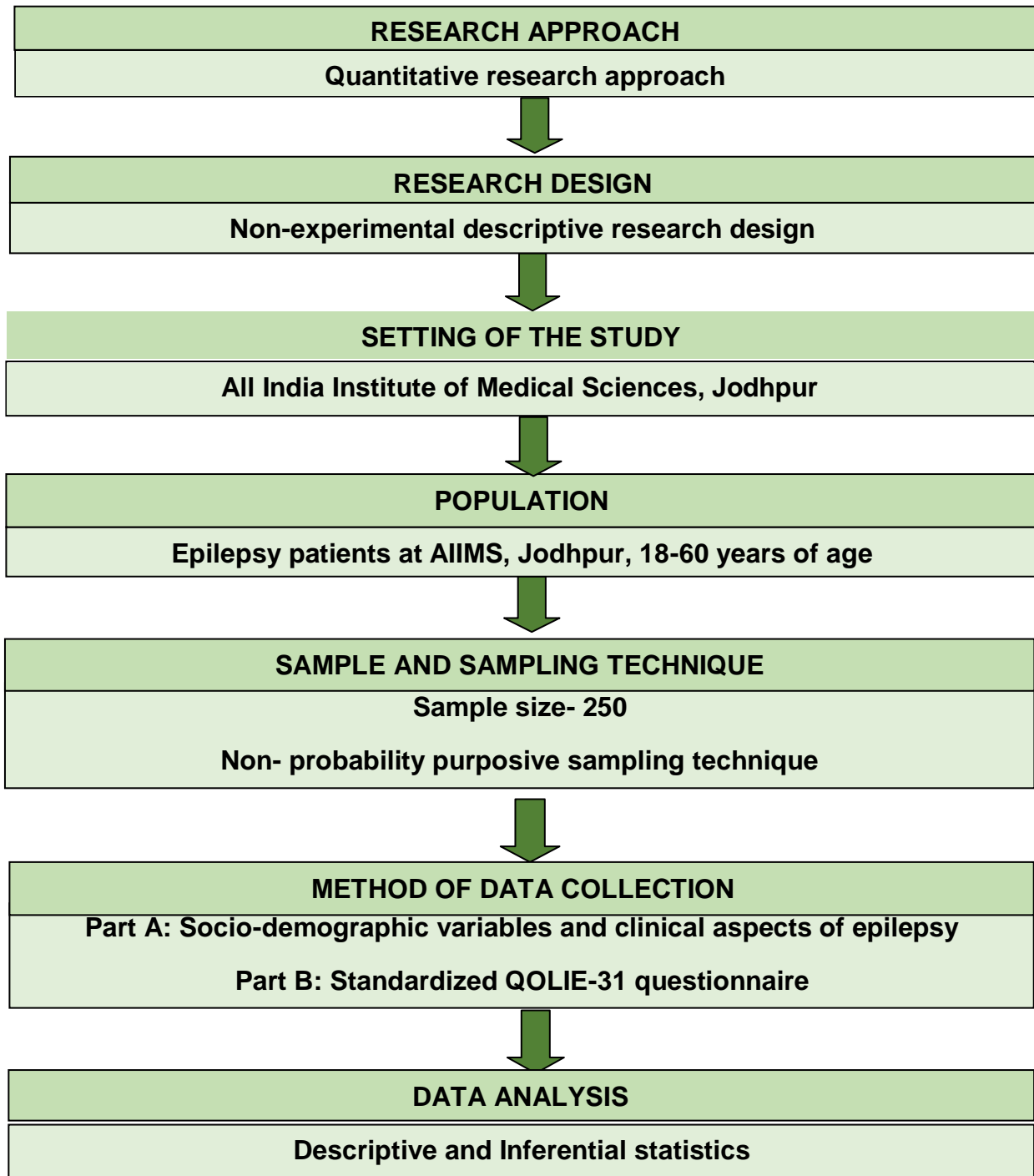


Fig.1. Schematic presentation of research methodology

Research approach-

Quantitative research approach was used in the present study to assess the quality of life among epilepsy patients at AIIMS, Jodhpur.

Research design-

Non-experimental descriptive research design was used in the present study.

Variables under study-

In present study, socio-demographic variables used are age, gender, marital status, employment status, educational level, social background and economic status and clinical variables of epilepsy like age of onset, type of seizure, duration of epilepsy, treatment, co-morbidity, family history, triggering factor and presence of seizure in past 4 weeks.

Study setting-

The study was conducted at All India Institute of Medical Sciences, Jodhpur.

AIIMS, Jodhpur was established by the Ministry of Health & Family welfare, Government of India under the Pradhan Mantri Swasthya Suraksha Yojna (PMSSY). The hospital is fully functioning since 2013 and day by day more and more departments and advanced facilities are adding up in current system. At present, all the departments are running their OPDs & IPDs, all the diagnostic tests and

operative services to the needies are provided. At present around 950 beds are functional for patient care.

Population-

The population of the present study comprises epilepsy patients at AIIMS, Jodhpur who are 18 -60 years of age.

Sample and sampling technique-

In the present study, sample comprises of the epilepsy patients at AIIMS, Jodhpur and non- probability purposive sampling technique was used to select the sample.

Sample size: -

Sample size is calculated through **Cochran** formula:

$$n_0 = \frac{Z^2 pq}{e^2}$$

Where:

- n_0 is the sample size.
- Z is 1.96 from Z table.
- e is the desired level of precision i.e. 5% (0.05)
- p is the (estimated) proportion of the population
- q is $1 - p$.

So, for the present study, p is 0.2 (prevalence of 20%) and q is 0.8.

$$n_0 = ((1.96)^2 (0.2) (0.8)) / (0.05)^2 = 245.76 \sim 246$$

In this study, a sample of 250 epilepsy patients coming to AIIMS, Jodhpur who are 18 to 60 years of age will be taken.

Criteria for sample selection:

It consists of two parts: -

Inclusion criteria

- Patients who are available during the time of data collection.
- Patients who are giving consent to participate in the study.
- Patients who are 18-60 years of age and diagnosed with epilepsy at-least one year or before.
- Patients who can understand Hindi or English.
- Patients having partial and generalized seizures.

Exclusion criteria

- Patients with head injuries, stroke, brain tumours, psychotic disorders, chronic disease or disability and learning disorders.
- Patients who developed seizure after brain surgery.

Development and selection of tools-

In the present study, data was collected in 2 parts:

Part A – Questionnaires to collect socio-demographic data (age, gender, marital status, employment status, educational level, social background and economic

status) and clinical variables of epilepsy (age of onset, type of seizure, duration of epilepsy, treatment, co-morbidity, family history, triggering factor and presence of seizure in past 4 weeks).

Part B – Quality of Life in Epilepsy -31 (QOLIE-31) questionnaire.

Description of tool-The QOLIE-31 is a standardized tool to assess the quality of life for adults who are 18 years or older suffering from epilepsy. This questionnaire is to be completed only by an epilepsy patient (not a friend or relative). It contains 31 items and has seven subscales:

Table I: - Sub-scale wise number of items

Sub-scale	Items	Number of items
Seizure worry	11,21,22,23,25	5
Overall QOL	1,14	2
Emotional well- being	3,4,5,7,9	5
Energy/fatigue	2,6,8,10	4
Cognitive functioning	12,15,16,17,18,26	6
Medication effects	24,29,30	3
Social functioning	13,19,20,27,28	5

Scoring of Tool-

The pre-coded numeric values of subscale items are converted to 0-100-point scale. T-scores are determined for each of the 0-100-point scale. Higher T-score reflect a more favourable quality of life. The value of T-score lies between 11 to 73.³⁹

Table II: - Range for T-score (to determine quality of life)

Quality of life	T-score
Poor	11-31
Fair	32-52
Good	53-73

Ethical consideration - The ethical consideration was taken from Institutional Ethical Committee of AIIMS, Jodhpur. The permission for using Standardised QOLIE-31 Tool was obtained through mail from the developer.

Informed consent was obtained from each patient and they were assured of confidentiality and autonomy to leave the study at any time of data collection.

Validity of tool- Part A of tool i.e. socio-demographic and clinical variables of epilepsy were validated from 5 experts of nursing department of various institutes and certain modifications were done in the tool according to expert's and guide's suggestions.

Reliability of tool-

The reliability of tool was determined by Cronbach's alpha.

Reliability of tool was 0.967 which is within acceptable range (0.91-1.00 - Excellent).

Pilot study-

A pilot study was conducted on 10% of the total sample size of the main study i.e. 25 epilepsy patients having epilepsy for at least 1 year and seeking treatment at AIIMS, Jodhpur.

Duration of pilot study was 2 weeks.

Data collection procedure-

- Prior to data collection, formal permission was obtained from the concerned authority of the Institute for collecting data.
- The permission of standardized QOLIE-31 tool was obtained from the tool developer through mail.
- Sample selection was done based on inclusion and exclusion criteria.
- Data collection was done from 1/11/2020 to 30/11/2020.
- Data collection was done through telephonic and face to face interview due to the pandemic COVID-19 condition.
- Self-introduction was given to subjects and the aim of the study was explained.
- Verbal informed consent was taken.
- Instructions about tool were explained.
- Questions were asked and responses were recorded in the data collection sheet.

Plan for data analysis-

The obtained data was analysed using the following plan of analysis: -

- Use of descriptive and inferential statistics for data analysis.
- Frequency and percentage distribution to describe the patient characteristic.
- Mean and standard deviation of sub-scales of different domains.
- Chi-square to determine association of quality of life with socio-demographic and clinical variables.
- Mean and standard deviation of T-score reflecting level of quality of life.

Plan for information booklet development

The information booklet on epilepsy will aim to improve the quality of life among epilepsy patients.

The title of the information booklet will be **“Epilepsy: Improving the quality of life.”**

It will contain information regarding the following:

- What is epilepsy
- Causes of epilepsy
- Symptoms of epilepsy
- Triggers of seizure attack
- Care during and after seizure attack
- Treatment of epilepsy
- Effect of epilepsy on activities of daily living
- Medication follow-up
- Myths and facts related to epilepsy

Summary

This chapter deals with the research methodology of the present study which includes research study approach, research study design, study variables, study population, study setting, study sample, sampling technique, description of tools, validity and reliability, ethical consideration, pilot study, data collection procedure, data analysis plan and plan for information booklet development.

CHAPTER IV

ANALYSIS AND INTERPRETATION

CHAPTER IV: ANALYSIS AND INTERPRETATION

The chapter deals with the analysis and interpretation of results of present study. Data collection is followed by analysis and interpretation of data in accordance with study objectives.

The analysis is based on the following **objectives of the study**: -

1. To assess the quality of life among epilepsy patients at AIIMS, Jodhpur.
2. To determine the association of quality of life among epilepsy patients with selected socio-demographic and clinical variables of epilepsy.

ORGANIZATION AND PRESENTATION OF DATA: -

Accordingly, the data was first tabulated and analysed in accordance with the objectives of the study.

The analysis of data is presented in the following sections:

SECTION 1: Socio-demographic variables of epilepsy patients.

SECTION 2: Clinical variables of epilepsy patients.

SECTION 3: Findings related to domains and quality of life among epilepsy patients.

SECTION 4: Findings related to association of overall quality of life score of epilepsy patients with selected socio-demographic variables.

SECTION 5: Findings related to association of overall quality of life score of epilepsy patients with clinical variables of epilepsy.

SECTION 1

Socio-demographic variables of epilepsy patients

250 epilepsy patients were included in the study. Information on socio-demographic variables - age, gender, marital status, employment status, educational level, social background and economic status were tabulated and analysed to obtain frequency and percentage distribution.

Table III deals with the socio-demographic variables of epilepsy patients.

Table III: - Frequency and percentage distribution of epilepsy patients as per socio-demographic variables

N=250			
S.No.	Variables	F	%
1.	Age (in years)		
	a) 18-25	103	41.2
	b) 26-35	79	31.6
	c) 36-60	68	27.2
2.	Gender		
	a) Male	159	63.6
	b) Female	91	36.4
3.	Marital status		
	a) Unmarried	75	30.0
	b) Married	175	70.0
4.	Education		
	a) Illiterate	10	4.0
	b) Primary	16	6.4
	c) Secondary	47	18.8
	d) Higher secondary	99	39.6
	e) Graduation	67	26.8
	f) Above graduation	11	4.4
5.	Occupation		
	a) Government employment	13	5.2
	b) Private employment	68	27.2
	c) Unemployment	70	28.0
	d) Self-employment	44	17.6
	e) Homemaker	55	22.0
6.	Social background		
	a) Rural	93	37.2
	b) Urban	157	62.8
7.	Income per month (in rupees)		
	<15,000	135	54.0
	16,000-25,000	47	18.8
	26,000-35,000	56	22.4
	36,000-45,000	12	4.8

Table 3 depicts the frequency and percentage distribution of epilepsy patients as per socio-demographic variables. It was found that 41.2% patients were in age group of 18-25 years, whereas 31.6% were in age group of 26-35 years and 27.2% were in age group of 36-60 years. The mean age of patients was 30.76. 63.6% of patients were male and 36.4% were female. 30% of patients were unmarried whereas 70% were married. Educational status: 4% of patients had no formal education, 6.4% had primary education, 18.8% had secondary education, 39.6% had higher secondary education, 26.8% had graduation degree and 4.4% were above graduation. 5.2% of patients had government employment, 27.2% had private employment, 28% were unemployed, 17.6% were self-employed and 22% were homemaker. 37.2% patients were from rural background and 62.8% from urban background. As regard to income per month, 54% subjects had family income less than rupees 15000, 18.8% subjects had family income between rupees 16000 to 25000, 22.4% subjects had family income between rupees 26000-35000 and 4.8% subjects had family income between 36000-45000 per month.

SECTION 2

Clinical variables of epilepsy patients

Information on clinical variables of epilepsy – Patient's age at onset, type of seizure, duration of epilepsy, treatment, co-morbidity, family history, triggering factor and presence of seizure in past 4 weeks were tabulated and analysed to obtain frequency and percentage distribution.

Table IV deals with the clinical variables of epilepsy patients.

Table IV: - Frequency and percentage distribution of epilepsy patients as per clinical variables

N=250

S.No.	Variables	f	%
1.	Patient's age at onset (in years)		
	a) 0-20	128	51.2
	b) 21-40	113	45.2
	c) 41-60	9	3.6
2.	Type of seizure		
	a) Partial seizure	23	9.2
	b) Generalized seizure	227	90.8
3.	Duration of epilepsy (in years)		
	a) 1-10	183	73.2
	b) 11-20	52	20.8
	c) 21-30	10	4.0
	d) 31-40	5	2.0
4.	Treatment		
	a) Monotherapy	43	17.2
	b) Polytherapy	197	78.8
	c) No treatment	10	4.0
5.	Co-morbidity		
	a) No	215	86.0
	b) Yes	35	14.0
	• Hypertension	23	65.71
	• Diabetes mellitus	4	11.42
	• Both hypertension and diabetes mellitus	2	5.71
	• Heart surgery	2	5.71
	• Cancer	1	2.85

	• Tuberculosis	1	2.85
	• Rectal prolapse	1	2.85
	• Skin problem	1	2.85
6.	Family history		
	a) No	241	96.4
	b) Yes	9	3.6
	• Mother	3	33.33
	• Father	1	11.11
	• Grandmother	1	11.11
	• Grandfather	1	11.11
	• Paternal uncle	1	11.11
	• Maternal uncle	1	11.11
	• Sister	1	11.11
7.	Any triggering factor known		
	a) No	208	83.2
	b) Yes	42	16.8
	• Stress	19	45.23
	• Lack of sleep	10	23.80
	• Missed dose	6	14.28
	• High temperature	3	7.14
	• Hunger	2	4.76
	• Headache	2	4.76
8.	Presence of seizure in past 4 weeks		
	a) Yes	45	18.0
	b) No	205	82.0

Table 4 depicts frequency and percentage distribution of epilepsy patients as per clinical variables. It was found that the age at onset of epilepsy was between 0-20

years for 51.2% of patients, 21-40 years for 45.2% patients and 41-60 years for 3.6% patients. 9.2% of patients had partial seizures whereas 90.8% patients had generalized seizures. The duration of epilepsy was between 1-10 years for 73.2% of patients, 11-20 years for 20.8% patients, 21-30 years for 4% patients and 31-40 years for 2% patients. 17.2% of patients were on monotherapy, 78.8% on polytherapy and 4% were not taking any treatment presently. 14% of patients were having some co-morbidity like hypertension, diabetes mellitus, both diabetes mellitus and hypertension, heart surgery, cancer, rectal prolapse, tuberculosis and skin problems whereas 86% patients were not having any co-morbidity. 3.6% of patients were having family history of epilepsy like mother, father, grandmother, grandfather, maternal uncle, paternal uncle and sister whereas 96.4% patients were not having any family history of epilepsy. 16.8% of patients were having some triggering factor known like stress, lack of sleep, missed dose, headache, high temperature and hunger whereas 83.2% patients were not knowing about any triggering factor. 18% of patients had presence of seizures in past 4 weeks whereas 82% patients were not having any seizure episode in past 4 weeks.

SECTION 3

Findings related to domains and quality of life among epilepsy patients.

This section deals with findings related to domains and quality of life among epilepsy patients.

Standardized Quality of Life in Epilepsy -31 (QOLIE-31) questionnaire consists of 31 questions based on seizure worry, overall QOL, emotional well-being, energy/fatigue, cognitive functioning, medication effects and social functioning.

After obtaining data of 250 samples, they were categorized among levels of quality of life based on T-scores.

Table V: Level of quality of life as per T-scores of patients

		N=250
Level of quality of life (T-score)	f (%)	Mean \pm SD
Poor (11-31)	11 (4.4)	56.88 \pm 11.46
Fair (32-52)	61 (24.8)	
Good (53-73)	178 (70.8)	

T-score shows level of quality of life. Higher T-score reflect more favourable quality of life.

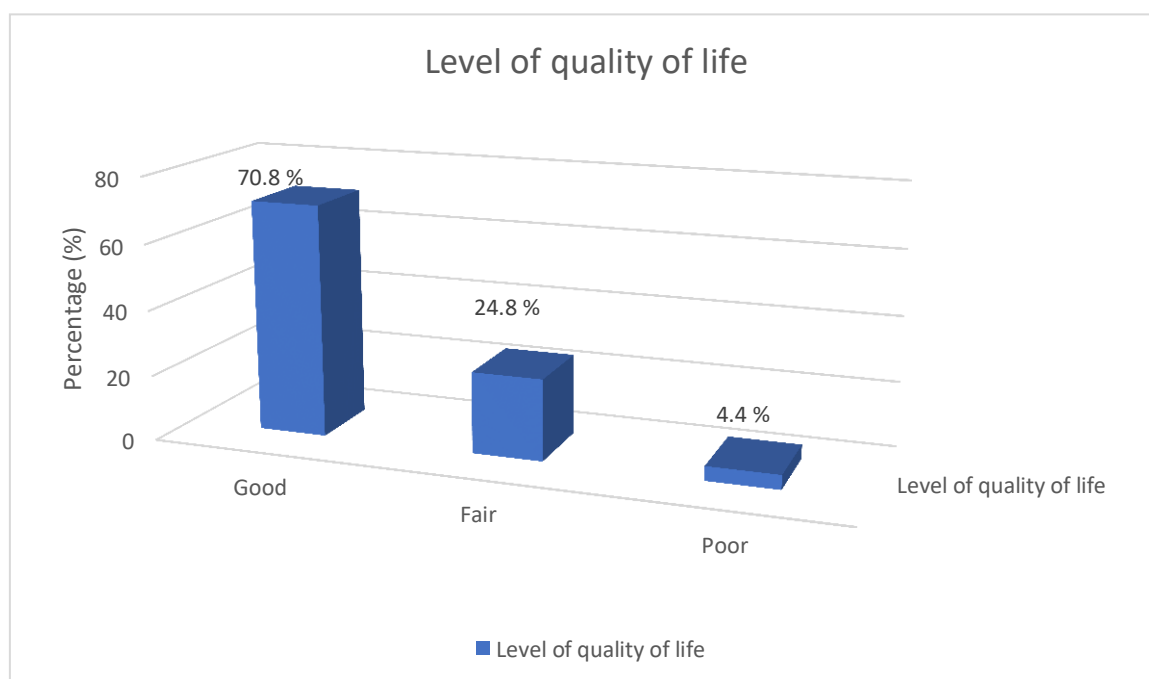


Figure. 2. Level of quality of life among epilepsy patients

Table 5 and figure 2 depicts level of quality of life among epilepsy patients as per T-scores. 70.8% patients had good quality of life, 24.8% had fair quality of life whereas 4.4% had poor quality of life. The mean quality of life score is 56.88 with standard deviation of 11.46 indicating overall good quality of life among epilepsy patients.

Table VI: Sub-scale wise mean and standard deviation of quality of life among epilepsy patients

N=250	
Sub-scale	Mean \pm SD
Seizure worry	58.82 \pm 25.75
Overall QOL	67.29 \pm 16.91
Emotional well-being	75.07 \pm 20.66
Energy/fatigue	65.78 \pm 23.11
Cognitive functioning	78.93 \pm 23.48
Medication effects	72.09 \pm 25.07
Social functioning	82.4 \pm 22.04

Table 6 depicts sub-scale wise mean and standard deviation of quality of life among epilepsy patients. The highest mean was for social functioning, 82.4 (22.04) followed by cognitive functioning, 78.93 (23.48) and lowest was for seizure worry, 58.82 (25.75) followed by energy/fatigue, 65.78 (23.11). This shows that social functioning is least affected for epilepsy patients as compared to worry about seizure and low energy which are more affected.

SECTION 4

Findings related to association of overall quality of life score of epilepsy patients with selected socio-demographic variables.

This section deals with association of overall quality of life score of epilepsy patients with selected socio-demographic variables.

To determine the significant association between overall quality of life score of epilepsy patients with selected socio-demographic variables, following research variables were selected:

- Age
- Gender
- Marital status
- Employment status
- Educational level
- Social background
- Economic status

Table VII: Association of overall quality of life score of epilepsy patients with selected socio-demographic variables

S.no.	Variables	Quality of life		X ²	df	N=250 p-value
		Poor/Fair	Good			
1.	Age					
	18-25	34	69	1.84 ^{NS}	2	0.39
	26-35	22	57			
	36-60	16	52			
2.	Gender					
	Male	43	116	0.65 ^{NS}	1	0.41
	Female	29	62			
3.	Marital status					
	Unmarried	27	48	2.70 ^{NS}	1	0.10
	Married	45	130			
4.	Education					
	Illiterate	4	6	14.87*	5	0.01
	Primary	10	6			
	Secondary	13	34			
	Higher secondary	28	71			
	Graduation	12	55			
	Above graduation	5	6			
5.	Occupation					
	Government employment	5	8	8.86 ^{NS}	4	0.06
	Private employment	13	55			
	Unemployment	27	43			
	Self-employment	9	35			
	Homemaker	18	37			
6.	Social background					
	Rural	28	65	0.12 ^{NS}	1	0.72
	Urban	44	113			
7.	Income per month					
	<15,000	51	84	13.31*	3	0.00
	16,000-25,000	9	38			
	26,000-35,000	8	48			
	36,000-45,000	4	8			

NS= Non-significant (>0.05); * = Significant (<0.05)

Note: Due to a smaller number of patients in poor category, it was merged with fair category.

Table 7 depicts association of overall quality of life score of epilepsy patients with selected socio-demographic variables. It was found that education and income per month were statistically significant with the overall quality of life score at $p < 0.05$ whereas age, gender, marital status, occupation and social background were not found significant at $p < 0.05$. This shows that patients having lower educational qualification have poor quality of life as compared to patients having higher educational qualification. Patients having low socio-economic status are having poor quality of life as compared to those having high socio-economic status.

SECTION 5

Findings related to association of overall quality of life score of epilepsy patients with clinical variables of epilepsy

This section deals with association of overall quality of life score of epilepsy patients with clinical variables of epilepsy.

To determine the significant association between overall quality of life score of epilepsy patients with clinical variables of epilepsy, following research variables were selected:

- Patient's age of onset
- Type of seizure
- Duration of epilepsy
- Treatment
- Co-morbidity
- Family history
- Triggering factor
- Presence of seizure in past 4 weeks

Table VIII: Association of overall quality of life score of epilepsy patients with clinical variables of epilepsy

S.No.	Variables	Quality of life		X ²	df	N=250 p-value
		Poor/Fair	Good			
1.	Patient's age at onset (in years)					
	0-20	41	87	3.05 ^{NS}	2	0.21
	21-40	27	86			
	41-60	4	5			
2.	Type of seizure					
	Partial seizure	8	15	0.44 ^{NS}	1	0.50
	Generalized seizure	64	163			
3.	Duration of epilepsy (in years)					
	1-10	53	130	2.74 ^{NS}	3	0.43
	11-20	13	39			
	21-30	3	7			
	31-40	3	2			
4.	Treatment					
	Monotherapy	8	35	2.63 ^{NS}	2	0.26
	Polytherapy	61	136			
	No treatment	3	7			
5.	Co-morbidity					
	Yes	11	24	0.13 ^{NS}	1	0.71
	No	61	154			
6.	Family history					
	Yes	4	5	1.11 ^{NS}	1	0.29
	No	68	173			
7.	Any triggering factor known					
	Yes	28	14	35.29*	1	0.00
	No	44	164			
8.	Presence of seizure in past 4 weeks					
	Yes	31	14	43.01*	1	0.00
	No	41	164			

NS= Non-significant (>0.05); * = Significant (<0.05)

Note: Due to a smaller number of patients in poor category, it was merged with fair category.

Table 8 depicts association of overall quality of life score of epilepsy patients with clinical variables of epilepsy. It was found that knowing any triggering factor and presence of seizure in past 4 weeks were statistically highly significant with the overall quality of life score at $p < 0.05$ whereas patient's age at onset, type of seizure, duration, treatment, co-morbidity and family history were not found to be statistically significant with overall quality of life score at $p < 0.05$. This shows that presence of triggering factor as well as more seizure frequency in epilepsy patients contribute to poor quality of life. Patients having presence of seizures in past 4 weeks have poor quality of life as compared to those not having any seizure episode in past 4 weeks.

Information booklet development-

The results of the present study revealed that social functioning is least affected for epilepsy patients as compared to worry about seizure and low energy which are more affected. So, the information booklet, with I-CVI and UA of 0.95 and 0.83 respectively, was developed under the following headings:

- What is epilepsy
- Causes of epilepsy
- Symptoms of epilepsy
- Triggers of seizure attack
- Care during and after seizure attack
- Treatment of epilepsy
- Effect of epilepsy on activities of daily living
- Reducing seizure worry and controlling emotions
- Overcoming low energy
- Reducing medication side-effects
- Improving cognitive functioning

- Myths and facts related to epilepsy

Summary

This chapter deals with analysis and interpretation of data including major findings of the study. Total 250 epilepsy patients were taken using Cochran formula. 70.8% patients had good quality of life, 24.8% had fair quality of life whereas 4.4% had poor quality of life. The mean of quality of life score is 56.88 with standard deviation of 11.46. Education, income per month, triggering factor, presence of seizure in past 4 weeks were found to be associated with overall quality of life score at $p < 0.05$ level of significance.

CHAPTER V

DISCUSSION

CHAPTER V: DISCUSSION

The present study was conducted to assess the quality of life among epilepsy patients at AIIMS, Jodhpur and develop an information booklet. The study was carried out at All India Institute of Medical Sciences, Jodhpur. The Quality of Life in Epilepsy -31 (QOLIE-31) standardized questionnaire was used to collect data.

The questionnaire consisted of 31 questions divided among 7 sub-scales. The sub-scales were seizure worry, overall quality of life, emotional well-being, energy/fatigue, cognitive functioning, medication effects and social functioning.

The scoring procedure for the QOLIE-31 first converts the pre-coded numeric values of items to 0-100-point scores, with higher converted scores reflecting good quality of life. T-scores were determined for each of these 0-100-point scale. Higher T-score reflect a more favourable quality of life. The value of T-score lies between 11 to 73.

The present study showed that 4.4% patients had poor quality of life, 24.8% had fair quality of life whereas 70.8% had good quality of life. The mean of quality of life score is 56.88 with standard deviation of 11.46. A study done by Addis B et al²⁰ showed similar result with 55.81 as the mean overall quality of life score. Similarly, Sureka RK et al²⁴ study also showed a mean quality of life score as 60.46. Whereas a study conducted by Jauhari R et al²¹ showed 39.12 as the mean quality of life score.

The highest mean was for social functioning, 82.4 (22.04) followed by cognitive functioning, 78.93 (23.48) and lowest was for seizure worry, 58.82 (25.75) followed by energy/fatigue, 65.78 (23.11). This shows that social functioning is least affected

for epilepsy patients as compared worry about seizure and low energy which are more affected.

The study also showed that the mean scores of seizure worry and energy sub-scales were the lowest indicating that quality of life in epilepsy patients is mostly affected by worry and energy aspects. A study conducted by Addis B et al²⁰ showed similar result that quality of life was low and mostly associated with energy and emotional aspects.

Study by Kaddumukasa M et al²² showed an inverse relationship between severity of seizure and the total QOLIE-31 score and seizure worry and study by Norsa'adah et al³² revealed that worrying about seizure was the main factor contributing to quality of life while medication effect was the least.

The present study showed that low educational qualification and low socio-economic status contributes to poor quality of life in epilepsy patients whereas patients having higher educational qualification and higher socio-economic status had good quality of life. Similar study done by Muche EA et al¹⁹ showed that illiteracy and unemployment are associated with poor quality of life. Jauhari R et al²¹ in his study also showed that unemployment and lower socio-economic class were associated with lower quality of life among epilepsy patients.

Shakir M et al³⁵ study shows that age, educational qualification, monthly income, duration of illness and frequency of seizures were significant determinants of quality of life among epilepsy patients.

A similar study done by Anu M et al²⁸ showed that patients having low educational qualification and poor control of seizures had significantly lower mean total quality of life score where as study by Singh P et al²⁵ concluded that seizure frequency, low

educational qualification and single status were having negative effect on quality of life among epilepsy patients.

An information booklet was developed based on the general information about epilepsy and sub-scales of quality of life questionnaire to improve the quality of life among epilepsy patients at AIIMS, Jodhpur. Information regarding all the sub-scales was included focussing more on the sub-scale which affects the quality of life more i.e., seizure worry and low energy.

The information booklet was validated by experts and given to epilepsy patients coming to AIIMS, Jodhpur.

Summary

This chapter includes the discussion of the study to assess the quality of life among epilepsy patients at AIIMS, Jodhpur. The standardized Quality of Life in Epilepsy-31 (QOLIE-31) questionnaire was used to collect data. The findings of the present study were compared to the available review of literature and similar studies.

CHAPTER VI

SUMMARY, CONCLUSION AND

RECOMMENDATION

CHAPTER VI: SUMMARY, CONCLUSION AND RECOMMENDATION

This chapter deals with the summary, findings and conclusion of the study.

Summary of major findings:

The present study aimed primarily to assess the quality of life among epilepsy patients at AIIMS, Jodhpur and to develop an information booklet.

Statement of the present study was **“A study to assess the quality of life among epilepsy patients at AIIMS, Jodhpur with a view to develop an information booklet.”**

The objectives of study were: -

1. To assess the quality of life among epilepsy patients at AIIMS, Jodhpur.
2. To determine the association of quality of life among epilepsy patients with selected socio-demographic and clinical variables of epilepsy.

Total 250 epilepsy patients were taken using Cochran formula. 70.8% patients had good quality of life, 24.8% had fair quality of life whereas 4.4% had poor quality of life. The mean of quality of life score is 56.88 with standard deviation of 11.46. Education, income per month, triggering factor, presence of seizure in past 4 weeks were found to be associated with overall quality of life score at $p < 0.05$ level of significance.

LIMITATIONS: -

The effectiveness of developed information booklet on quality of life among epilepsy patients was not evaluated.

IMPLICATION OF THE STUDY IN NURSING: -

Nursing practice: -

- Apart from incidental teaching, nursing personnel should organize teaching programme for epilepsy patients at AIIMS, Jodhpur.
- Teach the epilepsy patients about identifying the triggering factors and trying to avoid them so as to prevent seizure episodes.
- Teach regarding importance of taking medications timely and not to skip doses or take overdose of medications.
- Educating about possible side-effects of drugs and ways to identify and reduce them.
- Educating about adherence to anti-epileptic drug regime and regular follow-up for any change in drug regime.

Nursing education: -

- In nursing education, this study can be used to identify the domains that affect the quality of life among epilepsy the most.
- Student nurse can also use this study to educate patients and their family for better caring and identifying the triggering factors, ways to avoid them and adherence to medication regime.
- Nurses can educate the family members about the proper care of patient during seizure episode and prevent any kind of injury.

Patient education: -

- Educate the patients to take anti-epileptic drugs regularly, trying not to miss even a single dose.
- Missing a dose can lead to a seizure episode. Therefore, anti-epileptic drugs should be kept in stock so as to avoid missing of dose.

- Record of seizure episodes should be kept.
- Regular follow-up visits are essential for adjustment of doses and assessment of any side effects of anti-epileptic drug therapy.
- Instruct the patient not to work near fire, water, moving wheels, avoiding climbing trees and driving vehicles till seizures are fully controlled.
- Patients should not be left alone or made to sit idle. They should be kept involved in one or the other work to keep them distracted from anxiety or fear of coming seizure episode.

Nursing administration: -

- Nursing administration should provide necessary facilities and opportunities for nursing students and staff to equip themselves with improving the quality of life among epilepsy patients at AIIMS, Jodhpur.
- They can identify the learning needs of epilepsy patients and plan, conduct and evaluate their teaching.

Nursing research: -

- In nursing research, new researchers can use this study for identifying the domains that affect the quality of life among epilepsy patients.
- More focus can be done on reducing the anxiety and depression among epilepsy patients to improve their quality of life.

PROBLEMS FACED WHILE COLLECTING DATA: -

Some problems were faced during the time of data collection due to telephonic interview:

- Some patients were not willing to give data as they thought telephonic interview is not a reliable method to share personal information.

- Some patients did not give consent for giving data.
- Some patients did not pick up the call after giving consent.
- Some patients left the interview in between.
- It was difficult to conduct interview on call.

RECOMMENDATION: -

- The study can be replicated to compare the quality of life among epilepsy patients coming to various hospitals in Rajasthan.
- A similar study can be conducted to assess the quality of life between epilepsy patients and healthy individuals.

CONCLUSION: -

Based on findings of the present study, the following conclusions are drawn:

- The study findings revealed that worrying about seizure episodes and energy/fatigue had a major contribution in affecting the quality of life among epilepsy patients.
- Results of the study suggest that there is statistically significant association between the overall quality of life score and the selected socio-demographic and clinical variables of the study.

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APPENDICES

APPENDIX-I

ETHICAL CLEARANCE CERTIFICATE



अखिल भारतीय आयुर्विज्ञान संस्थान, जोधपुर
All India Institute of Medical Sciences, Jodhpur
संस्थागत नैतिकता समिति
Institutional Ethics Committee

No. AIIMS/IEC/2020/3079

Date: 01/06/2020

ETHICAL CLEARANCE CERTIFICATE

Certificate Reference Number: AIIMS/IEC/2020-21/2098

Project title: "A study to assess the quality of life among epilepsy patients at AIIMS, Jodhpur with a view to develop an information booklet"

Nature of Project: Research Project Submitted for Expedited Review
Submitted as: Student Research Project, as a part of Academic Programme
Investigator: Shweta Sharma
Supervisor: Dr. Ashok Kumar
Co-Supervisor: Dr. Samhita Panda & Mrs. Nimarta

Institutional Ethics Committee after thorough consideration accorded its approval on above project.

The investigator may therefore commence the research from the date of this certificate, using the reference number indicated above.

Please note that the AIIMS IEC must be informed immediately of:

- Any material change in the conditions or undertakings mentioned in the document.
- Any material breaches of ethical undertakings or events that impact upon the ethical conduct of the research.

The Principal Investigator must report to the AIIMS IEC in the prescribed format, where applicable, bi-annually, and at the end of the project, in respect of ethical compliance.

AIIMS IEC retains the right to withdraw or amend this if:

- Any unethical principle or practices are revealed or suspected
- Relevant information has been withheld or misrepresented

AIIMS IEC shall have an access to any information or data at any time during the course or after completion of the project.

Please Note that this approval will be rectified whenever it is possible to hold a meeting in person of the Institutional Ethics Committee. It is possible that the PI may be asked to give more clarifications or the Institutional Ethics Committee may withhold the project. The Institutional Ethics Committee is adopting this procedure due to COVID-19 (Corona Virus) situation.

If the Institutional Ethics Committee does not get back to you, this means your project has been cleared by the IEC.

On behalf of Ethics Committee, I wish you success in your research.


Dr. Praveen Sharma
Member Secretary
Member secretary
Institutional Ethics Committee
AIIMS, Jodhpur

APPENDIX -II

PERMISSION TO USE QUALITY OF LIFE IN EPILEPSY -31 (QOLIE-31) QUESTIONNAIRE

<p>QOLIE Development Group QOLIE-31 PERMISSION FOR ACADEMIC and COMMERCIAL USE</p>
--

Thank you for your interest in a translation of the QOLIE-31. RAND holds the copyright for the original English QOLIE-31. However, RAND did not want the copyright for translations or other versions. Thus, copyrights for all QOLIE-31 translations and other versions were given to and are held by the QOLIE Development Group.

The QOLIE Development Group grants permission to use the QOLIE-31 and Scoring Instructions for your study in accordance with the following conditions that shall be assumed by all to have been agreed as a consequence of accepting and using this document:

1. Copyright Statement to be printed on every version of the QOLIE-31:

<p>QOLIE-31 translations copyright 1998, QOLIE Development Group. (US English version 1.0 copyright 1993, RAND.) All rights reserved. Source reference: Cramer et al., <i>Epilepsia</i>. 1998; 39: 81-88.</p>

2. When the QOLIE-31 is described in a publication, the citation should be: Cramer JA, Perrine K, Devinsky O, Bryant-Comstock L, Meador K, Hermann BP Development and cross-cultural translation of a 31-item quality of life questionnaire (QOLIE-31) *Epilepsia* 1998; 39: 81-88.

3. Changes to the QOLIE-31 may not be made without the written permission of the QOLIE Development Group. (RAND does not accept changes to the original US English version.) If accepted, any such changes shall be clearly identified as having been made by the recipient. This restriction is necessary to maintain the structural integrity of the original instrument.

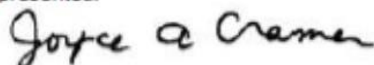
4. The user accepts full responsibility, and agrees to indemnify and hold the QOLIE Development Group harmless, for any consequences resulting from the use of the QOLIE-31.

5. The user accepts full responsibility, and agrees to indemnify and hold the QOLIE Development Group harmless, for the accuracy of any translations of the QOLIE-31 into another language and for any errors, omissions, misinterpretations, or consequences thereof.

6. **Licensing:** Commercial groups interested in using the QOLIE-31 translations should contact the QOLIE Development Group (Joyce.Cramer@gmail.com) for information and permission. No other group (e.g., professional translators) is authorized to provide copies of the questionnaires for any use. Commercial sponsors are asked to provide funds for the QOLIE Development Group in return for use of the instrument. The fee structure is \$2,500, plus \$200 for each language.

7. The QOLIE Development Group allows translation and cross-cultural adaptation of all instruments. The user agrees to provide the QOLIE Development Group with information about any other translations or cross-cultural adaptations of the QOLIE-31. All translations should include information about the translation process, sponsor, and the clinical trial or other use for which the translation was created. The user also agrees to provide a copy of the new version (paper and electronic) to the QOLIE Development Group (Joyce Cramer) when it is completed. All versions will be archived for distribution on request.

8. The user agrees to notify the QOLIE Development Group of any publications in which QOLIE-31 data are presented.



Joyce Cramer joyce.cramer@gmail.com
For the QOLIE Development Group



Search mail



Shweta Sharma <shweta.jodhpur24@gmail.com>

to Joyce.Cramer

Jan 8, 2020, 3:41 PM



Respected mam,

This is to inform you that I am Miss.Shweta Sharma, doing my M.Sc. Nursing from All India Institute of Medical Sciences, Jodhpur, India. I have to complete a research project during my course. The title of my research project is "A study to assess the quality of life of epilepsy patients coming in AIIMS,Jodhpur with a view to develop an information booklet". I want to use QOLIE-31 in my study as this is an effective and helpful tool . So, I need permission for the same. I will not make any modifications in the tool and use it as such. It would be very helpful to me if you grant me permission to use this tool.



joyce.cramer@gmail.com

to me

Jan 8, 2020, 8:03 PM



I am pleased to provide the Hindi translation of the QOLIE-31 with scoring and permission information.

Best wishes for success,

Joyce Cramer

APPENDIX III
SOCIO-DEMOGRAPHIC AND CLINICAL VARIABLE TOOL (ENGLISH AND HINDI
VERSION)

English – Tool

Part – A: Demographic variables

- 1) Age (in years)-
- 2) Gender-
 - a. Male
 - b. Female
- 3) Marital status
 - a. Unmarried
 - b. Married
- 4) Education
 - a. Illiterate
 - b. Primary
 - c. Secondary
 - d. Higher Secondary
 - e. Graduation
 - f. Above graduation
- 5) Occupation
 - a. Government Employment
 - b. Private Employment
 - c. Unemployment
 - d. Self- employment
 - e. Homemaker
- 6) Social background-
 - a. Rural
 - b. Urban
- 7) Income per month (in rupees)-.....

Clinical aspects of epilepsy

- 1) Patients age at onset (in years)-.....
- 2) Type of seizure-
 - a. Partial seizure
 - b. Generalized seizure
- 3) Duration of epilepsy (in years)-.....
- 4) Treatment-
 - a. Polytherapy
 - b. Monotherapy
 - c. No treatment
- 5) Co-morbidity-
 - a. Yes
 - b. No
- 6) Family history-
 - a. Yes
 - b. No
- 7) Any triggering factor known-
 - a. Yes
 - b. No

If yes, what.....

- 8) Presence of seizure in past 4 weeks-
 - a. Yes
 - b. No

Hindi- Tool

Part – A जनस ोख्ययकीय चर

1. उम्र (वर्ष में)-.....

2. लरोग-

a. नुरुर्

b. महिर

3. वैव हिक स्तर-

a. अववव हित

b. ववव हित

4. लिक्ष -

a. अन-औनच ररक

b. प्र थलमक

c. म ध्यलमक

d. उच्च म ध्यलमक

e. स्र तकोत्तर

f. उच्च स्र तकोत्तर

5. व्यवस य-

a. सरक री रोजग र

b. लनजी रोजग र

c. बेरोजग र

d. स्व रोजग र

e.

6.

a.

b.

7. म लसक (प्रलतम स) आय ()-.....

1. ()-.....

2. -

a.

b.

3. ()-.....

4. -

a.

b.

c.

5. -

a.

b.

6. -

a.

b.

7. -

a.

b.

,

8. 4 -

a.

b.

APPENDIX IV

QOLIE-31 (ENGLISH VERSION)

QUALITY OF LIFE IN EPILEPSY - QOLIE-31 (Version 1.0)

US English QOLIE-31 Copyright 1993, RAND. All rights reserved. The QOLIE-31 was developed in cooperation with Professional Postgraduate Services.

Today's Date ____ / ____ / ____
 mm dd yy

Patient's Name _____

Age: ____ years

INSTRUCTIONS

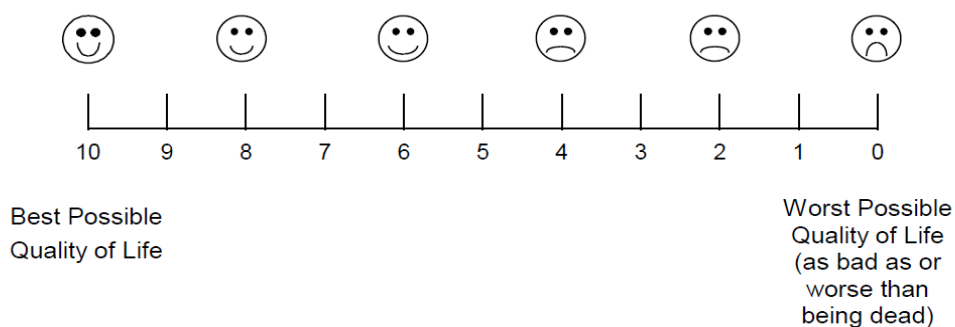
The QOLIE-31 is a survey of health-related quality of life for adults (18 years or older) with epilepsy. [Adolescents (ages 11-17 years) should complete the QOLIE-AD-48, which is designed for that age group.] This questionnaire should be completed only by the person who has epilepsy (not a relative or friend) because no one else knows how **YOU** feel.

There are 31 questions about your health and daily activities. Answer every question by circling the appropriate number (1, 2, 3...). If you are unsure about how to answer a question, please give the best answer you can and write a comment or explanation on the side of the page. These notes may be useful if you discuss the QOLIE-31 with your doctor. Completing the QOLIE-31 before and after treatment changes may help you and your doctor understand how the changes have affected your life.

This copy of the QOLIE-31 is provided by the Epilepsy Therapy Project, who bring you www.epilepsy.com, your trusted source for epilepsy information. We wish you success in living your life with epilepsy.

1. Overall, how would you rate your quality of life?

(Circle one number on the scale below)



These questions are about how you **FEEL** and how things have been for you during the **past 4 weeks**. For each question, please indicate the one answer that comes closest to the way you have been feeling.

How much of the time during the **past 4 weeks**...

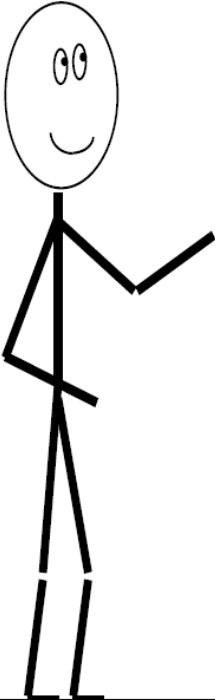
(Circle one number on each line)

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
2.	Did you feel full of pep?	1	2	3	4	5	6
3.	Have you been a very nervous person?	1	2	3	4	5	6
4.	Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
5.	Have you felt calm and peaceful?	1	2	3	4	5	6
6.	Did you have a lot of energy?	1	2	3	4	5	6
7.	Have you felt downhearted and blue?	1	2	3	4	5	6
8.	Did you feel worn out?	1	2	3	4	5	6
9.	Have you been a happy person?	1	2	3	4	5	6
10.	Did you feel tired?	1	2	3	4	5	6
11.	Have you worried about having another seizure?	1	2	3	4	5	6
12.	Did you have difficulty reasoning and solving problems (such as making plans, making decisions, learning new things)?	1	2	3	4	5	6
13.	Has your health limited your social activities (such as visiting with friends or close relatives)?	1	2	3	4	5	6

14. How has the **QUALITY OF YOUR LIFE** been during the **past 4 weeks** (that is, how have things been going for you)?

(Circle
one
number)

Very well: could hardly be better	1
Pretty good	2
Good & bad parts about equal	3
Pretty bad	4
Very bad: could hardly be worse	5



The following question is about **MEMORY**.

(Circle one number)

	Yes, a great deal	Yes, somewhat	Only a little	No, not at all
15. In the past 4 weeks, have you had any trouble with your memory?	1	2	3	4

Circle one number for **how often** in the **past 4 weeks** you have had trouble *remembering* or **how often** this memory problem has interfered with your normal work or living.

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
16. Trouble remembering things people tell you	1	2	3	4	5	6

The following questions are about **CONCENTRATION** problems you may have. Circle one number for **how often** in the **past 4 weeks** you had trouble concentrating or **how often** these problems interfered with your normal work or living.

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
17. Trouble concentrating on reading	1	2	3	4	5	6
18. Trouble concentrating on doing one thing at a time	1	2	3	4	5	6

The following questions are about problems you may have with certain **ACTIVITIES**. Circle one number for **how much** during the **past 4 weeks** your epilepsy or antiepileptic medication has caused trouble with...

	A great deal	A lot	Somewhat	Only a little	Not at all
19. Leisure time (such as hobbies, going out)	1	2	3	4	5
20. Driving	1	2	3	4	5

The following questions relate to the way you **FEEL** about your **seizures**.

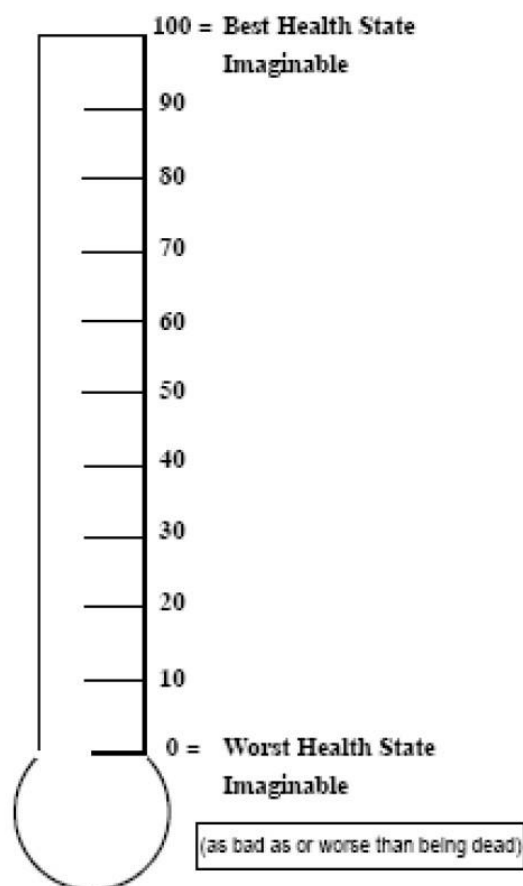
(Circle one number on each line)

		Very fearful	Somewhat fearful	Not very fearful	Not fearful at all
21.	How fearful are you of having a seizure during the next month?	1	2	3	4
22.	Do you worry about hurting yourself during a seizure?	1	2	3	
		Very worried	Somewhat worried	Not very worried	Not at all worried
23.	How worried are you about embarrassment or other social problems resulting from having a seizure during the next month?	1	2	3	4
24.	How worried are you that medications you are taking will be bad for you if taken for a long time?	1	2	3	4

For each of these **PROBLEMS**, circle one number for **how much they bother you** on a scale of 1 to 5 where 1 = Not at all bothersome, and 5 = Extremely bothersome.

		Not at all bothersome				Extremely bothersome
25.	Seizures	1	2	3	4	5
26.	Memory difficulties	1	2	3	4	5
27.	Work limitations	1	2	3	4	5
28.	Social limitations	1	2	3	4	5
29.	Physical effects of antiepileptic medication	1	2	3	4	5
30.	Mental effects of antiepileptic medication	1	2	3	4	5

31. How good or bad do you think your health is? On the thermometer scale below, the best imaginable state of health is 100 and the worst imaginable state is 0. Please indicate how you feel about your health by circling one number on the scale. **Please consider your epilepsy as part of your health when you answer this question.**



APPENDIX V
QOLIE-31 (HINDI VERSION)

QUALITY OF LIFE IN EPILEPSY
QOLIE-31 (Version 1.0 Hindi)

रोगी सूची-पत्र

आज की तिथि _____ / _____ / _____
 माह दिन वर्ष

रोगी का नाम _____

रोगी की पहचान सं. _____

लिंग : ☐ पुरुष ☐ महिला

जन्मतिथि _____ / _____ / _____
 दिन माह वर्ष

निर्देश

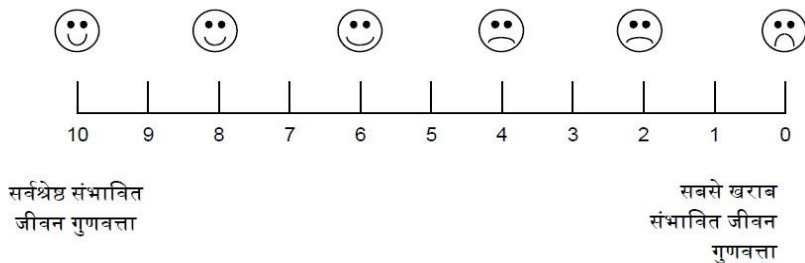
इस सर्वेक्षण आपके स्वास्थ्य और दैनिक गतिविधियों के बारे में पूछा गया है। उपयुक्त संख्या (1, 2, 3...) को घेरकर प्रत्येक प्रश्न का उत्तर दें।

यदि आप यह तय नहीं कर पा रहे कि किसी प्रश्न का उत्तर कैसे दें तो कृपया अपनी तरफ से सबसे उपयुक्त उत्तर दें और टिप्पणियों पर अपनी टिप्पणी या व्याख्या लिख दें।

यदि आपको इस फॉर्म को पढ़ने या जवाब देने में मदद चाहिए तो कृपया किसी से मदद लेने में न झिझकें।

1. कुल मिलाकर, आप अपने जीवन की गुणवत्ता का मूल्यांकन कैसे करेंगे ?

(नीचे दिए गए मापदंड पर एक संख्या को घेर दें)



(मरने जितना खराब या
उससे भी ज्यादा खराब)

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न लिखें

ये प्रश्न इस बारे में हैं कि आप पिछले 4 सप्ताह के दौरान कैसा महसूस करते रहे हैं। प्रत्येक प्रश्न के लिए कृपया वह उत्तर चुनें जो आपके अनुभव के सबसे निकट है।

पिछले 4 सप्ताह के दौरान कितने समय तक....

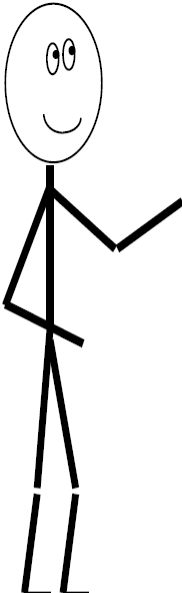
(प्रत्येक रेखा पर एक संख्या को घेर दें)

	हमेशा	ज्यादातर	अच्छा-		थोड़े	किसी
			समय	समय		
	1	2	3	4	5	6
2. क्या आप जीवंतता से भरा हुआ महसूस करते थे?	1	2	3	4	5	6
3. क्या आप बहुत आसानी से घबरा जाने वाले व्यक्ति रहे हैं?	1	2	3	4	5	6
4. क्या आप इतना उदास और निराश महसूस करते रहे हैं कि कोई भी बात आपको प्रसन्न नहीं कर सकती?	1	2	3	4	5	6
5. क्या आप शांत और निरुद्धि महसूस करते रहे हैं?	1	2	3	4	5	6
6. क्या आप में भरपूर ऊर्जा थी?	1	2	3	4	5	6
7. क्या आप बहुत आसानी से घबरा जाने वाले व्यक्ति रहे हैं?	1	2	3	4	5	6
8. क्या आप थका-हारा महसूस करते थे?	1	2	3	4	5	6
9. क्या आप एक प्रसन्न व्यक्ति रहे हैं?	1	2	3	4	5	6
10. क्या आप थका हुआ महसूस करते थे?	1	2	3	4	5	6
11. क्या आप फिर से दौरा पड़ने को लेकर चिंतित हैं?	1	2	3	4	5	6
12. क्या आपको तर्कसंगत ढंग से सोचने और समस्याओं को हल करने में कठिनाई हुई (जैसे कि योजना बनाना, निर्णय लेना, नई बातें सीखना)?	1	2	3	4	5	6
13. क्या आपके स्वास्थ्य ने आपकी सामाजिक गतिविधियों को सीमित कर दिया है (जैसे कि दोस्तों या निकट संबंधियों से मुलाकात करना)?	1	2	3	4	5	6

14. पिछले 4 सप्ताह के दौरान आपके जीवन की गुणवत्ता कैसी रही (यानी आप का हाल-चाल कैसा रहा है)?

(एक संख्या को घेर दें)

बहुत अच्छा : शायद ही इससे बेहतर हो सकता हो	1
काफी अच्छा	2
अच्छे और बुरे पहलू बराबर-बराबर	3
काफी बुरा	4
बहुत बुरा : शायद ही इससे बदतर हो सकता हो	5



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नीचे दिया गया सवाल स्मरणशक्ति के बारे में है।

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(एक संख्या को घेर दें)

	हां, बहुत अधिक	हाँ थोड़ी-बहुत	बस थोड़ी-सी नहीं, बिलकुल नहीं	
15. पिछले 4 सप्ताह में, क्या आपको अपनी स्मरणशक्ति को लेकर कोई परेशानी हुई है	1	2	3	4

एक संख्या को घेर कर बताएँ कि पिछले 4 सप्ताह में आपको याद रखने में कितनी बार परेशानी हुई या कितनी बार स्मरणशक्ति की समस्या ने आपके सामान्य कामकाज या जीवन में बाधा डाली।

	अच्छा- ज्यादातर हर समय	ज्यादातर समय	खासा समय	कुछ समय तक	थोड़े समय तक	किसी समय नहीं
16. लोगों द्वारा बताई गई बातें याद रखने में परेशानी हुई	1	2	3	4	5	6

नीचे दिए गए सवाल आपको हो सकने वाली ध्यान केंद्रित करने से संबंधित समस्याओं के बारे में हैं। एक संख्या को घेर कर बताएँ कि पिछले 4 सप्ताह में आपको ध्यान केंद्रित करने में कितनी बार परेशानी हुई या कितनी बार इन समस्याओं ने आपके सामान्य कामकाज या जीवन में बाधा डाली।

	अच्छा- ज्यादातर हर समय	ज्यादातर समय	खासा समय	कुछ समय तक	थोड़े समय तक	किसी समय नहीं
17. पढ़ने पर ध्यान केन्द्रित करने में परेशानी हुई	1	2	3	4	5	6
18. एक बार में एक काम करने पर ध्यान केन्द्रित करने में परेशानी हुई	1	2	3	4	5	6

नीचे दिए गए सवाल आपको कुछ गतिविधियों के संबंध में हो सकने वाली समस्याओं के बारे में हैं। एक संख्या को घेर कर बताएँ कि पिछले 4 सप्ताह में आपकी मिर्गी या मिगीरोधी दवाओं के कारण नीचे दी गई गतिविधियों के संबंध में आपको कितनी परेशानी हुई...

	बहुत अधिक	काफी	कुछ-कुछ	बस थोड़ा-सा	बिलकुल नहीं
19. फुरसत की गतिविधियाँ (जैसे शौक पूरे करना, बाहर जाना)	1	2	3	4	5
20. ड्राइविंग	1	2	3	4	5

नीचे दिए गए सवाल इस बारे में हैं कि आप दौरों के बारे में कैसा महसूस करते हैं।

(प्रत्येक रेखा पर एक संख्या को घेर दें)

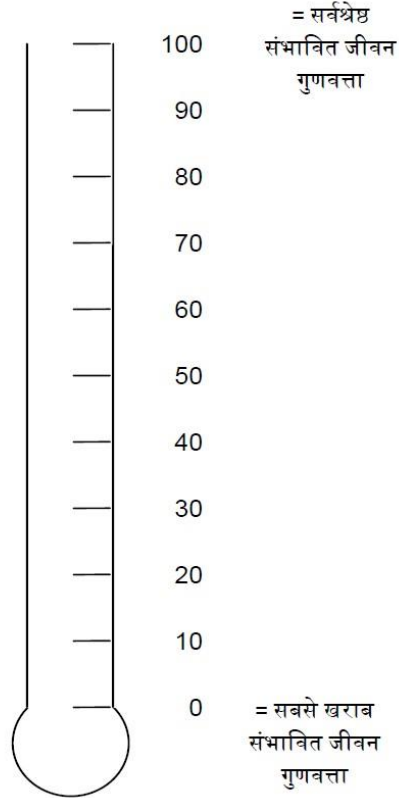
		बहुत डरे हुए हैं	कुछ-कुछ डरे हुए हैं	ज़्यादा डरे हुए नहीं हैं	बिलकुल डरे हुए नहीं हैं
21.	अगले माह दौरा पड़ने को लेकर आप कितने डरे हुए हैं?	1	2	3	4
		काफी चिंतित हूँ	कभी-कभी चिंतित	बिलकुल चिंतित नहीं हूँ	
22.	क्या आप किसी दौरे के दौरान चोट लग जाने को लेकर चिंतित रहते हैं?	1	2	3	
		बहुत अधिक चिंतित	कुछ-कुछ चिंतित	ज़्यादा चिंतित नहीं	बिलकुल चिंतित नहीं
23.	अगले माह में दौरा पड़ने के कारण होने वाली शर्मिंदगी या अन्य सामाजिक समस्याओं के बारे में आप कितने चिंतित हैं?	1	2	3	4
24.	आप इस बात से कितने चिंतित हैं कि आप द्वारा ली जा रही दवाएं अगर लंबे समय तक ली गईं तो आपके लिए नुकसानदेह होंगी?	1	2	3	4

इनमें से प्रत्येक समस्या के लिए, किसी एक संख्या पर गोला बनाकर 1 से 5 के पैमाने पर बताएँ कि इनसे आपको कितनी परेशानी होती है जिनमें 1 = कभी परेशानी नहीं होती है और 5 = बेहद ज़्यादा परेशानी होती है।

	कभी परेशानी नहीं होती है				बेहद ज्यादा परेशानी होती है	
25.	दौरे	1	2	3	4	5
26.	स्मरणशक्ति की समस्याएं	1	2	3	4	5
27.	कार्य संबंधी सीमाएं	1	2	3	4	5
28.	सामाजिक सीमाएं	1	2	3	4	5
29.	मिर्गीरोधी दवा के शारीरिक प्रभाव	1	2	3	4	5
30.	मिर्गीरोधी दवा के मानसिक प्रभाव	1	2	3	4	5

31. आपके विचार से आपका स्वास्थ्य कितना अच्छा या बुरा है? नीचे दिए गए पैमाने पर, 100 का अंक स्वास्थ्य की सर्वोत्तम कल्पनीय स्थिति को बताता है और सबसे बुरी कल्पनीय स्थिति (0) है। कृपया पैमाने पर किसी एक संख्या को घेरकर बताएं कि अपने स्वास्थ्य के बारे में आप कैसा महसूस करते हैं? कृपया इस प्रश्न का उत्तर देते समय अपनी मिर्गी को अपने स्वास्थ्य का एक भाग समझें।

इस
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न लिखें



(मरने जितना खराब या उससे भी ज़्यादा खराब)

APPENDIX VI

CONSENT FORM (ENGLISH VERSION)

Title of the research study: A study to assess the quality of life among epilepsy patients at AIIMS, Jodhpur with a view to develop an information booklet

Name of the Investigator: Shweta Sharma (M.Sc. Nursing)

Subject Identification No:

I, _____ S/o, _____ D/o _____ or
W/o _____ R/o _____

_____ give my full, free, voluntary consent to be a part of the study " A study to assess the quality of life among epilepsy patients at AIIMS, Jodhpur with a view to develop an information booklet", the procedure and nature of which has been explained to me in my own language to my full satisfaction. I confirm that I have had the opportunity to ask questions.

I understand that my participation is voluntary and am aware of my right to opt out of the study at any time without giving any reason.

I understand that the information collected about me and any of my medical records may be looked at by responsible individual from All India Institute of Medical Sciences Jodhpur Rajasthan. I give permission for these individuals to have access to my records.

Date: _____

Place: _____

Signature/Left thumb impression

This to certify that the above consent has been obtained in my presence.

Date: _____

Place: _____

Signature of Investigator

APPENDIX VII
CONSENT FORM (HINDI VERSION)

नररयोजन क : अ अ ऑफ फ अ
िीरक

अ फ

अन्वेक क न म :

निच न सोयय : _____

मैं _____ /

नली/नुत्री _____ लनव सी _____

“अ अ ऑफ फ अ

अ

फ ” न मक अध्ययन खसकी पहिय और प्रकृत मुझे मेरी अननी भ र् में
नूर्ष सौतुविके

स थ समझ दी गयी है, मैं भ ग रेने के लए अननी नूर्ष स्वतंत्र एवो स्वैखिक सिमलत दे ता/
दे ती िूँ । मैं नुवि करता/ करती

िूँ हक मुझे सव र नूिने क अवसर हदय गय है । मैं समझता/ समझती िूँ हक मेरी भ गीद री
स्वैखिक है और मैं अनने इस अलधक र से अवगत िूँ की मैं हकसी भी समय वबन कोई क र हदए इस
अध्ययन से अनन न म व नस रे सकता/सकती

िूँ । मैं समझता/ समझती िूँ हक मेरे ब रे में एकत्र ज नक री एम्स जोधनुर के हकसी भी
हजम्मेद र व्यवि द्दर य लनय मक अलधक ररयो द्दर देखी ज सकती है । मैं उनरो वि व्यवियों को मेरे
द्दर दी गई ज नक री देखने की अनुमलत दे ता/ दे ती िूँ ।

हदनोक: _____

स्थ न: _____

िस्त क्षर

यि प्रम ख्त है हक उनरो सिमलत मेरी उनस्थलत में प्राप्त की गयी है ।

हदनोक: _____

स्थ न: _____

िस्त क्षर – अन्वेक

APPENDIX VIII
PARTICIPANT INFORMATION SHEET (ENGLISH VERSION)

Participant Information Sheet

Part-I

1. Purpose of the research study- To assess the quality of life among epilepsy patients at AIIMS, Jodhpur with a view to develop an information booklet.
2. Study procedure to be followed- The data will be collected through standardized questionnaire after obtaining informed consent from the patients.
3. Benefits from the study- The information booklet developed from this study will help to improve the quality of life among epilepsy patients in the near future.
4. Risk of the study: None
5. Complication of the study: None
6. Confidentiality: Data collected from the participants shall not be shared with anyone except the study investigator.
7. Rights of the participants: Participants would have the freedom to share their data and to continue or leave the study if they desire so at any point of time.

Participant Signature:

Participant Name:

Name:

Part 2:

Investigator's word

I have explained the purpose, procedure, benefits, and harms of the study in details to the participants. All the information regarding study has been disclosed and enough opportunity for asking questions regarding the study was given to study participant.

Principal Investigator Signature

Witness signature

Name:

Name:

Date:

Date:

APPENDIX IX
PARTICIPANT INFORMATION SHEET (HINDI VERSION)

प्रतिभागी जानकारी

भाग-1

1. अध्ययन का उद्देश्य : टू असेस द क्वालिटी ऑफ लाइफ अमोंग एपीलेपसी पेशंट्स एट एम्स जोधपुर विथ अ व्यू टू डवलप एन इनफार्मेशन बुकलेट
2. अध्ययन प्रक्रिया: मरीजों से सूचित लिखित सहमति प्राप्त करने के बाद डेटा को मानकीकृत प्रश्नावली के माध्यम से एकत्र किया जाएगा
3. अध्ययन से लाभ : इस अध्ययन से विकसित सूचना पुस्तिका निकट भविष्य में भिगी रोगियों के जीवन की गुणवत्ता में सुधार करने में मदद करेगी।
4. अध्ययन का खतरा: कोई नहीं
5. अध्ययन की जटिलता : कोई नहीं
6. गोपनीयता : प्रतिभागी से एकत्र किये गये आंकड़ों का अध्ययन अन्वेषक को छोड़कर किसी के साथ साझा नहीं किया
7. प्रतिभागी के अधिकार : प्रतिभागियों को अपने आंकड़ों को साझा करने ,जारी रखने या अध्ययन छोड़ने के लिए किसी भी समय के किसी भी बिंदु पर स्वतंत्र होंगे

प्रतिभागी हस्ताक्षर :

प्रतिभागी नाम :

दिनांक :

भाग 2:

अन्वेषक के शब्द :

मैंने प्रतिभागियों को अध्ययन के उद्देश्य ,प्रक्रिया ,लाभ और नुकसान के बारे में विस्तार से बताया है। अध्ययन के बारे में समस्त जानकारी का खुलासा किया गया है और अध्ययन के बारे में प्रश्न पूछने के लिए पर्याप्त अवसर अध्ययन प्रतिभागी को दिया गया था।

प्रधान अन्वेषक हस्ताक्षर गवाह हस्ताक्षर

नाम : नाम :

तिथि: तिथि:

APPENDIX X

CONTENT VALIDITY

A LETTER REQUESTING OPINION AND SUGGESTION OF EXPERTS FOR CONTENT VALIDITY OF TOOL

From:

Miss. Shweta Sharma
M.Sc. Nursing (Batch-2019)
College of Nursing, AIIMS, Jodhpur
To,

.....
.....

Subject: Expert Opinion on Validity of demographic variables of my study tool (standardized tool- QOLIE-31).

Respected Sir/Madam,

I, Miss. Shweta Sharma, M.Sc. Nursing (Batch-2019) student at College of Nursing, AIIMS, Jodhpur. I have undertaken the following topic for research project: "A study to assess the quality of life among epilepsy patients at AIIMS, Jodhpur with a view to develop an information booklet" under the supervision of Dr. Ashok Kumar, Associate Professor, College of Nursing, AIIMS, Jodhpur.

Objectives of the study are:

- (1) To assess the quality of life of epilepsy patients.
- (2) To develop an information booklet.
- (3) To see the association of quality of life with demographic variables.

I request you to kindly go through the tool and give your opinion for any modification and improvement needed. Your esteemed opinion and critical comments will provide the required direction and contribute immensely to the quality and content of my final research.

Looking forward to your expert guidance and suggestions.

Thanking you in anticipation

Your Sincerely

Miss. Shweta Sharma
M.Sc. Nursing (Batch-2019)
College of Nursing, AIIMS, Jodhpur

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All India Institute of Medical Sciences, Jodhpur

Enclosure:

- Brief Methodology
- Tool for data collection:
 - Section A: Self-structured questionnaire for Socio-demographic data
 - Section B: Standardized tool
- Evaluation criteria checklist for validation of tools
- Certificate for validation

APPENDIX XI
LIST OF EXPERTS FOR TOOL VALIDATION

Mr. Nipin Kalal

Assistant Professor, College of Nursing

All India Institute of Medical Sciences

Jodhpur, Rajasthan, India

Mrs. Vandna Pandey

Assistant Professor, College of Nursing

All India Institute of Medical Sciences

Jodhpur, Rajasthan, India

Mr. Maneesh Sharma

Assistant Professor, College of Nursing

All India Institute of Medical Sciences

Rishikesh, India

Dr. Rakesh Sharma, BSN, MSN, PhD

Assistant Professor, College of Nursing

All India Institute of Medical Sciences

Rishikesh, India

Mr. L Anand

Reader/Associate Professor, College of Nursing

All India Institute of Medical Sciences

Bhubaneswar, India

APPENDIX XII

INFORMATION BOOKLET VALIDATION

A LETTER REQUESTING OPINION AND SUGGESTION OF EXPERTS FOR CONTENT VALIDITY OF INFORMATION BOOKLET

From:

Miss. Shweta Sharma

M.Sc. Nursing (Batch-2019)

College of Nursing, AIIMS, Jodhpur

To,

Subject: Expert Opinion on Validity of Information Booklet.

Respected Sir/Madam,

I Miss. Shweta Sharma, M.Sc. Nursing (Batch-2019) student at College of Nursing, AIIMS, Jodhpur. I have undertaken the following topic for research project: **"A study to assess the quality of life among epilepsy patients at AIIMS, Jodhpur with a view to develop an information booklet"** under the supervision of Dr. Ashok Kumar, Associate Professor, College of Nursing, AIIMS, Jodhpur.

Objectives of the study are:

1. To assess the quality of life among epilepsy patients at AIIMS, Jodhpur.
2. To determine the association of quality of life among epilepsy patients with selected socio-demographic and clinical variables of epilepsy.

I request you to kindly go through the information booklet and give your opinion for any modification and improvement needed. Your esteemed opinion and critical comments will provide the required direction and contribute immensely to the quality and content of my final research.

Looking forward to your expert guidance and suggestions.

Thanking you in anticipation

Your Sincerely

Miss. Shweta Sharma

M.Sc. Nursing (Batch-2019)

College of Nursing, AIIMS, Jodhpur

Guide:

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Co-Guide:

Mrs. Nimarta
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Co-Guide:

Dr. Samhita Panda
Additional Professor and
Head
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Principal

College of Nursing, AIIMS, Jodhpur

Enclosure:

- Brief Methodology
- Abstract of the study
- Information booklet
- Evaluation criteria checklist
- Certificate for validation

APPENDIX XIII

LIST OF EXPERTS FOR INFORMATION BOOKLET VALIDATION

Mr. Nipin Kalal

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Dr. Sucharita

Assistant Professor, Department of Neurology

All India Institute of Medical Sciences

Jodhpur, Rajasthan, India

APPENDIX XIV

CODING SHEET OF SOCIO-DEMOGRAPHIC AND CLINICAL VARIABLES

S.NO.	CONTENT	CODING
1.	Age (in years)- a. 18-25 b. 26-35 c. 36-60	1 2 3
2.	Gender- a. Male b. Female	1 2
3.	Marital status- a. Unmarried b. Married	1 2
4.	Education- a. Illiterate b. Primary c. Secondary d. Higher Secondary e. Graduation f. Above graduation	1 2 3 4 5 6
5.	Occupation - a. Government Employment b. Private Employment c. Unemployment d. Self- employment e. Homemaker	1 2 3 4 5
6.	Social background- a. Rural b. Urban	1 2
7.	Income per month (in rupees)- a. <15,000 b. 16,000-25,000 c. 26,000-35,000 d. 36,000-45,000	1 2 3 4
8.	Patient's age at onset (in years)- a. <20 b. 21-40 c. 41-60	1 2 3
9.	Type of seizure- a. Partial seizure b. Generalized seizure	1 2
10.	Duration of epilepsy (in years)- a. 1-10 b. 11-20 c. 21-30 d. 31-40	1 2 3 4
11.	Treatment- a. Polytherapy b. Monotherapy	1 2

	c. No treatment	3
12.	Co-morbidity- a. Yes b. No	1 2
13.	Family history- a. Yes b. No	1 2
14.	Any triggering factor known- a. Yes b. No	1 2
15.	Presence of seizure in past 4 weeks- a. Yes b. No	1 2

APPENDIX XV

SCORING MANUAL OF QOLIE-31 QUESTIONNAIRE

SCORING MANUAL FOR THE QUALITY OF LIFE IN EPILEPSY INVENTORY-31 (QOLIE-31)

CONTENT OF THE QOLIE-31

The Quality of Life in Epilepsy Inventory (QOLIE-31) contains seven multi-item scales that tap the following health concepts: emotional well-being, social functioning, energy/fatigue, cognitive functioning, seizure worry, medication effects, and overall quality of life. A QOLIE-31 overall score is obtained using a weighted average of the multi-item scale scores. The QOLIE-31 also includes a single item that assesses overall health.

Sixteen of the QOLIE-31 items were drawn from existing sources and 15 items were developed *de novo* by the QOLIE Development Group (Table 1). The five-item emotional well-being and four-item energy/fatigue scales of the QOLIE-31 are identical to these scales in the RAND 36-Item Health Survey 1.0 (also known as the SF-36) (Hays, Sherbourne, and Mazel, 1993; Ware and Sherbourne, 1992). Items in this 36-item measure were adapted from longer instruments completed by patients participating in the Medical Outcomes Study (MOS), an observational study of variations in physician practice styles and patient outcomes in different systems of health care delivery (Stewart, Sherbourne, Hays, et al, 1992). The QOLIE-31 cognitive function and social function scales each contain one item incorporated from MOS instruments.

The QOLIE-31 also contains an overall quality of life scale that is comprised of one item from a study on patient preferences (Hadorn and Hays, 1991) and one Dartmouth COOP Chart (Nelson, Landgraf, Hays, et al, 1990). One seizure worry item and one cognitive functioning item were originally developed for the Epilepsy Surgery Inventory-55 (Vickrey, Hays, Graber, et al, 1992).

The single item on overall health was adapted from an existing visual analogue scale (Brazier, Jones, and Kind, 1993) and added to the QOLIE-31 subsequent to field testing of the other 30 items.

FIELD TESTING

Item selection for the QOLIE-31 was based on analysis of data collected from a cohort of 304 adult men and women having simple partial, complex partial, grand mal, absence, and/or myoclonic seizures of mild to moderate severity. These patients were enrolled from 25 sites across the US.

All subjects completed an initial 98-item QOLIE test battery; the majority of subjects completed this same battery again within three weeks of the first visit. A brief neuropsychological test battery, selected neurological exam features, a proxy's assessment of the subject's quality of life, and information about seizure occurrence, medications, demographic characteristics, and health care utilization were also obtained (Devinsky, Vickrey, Cramer, et al, 1993; Perrine, 1993; Devinsky, 1993).

Data from this study were analyzed, and three measures of quality of life were developed, differing in their number of items: the QOLIE-89 (Vickrey, Perrine, Hays, et al. Scoring Manual for the QOLIE-89), the QOLIE-31, and the QOLIE-10.

SCORING RULES

Precoded numeric values for responses on some QOLIE-31 items are in the direction such that a higher number reflects a more favorable health state. For example, a circled response of '10' for item 1 corresponds to "Best Possible Quality of Life", while a circled response of '0' corresponds to "Worst Possible Quality of Life." However, precoded numeric values for some other items on the QOLIE-31 are in the direction such that a *lower* number reflects a more favorable health state. For example, a circled response of '1' for item 14 corresponds to more favorable quality of life, while a value of '5' on this item corresponds to less favorable quality of life. As these examples also demonstrate, different items in the QOLIE-31 have different ranges of precoded numeric values.

To account for these differences, the scoring procedure for the QOLIE-31 first converts the raw precoded numeric values of items to 0-100 point scores, with higher converted scores always reflecting better quality of life (Table 2). To perform this step, write in the converted score for each item in the column labeled "Subtotal" in Table 2. Next, sum the subtotal scores for each scale and write in these values in the places marked "Total." Finally, divide each "Total" by the

number of items that the respondent answered within each scale to get the "Final Score." The possible range of each scale's final score is now from 0 to 100 points. Higher scores reflect better quality of life; lower ones, worse quality of life.

Note that Table 2 shows the divisors to be used only in situations where every item within a given scale has been answered. For example, if item 11 in the Seizure Worry scale was left blank and the other four items in the scale were answered, then the "Total" score for Seizure Worry would be divided by '4' (instead of '5') to obtain the "Final Score."

T-scores can be determined for each of these 0-100 point scale scores using the key in Table 3. These T-scores represent linear transformations of the scores that produce a mean of 50 and standard deviation of 10 for the cohort of 304 adults with epilepsy. Thus, a person with a T-score of 50 has a score equal to that of the mean for the epilepsy cohort. T-scores were computed using the following formula:

$$50 + \left[10 \left(\frac{\text{Observed scale score—scale mean in Table 5}}{\text{Scale standard deviation in Table 5}} \right) \right]$$

Higher T-scores reflect a more favorable quality of life.

OVERALL SCORE

A QOLIE-31 overall score can be derived by weighting and summing QOLIE-31 scale scores (Table 4). QOLIE-31 scale weights were derived from a regression analysis that used a summary score from the QOLIE-89.

This QOLIE-89 summary score was based on results of a factor analysis of the 17 QOLIE-89 scales. A four factor solution yielded unique placement of scales into domains of mental health, physical health, cognitive function, and epilepsy-specific areas, based on the magnitude of each scale's factor loadings. A factor score for each of these domains was derived using the factor loadings to weight each scale's contribution to that domain. These four factor scores were then averaged to produce a summary score.

To derive QOLIE-31 scale weights, this QOLIE-89 summary score was regressed on the seven QOLIE-31 multi-item scales. Standardized beta coefficients from this regression analysis were summed, and each beta coefficient was divided by the sum to derive the relative weight for each QOLIE-31 scale listed in Table 4.

The QOLIE-31 overall score is calculated by summing the product of each scale score times its weight and summing over all scales (Table 4). This score can be converted to a T-score using the key in Table 3.

DESCRIPTIVE STATISTICS AND INTERNAL CONSISTENCY RELIABILITY

Table 5 presents information on the reliability, central tendency and variability of the QOLIE-31 scales and the overall score in the group of 304 adults with epilepsy who participated in the QOLIE development study. Internal consistency reliabilities for the multi-item scales range from 0.77 to 0.85, exceeding the 0.70 standard for group-level comparisons (Nunnally, 1978). Test-retest reliabilities (Pearson correlation coefficients) also exceed this standard except for the medication effects scale ($r = 0.64$).

TABLE 1
KEY TO SOURCES OF ITEMS IN THE QOLIE-31

Item number	Source
1	Adapted from the Faces Scale (Andrews & Withey, 1976) by David Hadorn (Hadorn and Hays, 1991)
2,6,8,10	Energy/fatigue scale from RAND 36-Item Health Survey 1.0 (aka SF-36)
3,4,5,7,9	Emotional well-being scale from RAND 36-Item Health Survey 1.0 (aka SF-36)
11,15	From Epilepsy Surgery Inventory (ESI)-55 (Vickrey, Hays, Graber, et al, 1992)
12,13	From longer instruments in the Medical Outcomes Study (Stewart, Sherbourne, Hays, et al, 1992)
14	Dartmouth COOP Chart (Nelson, Landgraf, Hays, et al, 1990)
16-30	Developed <i>de novo</i> by QOLIE Development Group
31	Visual analogue item adapted from existing measure (Brazier, Jones, and Kind, 1993)

TABLE 2
QOLIE-31 SCORING FORM

Scale/Item Numbers	Response						Subtotal	Final Score, 0-100 point scale
	1	2	3	4	5	6		
Seizure Worry								
11.	0	20	40	60	80	100	_____	
21.	0	33.3	66.7	100	—	—	_____	
22.	0	50	100	—	—	—	_____	
23.	0	33.3	66.7	100	—	—	_____	
25.	100	75	50	25	0	—	_____	
						TOTAL:	_____	÷ 5 = _____
Overall Quality of Life								
1.	(multiply response by 10)						_____	
14.	100	75	50	25	0	—	_____	
						TOTAL:	_____	÷ 2 = _____
Emotional Well-Being								
3.	0	20	40	60	80	100	_____	
4.	0	20	40	60	80	100	_____	
5.	100	80	60	40	20	0	_____	
7.	0	20	40	60	80	100	_____	
9.	100	80	60	40	20	0	_____	
						TOTAL:	_____	÷ 5 = _____
Energy/Fatigue								
2.	100	80	60	40	20	0	_____	
6.	100	80	60	40	20	0	_____	
8.	0	20	40	60	80	100	_____	
10.	0	20	40	60	80	100	_____	
						TOTAL:	_____	÷ 4 = _____
Cognitive								
12.	0	20	40	60	80	100	_____	
15.	0	33.3	66.7	100	—	—	_____	
16.	0	20	40	60	80	100	_____	
17.	0	20	40	60	80	100	_____	
18.	0	20	40	60	80	100	_____	
26.	100	75	50	25	0	—	_____	
						TOTAL:	_____	÷ 6 = _____
Medication Effects								
24.	0	33.3	66.7	100	—	—	_____	
29.	100	75	50	25	0	—	_____	
30.	100	75	50	25	0	—	_____	
						TOTAL:	_____	÷ 3 = _____
Social Function								
13.	0	20	40	60	80	100	_____	
19.	0	25	50	75	100	—	_____	
20.	0	25	50	75	100	—	_____	
27.	100	75	50	25	0	—	_____	
28.	100	75	50	25	0	—	_____	
						TOTAL:	_____	÷ 5 = _____

Note: The total number of items in each scale is listed as the divisor for each subtotal. However, due to missing data, the divisor might actually be less than that as noted in the text "Scoring Rules," pages 2-3.

TABLE 3
QOLIE-31 PROFILE SHEET

T	Seizure Worry	Overall Quality of Life	Emotional Well-Being	Energy/ Fatigue	Cognitive	Medication Effects	Social Function	Overall Score	T
73								100	73
72								98-99	72
71				99-100				97	71
70				97-98				95-96	70
69				95-96				94	69
68		100		93-94	100			92-93	68
67		98-99	100	91-92	98-99			90-91	67
66	99-100	96-97	98-99	89-90	96-97			89	66
65	96-98	94-95	96-97	86-88	93-95	100		87-88	65
64	94-95	92-93	94-95	84-85	91-92	97-99		85-86	64
63	91-93	91	92-93	82-83	89-90	94-96		84	63
62	88-90	89-90	90-91	80-81	87-88	91-93	99-100	82-83	62
61	86-87	87-88	88-89	78-79	84-86	88-90	96-98	80-81	61
60	83-85	85-86	86-87	76-77	82-83	85-87	93-95	79	60
59	81-82	83-84	84-85	74-75	80-81	82-84	91-92	77-78	59
58	78-80	81-82	82-83	72-73	78-79	79-81	88-90	76	58
57	76-77	80	80-81	70-71	75-77	76-78	85-87	74-75	57
56	73-75	78-79	78-79	67-69	73-74	73-75	83-84	72-73	56
55	70-72	76-77	76-77	65-66	71-72	70-72	80-82	71	55
54	68-69	74-75	74-75	63-64	68-70	67-69	77-79	69-70	54
53	65-67	72-73	73	61-62	66-67	63-66	74-76	67-68	53
52	63-64	70-71	71-72	59-60	64-65	60-62	72-73	66	52
51	60-62	69	69-70	57-58	62-63	57-59	69-71	64-65	51
50	58-59	67-68	67-68	55-56	59-61	54-56	66-68	63	50
49	55-57	65-66	65-66	53-54	57-58	51-53	64-65	61-62	49
48	52-54	63-64	63-64	51-52	55-56	48-50	61-63	59-60	48
47	50-51	61-62	61-62	48-50	52-54	45-47	58-60	58	47
46	47-49	59-60	59-60	46-47	50-51	42-44	56-57	56-57	46
45	45-46	58	57-58	44-45	48-49	39-41	53-55	54-55	45
44	42-44	56-57	55-56	42-43	46-47	36-38	50-52	53	44
43	39-41	54-55	53-54	40-41	43-45	33-35	48-49	51-52	43
42	37-38	52-53	51-52	38-39	41-42	30-32	45-47	50	42
41	34-36	50-51	49-50	36-37	39-40	27-29	42-44	48-49	41
40	32-33	48-49	47-48	34-35	37-38	24-26	40-41	46-47	40
39	29-31	47	46	32-33	34-36	21-23	37-39	45	39
38	27-28	45-46	44-45	29-31	32-33	18-20	34-36	43-44	38
37	24-26	43-44	42-43	27-28	30-31	15-17	31-33	41-42	37
36	21-23	41-42	40-41	25-26	27-29	12-14	29-30	40	36
35	19-20	39-40	38-39	23-24	25-26	9-11	26-28	38-39	35
34	16-18	37-38	36-37	21-22	23-24	5-8	23-25	36-37	34
33	14-15	36	34-35	19-20	21-22	2-4	21-22	35	33
32	11-13	34-35	32-33	17-18	18-20	0-1	18-20	33-34	32
31	9-10	32-33	30-31	15-16	16-17		15-17	32	31
30	6-8	30-31	28-29	13-14	14-15		13-14	30-31	30
29	3-5	28-29	26-27	10-12	12-13		10-12	28-29	29
28	1-2	26-27	24-25	8-9	9-11		7-9	27	28
27	0	24-25	22-23	6-7	7-8		5-6	25-26	27
26		23	20-21	4-5	5-6		2-4	23-24	26
25		21-22	19	2-3	2-4		0-1	22	25
24		19-20	17-18	0-1	0-1			20-21	24
23		17-18	15-16					19	23
22		15-16	13-14					17-18	22
21		13-14	11-12					15-16	21
20		12	9-10					14	20
19		10-11	7-8					12-13	19
18		8-9	5-6					10-11	18
17		6-7	3-4					9	17
16		4-5	1-2					7-8	16
15		2-3	0					5-6	15
14		1						4	14
13		0						2-3	13
12								1	12
11								0	11

TABLE 4
FORMULA FOR CALCULATING QOLIE-31 OVERALL SCORE

QOLIE-31 Scale	Final Scale Score	Weight	Subtotal
Seizure worry	_____ ×	.08 =	_____ (a)
Overall quality of life	_____ ×	.14 =	_____ (b)
Emotional well-being	_____ ×	.15 =	_____ (c)
Energy/fatigue	_____ ×	.12 =	_____ (d)
Cognitive functioning	_____ ×	.27 =	_____ (e)
Medication effects	_____ ×	.03 =	_____ (f)
Social functioning	_____ ×	.21 =	_____ (g)
OVERALL SCORE: Sum subtotals (a) through (g) = _____			

TABLE 5
RELIABILITY, CENTRAL TENDENCY, AND VARIABILITY OF QOLIE-31 SCALES^a

Scale	Number of Items	Reliability		Mean (0-100 range)	Standard Deviation	Observed Range
		Alpha	Test-retest ^b			
Seizure worry	5	0.79	0.84	58.29	25.76	0-100
Overall quality of life	2	0.79	0.84	67.17	18.38	5-100
Emotional well-being	5	0.83	0.77	67.20	19.28	16-100
Energy/fatigue	4	0.84	0.75	55.30	21.10	0-100
Cognitive functioning	6	0.85	0.85	59.96	22.76	0-100
Medication effects	3	0.78	0.64	55.34	30.52	0-100
Social functioning	5	0.77	0.82	67.25	26.88	0-100
Overall score	30	0.93 ^c	0.89	62.87	16.31	15-97

N ranged from 298 to 304 patients with mild or moderate epilepsy for all data except test-retest reliability.

N ranged from 229 to 232 in the subset of epilepsy patients who were clinically stable and whose test-retest interval ranged from 1 to 21 days.

Estimated using Mosier's (1943) formula.

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APPENDIX XVI : MASTER DATA SHEET																									
S.NO.	Age	Gender	Marital status	Education	Occupation	Social background	Income	Age at onset	Seizure type	Duration	Treatment	Co-morbidity	Family history	Trigger	Seizure in last 4 week	SEIZURE WORRY	OVERALL QOL	EMOTIONAL WELL-BEING	ENERGY	COGNITIVE	MEDICATION EFFECTS	SOCIAL FUNCTION	OVERALL SCORE	T-SCORE	QOL
1	1	1	1	2	2	3	1	1	1	1	2	2	2	2	2	20	32.5	52	40	83.33	52.76	60	55.42	45	1
2	3	1	2	6	1	2	4	3	1	1	1	1	2	2	2	91	72.5	92	70	73.61	100	86	80.56	61	2
3	2	1	2	6	2	2	4	2	1	1	2	2	2	2	2	95	60	52	30	45.55	19.43	87	58.54	48	1
4	1	2	2	3	5	1	1	1	2	1	2	2	2	1	2	10.66	30	28	30	10	8.33	22	20.41	24	1
5	2	2	1	1	3	1	1	1	2	3	2	2	2	2	2	23.32	50	28	40	0	33.33	0	18.85	23	1
6	2	2	2	5	2	2	1	2	2	1	1	2	2	1	2	61.34	60	68	35	39.71	63.9	43	49.36	41	1
7	1	1	2	6	3	1	1	1	2	1	3	2	2	2	1	95	90	96	100	96.66	61.1	76	90.48	67	2
8	1	1	1	5	3	2	1	1	2	3	1	2	2	2	2	67.68	72.5	64	60	100	91.66	100	83.1	62	2
9	1	1	1	2	3	1	1	1	2	1	1	2	2	2	1	0	5	4	15	0	16.66	5	4.64	15	1
10	1	1	1	1	3	1	1	1	2	2	2	1	2	2	2	38.68	40	72	95	93.33	91.66	62	71.84	56	2
11	1	1	1	2	2	1	1	1	2	1	2	2	2	2	1	39	50	64	55	83.33	38.9	42	58.79	48	1
12	1	1	1	4	3	2	1	1	2	2	2	2	2	2	2	27	65	72	70	55.83	8.33	75	61.52	49	1
13	2	1	2	2	3	1	1	1	2	1	2	2	2	2	1	10.66	32.5	16	20	37.21	27.76	34	28.21	29	1
14	2	1	2	6	2	1	3	2	2	2	2	2	2	1	2	63.66	75	80	70	66.95	33.33	85	72.9	56	2
15	3	1	1	2	3	1	1	1	2	4	2	2	2	1	1	16.66	55	28	5	83.33	8.33	80	53.36	44	1
16	1	2	1	3	3	2	1	1	2	1	2	2	2	2	2	95	87.5	100	100	100	91.66	100	97.59	72	2
17	1	1	1	4	3	2	1	1	2	1	2	2	2	2	1	6.66	32.5	4	20	41.38	27.76	57	32.01	31	1
18	1	1	1	4	3	1	1	1	2	1	2	2	2	2	2	14	55	68	50	51.38	25	30	45.94	40	1
19	3	1	2	3	1	1	1	2	2	2	1	1	2	2	1	76.66	62.5	96	85	68.61	80.56	80	77.21	59	2
20	2	1	2	2	4	1	1	2	2	1	2	2	2	2	2	78.34	70	92	80	80.28	72.23	95	83.24	62	2
21	2	2	1	6	1	2	2	1	2	1	2	2	2	1	1	22.32	55	48	50	77.5	16.66	56	55.85	46	1
22	3	1	2	5	3	2	1	1	2	4	2	1	2	1	2	80	67.5	76	45	61.38	66.66	61	64.02	51	1
23	1	1	1	4	3	2	1	1	2	1	1	2	1	2	2	51	62.5	84	75	100	61.1	85	81.11	61	2
24	3	1	2	3	1	1	2	3	2	1	2	1	2	2	2	65.34	40	68	25	83.33	55.56	69	62.66	50	1
25	1	1	1	5	2	2	3	1	2	2	1	2	2	2	2	66	77.5	92	80	100	88.9	100	90.19	67	2
26	1	1	1	4	3	1	1	1	2	1	2	2	2	2	2	50.32	77.5	84	80	71.38	69.43	100	79.42	60	2
27	3	1	2	4	3	1	1	3	2	1	2	1	2	2	2	6.66	60	40	45	93.33	83.33	37	55.78	46	1
28	1	2	1	3	3	1	1	1	2	1	2	2	2	1	2	74.34	87.5	92	90	83.33	100	100	89.28	66	2
29	1	1	1	4	2	2	1	1	2	1	2	2	2	1	2	86	87.5	92	90	73.61	100	100	87.6	65	2
30	2	2	2	2	5	2	1	1	1	1	2	2	2	2	2	52	55	56	45	80.28	77.76	95	69.61	54	2
31	2	1	2	6	2	2	3	1	2	1	2	2	2	2	2	47	50	68	85	78.05	69.43	100	75.31	57	2
32	3	1	2	6	2	1	3	2	2	2	2	2	2	2	2	63.66	75	80	70	66.95	33.33	85	72.9	56	2
33	1	2	1	3	3	2	1	1	2	1	2	2	2	2	2	95	82.5	100	100	100	91.66	100	96.89	71	2
34	3	2	2	3	5	2	1	2	2	1	2	2	2	1	2	22.32	55	48	50	77.5	16.66	56	55.85	46	1
35	3	1	2	5	2	2	3	3	2	1	1	1	2	1	2	16.66	55	28	5	83.33	8.33	80	53.36	44	1
36	2	2	2	5	5	2	1	2	2	1	1	2	2	2	2	79.34	82.5	92	80	86.95	100	100	88.76	66	2
37	2	1	2	5	2	2	2	2	2	1	2	2	2	2	1	32.32	32.5	32	20	61.38	61.1	53	43.86	38	1
38	1	1	1	4	3	2	1	1	2	1	1	2	2	2	2	72.68	77.5	84	80	100	91.66	90	87.5	65	2
39	1	1	1	5	2	2	2	1	2	1	1	2	2	2	2	72.68	82.5	92	80	96.66	88.9	100	90.51	67	2
40	1	2	2	4	5	1	1	1	2	1	2	2	2	2	2	10.66	30	28	30	10	8.33	22	20.41	24	1
41	2	1	2	3	2	2	2	1	2	2	2	2	2	2	2	47	77.5	84	70	100	77.76	100	85.94	64	2
42	3	1	2	4	2	2	3	2	2	2	2	2	2	2	2	50.68	87.5	92	90	100	80.56	95	90.26	67	2
43	2	1	2	4	4	1	2	1	2	2	2	1	2	2	2	45.32	65	76	70	70.28	61.1	76	69.28	54	2
44	2	1	2	5	1	2	4	1	2	2	2	2	2	2	2	62.68	65	92	80	100	100	90	86.41	64	2
45	1	1	2	5	2	2	3	1	2	1	2	2	2	2	1	62.68	60	80	65	76.95	72.23	80	72.94	56	2
46	3	1	2	5	3	2	1	1	2	4	1	1	2	2	2	83.34	87.5	84	75	96.66	100	95	89.55	66	2
47	3	1	2	2	4	2	3	1	2	3	2	2	2	2	2	40.32	70	84	80	67.21	83.33	95	75.8	58	2
48	2	1	2	3	2	2	2	2	2	1	2	2	2	2	2	40.32	55	48	50	72.78	66.66	71	60.67	49	1
49	2	1	2	3	4	2	2	2	2	1	2	2	2	2	2	90	65	84	75	100	100	100	88.9	66	2
50	3	1	2	4	2	2	3	2	2	2	2	1	2	2	2	45.32	65	76	70	70.28	61.1	76	69.28	54	2
51	2	1	2	4	2	2	3	2	1	1	1	2	2	2	2	90	87.5	92	90	100	100	100	95.05	70	2
52	3	1	2	2	4	2	2	2	2	2	2	1	1	2	2	63.66	75	80	70	66.95	33.33	85	72.9	56	2
53																									

57	3	2	2	1	5	2	1	2	2	2	2	2	2	2	2	65.34	40	68	25	83.33	55.56	69	62.66	50	1
58	1	2	2	4	5	2	1	1	2	2	2	2	2	2	2	10.66	30	28	30	10	8.33	22	20.41	24	1
59	2	2	1	6	1	2	2	1	2	1	2	2	2	2	1	22.32	55	48	50	77.5	16.66	56	55.85	46	1
60	2	2	2	5	5	1	1	2	2	1	1	2	2	2	2	72.68	82.5	92	80	96.66	88.9	100	90.51	67	2
61	3	1	2	4	2	2	3	3	2	1	3	2	2	2	2	95	87.5	92	80	100	100	100	94.25	69	2
62	3	2	2	4	4	1	2	2	2	1	2	2	2	2	2	67.68	72.5	64	60	100	91.66	100	83.1	62	2
63	2	2	2	5	2	2	3	1	2	2	2	2	2	2	2	76.66	50	92	80	68.61	80.56	80	74.26	57	2
64	3	1	2	4	4	1	2	2	2	1	2	2	2	2	2	15.66	77.5	80	70	100	100	95	82.45	62	2
65	1	1	1	4	3	2	1	1	2	2	1	3	2	2	2	70	60	72	25	72.78	33.33	70	63.14	50	1
66	1	1	1	5	3	1	1	1	2	2	1	2	2	2	2	95	87.5	92	80	90.28	77.76	100	90.95	67	2
67	2	2	2	2	5	1	1	1	2	2	2	2	2	2	1	0	32.5	40	25	58.05	61.1	72	46.17	40	1
68	1	2	1	4	5	2	1	1	1	1	1	2	2	2	2	27	65	72	70	55.83	8.33	75	61.52	49	1
69	3	2	2	3	5	2	1	2	2	1	1	2	2	1	2	7.16	60	64	45	64.72	75	62	56.71	46	1
70	1	2	1	4	5	2	1	1	2	1	2	2	2	2	1	6.66	60	40	45	93.33	83.33	37	55.78	46	1
71	2	2	2	4	2	2	3	1	1	1	1	2	2	2	2	95	82.5	100	100	100	91.66	100	96.89	71	2
72	3	1	2	3	4	2	2	2	2	1	2	2	2	2	2	72.68	77.4	84	80	100	91.66	90	87.5	65	2
73	1	2	1	5	1	2	3	1	2	1	2	2	1	1	1	11.66	50	64	40	28.88	33.33	20	35.31	33	1
74	3	1	2	4	2	2	3	2	2	1	2	2	2	2	2	50.68	87.5	92	90	100	80.56	95	90.26	67	2
75	3	1	2	2	2	2	3	2	2	1	2	1	2	2	2	45.32	75	48	20	71.38	58.3	90	63.63	51	1
76	2	1	2	4	2	2	3	2	2	1	2	2	2	2	2	52	82.5	92	90	100	80.56	100	90.72	67	2
77	3	1	2	3	4	1	2	2	2	1	2	2	2	2	2	71	87.5	92	90	100	100	100	93.53	69	2
78	1	1	1	4	3	2	1	1	2	2	2	2	2	1	2	37.32	55	48	30	76.66	33.33	85	61.01	49	1
79	3	2	2	1	5	1	1	2	2	2	2	1	2	2	2	91	72.5	92	70	73.61	100	86	80.56	61	2
80	2	2	2	3	5	1	1	1	2	3	2	2	1	2	1	0	5	4	15	0	16.66	5	4.64	15	1
81	2	2	2	4	5	2	1	2	2	1	2	2	2	2	2	48	65	60	60	96.66	69.43	91	76.42	58	2
82	3	1	2	4	4	2	3	3	2	1	2	2	1	1	2	61	50	88	75	34.16	41.66	95	64.49	51	1
83	2	1	2	4	2	1	4	2	1	1	2	2	2	1	2	95	60	52	30	45.55	19.43	87	58.54	48	1
84	1	1	1	3	3	2	1	1	2	2	2	2	2	2	2	81.66	60	56	35	13.33	50	38	40.6	37	1
85	1	1	1	4	3	2	1	1	2	2	1	2	2	2	2	50.32	77.5	84	80	71.38	69.43	100	79.42	60	2
86	1	1	1	4	3	2	1	1	1	1	1	2	2	2	2	66	77.5	92	80	100	88.9	100	90.19	67	2
87	3	1	2	4	3	1	1	2	2	2	2	1	2	2	2	80	67.5	76	45	61.38	66.66	61	64.02	51	1
88	1	1	1	5	2	1	3	1	2	1	2	2	2	2	2	51	62.5	84	75	100	61.1	85	81.11	61	2
89	2	2	2	4	4	2	3	2	2	1	2	2	2	2	2	74.34	87.5	92	90	83.33	100	100	89.28	66	2
90	1	1	1	4	3	2	1	1	2	1	2	2	2	2	2	86	87.5	92	90	73.61	100	100	87.6	65	2
91	3	1	2	4	4	1	3	2	2	1	2	2	2	2	2	22.32	55	48	50	77.5	16.66	56	55.85	46	1
92	1	2	2	4	5	2	1	2	2	1	2	2	2	1	1	39	50	64	55	83.33	38.9	42	58.79	48	1
93	2	1	2	4	4	2	3	2	2	1	2	2	2	2	2	72.68	82.5	92	80	96.66	88.9	100	90.51	67	2
94	1	2	1	5	3	2	1	1	2	1	1	2	2	2	2	83.34	87.5	84	75	96.66	100	95	89.55	66	2
95	1	2	2	5	2	1	2	1	2	1	2	2	2	2	2	62.68	65	92	80	100	100	90	86.41	64	2
96	1	2	1	4	3	1	1	1	2	1	2	2	2	2	2	16.66	55	28	5	83.33	8.33	80	53.36	44	1
97	1	1	2	5	3	1	1	1	2	1	2	2	2	2	2	79.34	82.5	92	80	86.95	100	100	88.76	66	2
98	1	1	2	5	2	2	3	2	1	1	1	2	2	2	2	63.66	75	80	70	66.95	33.33	85	72.9	56	2
99	1	1	1	4	3	1	1	1	2	2	2	2	2	2	2	95	87.5	100	100	100	91.66	100	97.59	72	2
100	2	2	2	5	2	1	3	2	2	1	2	2	2	2	2	95	90	96	100	96.66	61.1	76	90.48	67	2
101	3	1	2	3	4	1	3	2	2	2	2	1	2	2	2	95	87.5	92	80	100	100	100	94.25	69	2
102	1	2	1	2	3	1	1	1	2	2	2	2	2	2	2	20	32.5	52	40	83.33	52.76	60	55.42	45	1
103	1	1	2	5	2	1	3	1	2	1	2	2	2	2	2	52	55	56	45	80.28	77.76	95	69.61	54	2
104	1	1	1	3	3	2	1	1	2	1	2	2	2	2	2	76.66	50	92	80	68.61	80.56	80	74.26	57	2
105	2	2	2	4	4	2	3	1	2	2	2	2	2	2	2	95	87.5	92	80	90.28	77.76	100	90.95	67	2
106	1	1	2	5	2	2	4	2	1	1	1	2	2	2	2	90	87.5	92	90	100	100	100	95.05	70	2
107	2	2	2	4	4	2	3	2	2	1	2	2	2	2	2	61.34	60	68	35	39.71	63.9	43	49.36	41	1
108	2	2	2	5	1	2	4	2	2	1	2	2	2	1	1	23.32	50	28	40	0	33.33	0	18.85	23	1
109	2	1	2	4	2	2	4	2	1	1	2	2	2	1	2	47	77.5	84	70	100	77.76	100	85.94	64	2
110	3	2	2	3	5	2	1	2	2	2	2	1	2	2	2	40.32	70	84	80	67.21	83.33	95	75.8	58	2
111	2	1	2	5	2	2	3	2	2	1	2	2	2	2	1	32.32	32.5	32	20	61.38	61.1	53	43.86	38	1
112	2	2	2	4	4	2	3	2	2	1	2	2	2	2	2	45.32	65	76	70	70.28	61.1	76	69.28	54	2
113	1	1	1	4	3	1	1	1	2	1	2	2	2	2	2	11.66	77.5	84	80	100	100	95	83.93	63	2
114	2	2	2	5	2	2	2	1	2	1	2	2	2	2	2	90	65	84	75	100	100	100	88.9	66	2
115	1	2	1	4	3	1	1	1	2	1	3	2	2	2	2	90	87.5	92	80	100	100	100	93.85	69	2
116	1	2	2	3	5	1	1	1	2	1	2	2	2	1	2	44.32	60	56	40	44.16	63.9	95	58.92	48	1
117	2	2	2	5	2	1	2	1	2	1	2	2	2	2	2	45.32	65	76	70	70.28	61.1	76	69.28	54	2
118	2	1	2	4	4	2	3	2	2	1	2	2	2	2	1	40.32	55	48	50	72.78	66.66	71	60.67	49	1
119	3	1	2	4	4	2	3	2	2	1	2	2	2	2	2	62.68	60	80	65	76.95	72.23	80	72.92	56	2

120	3	1	2	3	4	1	3	2	2	2	2	1	1	2	2	71.68	82.5	84	80	100	77.76	100	89.81	67	2
121	1	1	1	4	3	1	1	1	2	2	3	2	2	2	1	60	37.5	32	40	16.66	66.66	80	42.93	38	1
122	3	2	2	4	5	1	1	1	2	3	2	2	2	1	2	62.68	65	84	80	100	88.9	100	86.97	65	2
123	2	1	1	3	4	2	2	1	2	3	2	2	2	2	2	83.34	87.5	84	80	100	61.1	85	87.79	65	2
124	2	1	2	4	4	2	3	2	2	1	2	2	2	2	2	65	75	92	60	81.38	69.43	100	81.75	62	2
125	3	2	2	4	5	1	1	2	2	1	2	2	2	2	2	56	70	92	80	96.66	63.9	100	86.68	65	2
126	2	2	2	4	5	2	1	2	2	1	2	2	2	2	2	58.68	60	80	55	86.95	72.23	100	78.32	59	2
127	2	1	2	5	2	2	3	2	2	1	2	2	2	2	2	58.68	60	80	75	96.66	61.1	95	81.96	62	2
128	1	2	2	2	5	1	1	2	2	2	1	2	2	2	1	0	32.5	40	20	86.66	33.33	62	50.35	42	1
129	1	2	1	4	3	1	1	1	2	1	3	2	2	2	2	86	65	88	65	83.61	83.33	95	81.99	62	2
130	1	1	1	4	3	1	1	1	2	1	2	2	2	2	2	47	70	92	80	83.61	72.23	85	79.54	61	2
131	3	1	2	4	4	2	2	2	2	1	2	1	2	2	2	62.68	87.5	88	80	96.66	69.43	95	88.18	65	2
132	3	1	2	3	3	1	1	3	2	1	2	2	2	2	2	62.68	60	80	70	83.61	80.56	95	78.74	60	2
133	1	1	1	4	3	2	1	1	2	1	2	2	2	2	1	62	70	92	80	100	69.43	100	88.24	65	2
134	1	1	2	4	3	2	1	1	2	1	3	2	2	2	2	79.34	87.5	92	90	100	69.43	100	93.27	68	2
135	3	2	2	3	5	2	1	1	2	4	2	2	2	2	2	91	77.5	92	80	100	91.66	100	92.27	68	2
136	1	1	1	5	3	1	1	1	2	1	2	2	2	2	2	41.32	60	92	85	100	88.9	80	82.16	62	2
137	1	1	1	4	3	2	1	1	2	1	2	2	2	1	1	10.66	37.5	64	40	96.66	61.1	61	61.23	49	1
138	1	1	2	5	2	2	2	1	2	1	2	2	2	2	2	62	70	80	80	86.66	69.43	96	81.99	62	2
139	2	2	2	5	5	1	1	2	2	1	2	2	2	2	2	52	77.5	80	80	80.28	80.56	95	80.64	61	2
140	2	1	2	4	4	2	3	2	2	1	2	2	2	2	2	57	60	72	80	100	72.23	95	82.47	62	2
141	2	1	2	5	1	1	4	2	2	1	2	2	2	2	1	67.68	77.5	92	75	100	91.66	80	85.6	64	2
142	3	1	2	3	3	2	1	3	2	1	2	2	2	2	2	67.68	77.5	84	70	84.45	100	95	83.01	62	2
143	1	1	2	5	2	2	3	2	2	1	2	2	2	2	2	81	87.5	92	80	74.71	91.66	100	86.04	64	2
144	1	1	1	4	4	1	3	1	1	1	2	2	2	2	1	56	82.5	92	80	100	100	100	90.43	67	2
145	1	1	1	3	3	2	1	1	2	3	2	2	1	1	1	11.66	72.5	72	55	51.38	41.66	71	58.5	47	1
146	1	1	1	4	3	2	1	1	2	1	2	2	2	2	2	44	77.5	76	55	70.28	52.76	85	70.77	54	2
147	1	1	2	5	2	1	3	2	2	1	2	2	2	2	2	62.68	82.5	92	80	96.66	88.9	100	89.71	67	2
148	1	1	1	3	3	1	1	1	2	1	2	2	2	2	2	57.68	60	76	70	54.71	72.23	66	63.6	51	1
149	2	1	2	5	1	2	4	1	2	3	2	2	2	2	1	95	87.5	92	90	100	100	100	95.45	70	2
150	2	1	1	4	3	2	1	2	2	1	2	2	2	2	2	52	65	76	55	76.95	41.66	58	65.45	51	1
151	1	1	1	4	3	2	1	1	2	1	3	2	2	2	2	70	60	72	25	72.78	33.33	70	63.14	50	1
152	1	1	1	4	3	1	1	1	2	1	2	2	2	2	2	70	52.5	72	25	91.66	33.33	85	70.33	54	2
153	1	2	1	4	3	1	1	1	2	1	2	2	2	2	2	95	87.5	92	90	100	100	100	95.45	70	2
154	1	2	1	4	3	1	1	1	1	1	1	2	2	2	2	77.68	82.5	80	80	96.66	88.9	96	88.27	65	2
155	3	1	2	1	3	2	1	2	2	2	2	2	2	2	2	65.34	40	68	25	83.33	55.56	69	62.66	50	1
156	3	1	2	5	2	2	3	1	2	2	1	2	2	1	2	11.66	77.5	84	80	100	100	95	83.93	63	2
157	1	1	1	4	3	2	1	1	2	1	2	2	2	2	1	47	50	68	85	78.05	69.43	100	75.31	57	2
158	2	1	2	4	2	2	2	2	2	1	2	2	2	2	2	62.68	77.5	72	75	100	88.9	100	86.32	64	2
159	2	1	1	3	2	2	1	1	2	1	2	2	2	2	2	79.34	87.5	96	75	100	100	100	92.99	68	2
160	3	2	2	3	4	1	2	2	2	2	2	2	2	2	2	76.68	77.5	92	80	100	72.23	95	89.49	66	2
161	2	2	2	5	2	1	4	2	2	1	2	2	2	2	2	81.68	87.5	92	80	100	88.9	95	91.79	68	2
162	1	1	2	5	2	1	3	1	2	1	2	2	2	2	2	57.68	60	84	70	80.28	72.23	85	75.69	58	2
163	3	1	2	2	4	1	2	2	2	2	2	1	2	2	2	62.68	65	84	75	80.28	88.9	85	77.89	59	2
164	2	1	2	5	2	1	2	2	2	1	2	2	2	2	2	62.68	82.5	84	80	100	100	100	89.76	67	2
165	1	2	1	4	3	1	1	1	2	1	2	2	2	1	1	15.66	42.5	40	30	57.21	61.1	66	47.93	41	1
166	2	1	2	5	2	1	2	2	2	1	2	2	2	2	2	72.68	82.5	84	80	100	100	100	90.56	67	2
167	3	2	2	4	5	2	1	2	2	1	2	2	2	2	2	56	77.5	84	75	80.28	88.9	85	79.11	60	2
168	2	1	2	5	2	2	2	2	2	1	2	2	2	2	2	56	77.5	84	75	80.28	88.9	85	79.11	60	2
169	1	1	2	4	4	1	3	1	2	1	2	2	2	1	2	85	87.5	92	90	100	88.9	100	94.31	69	2
170	1	1	2	5	2	1	4	1	2	1	2	2	1	2	2	69.34	77.5	88	80	96.66	91.66	85	85.87	64	2
171	2	2	2	3	5	2	1	2	2	1	2	2	2	2	1	28.32	55	52	35	64.71	83.33	75	57.67	47	1
172	1	2	2	3	5	1	1	1	2	1	2	2	2	2	2	79.34	77.5	88	80	96.66	91.66	95	88.77	66	2
173	2	2	2	3	5	2	1	2	2	1	2	2	2	2	2	83.34	82.5	92	80	100	91.66	95	91.3	67	2
174	3	1	2	4	4	2	3	2	2	2	2	2	2	2	2	69.34	72.5	72	50	96.66	91.66	95	81.27	61	2
175	2	2	2	4	5	2	1	2	2	1	2	2	2	2	2	62.68	77.5	92	80	76.95	83.33	90	81.42	61	2
176	2	2	2	5	5	2	1	1	2	1	2	2	2	2	2	62.68	67.5	92	80	80.28	83.33	90	80.92	61	2
177	2	1	2	5	2	1	3	2	2	1	2	2	2	2	2	79.34	82.5	92	90	100	83.33	100	92.98	68	2
178	1	1	1	4	3	2	1	1	2	1	2	2	2	2	2	69.34	82.5	92	90	100	83.33	100	92.18	68	2
179	1	2	2	3	5	1	1	2	2	1	2	2	2	2	2	62.68	60	72	60	76.95	83.33	95	74.62	57	2
180	3	1	2	3	3	1	1	2	2	2	2	2	1	2	2	62.68	77.5	84	75	76.95	83.33	95	80.67	61	2
181	1	2	1	4	3	2	1	1	1	1	1	2	2	2	1	77.68	82.5	88	90	100	80.56	95	91.12	67	2
182	3	1	2	5	2	2	2	2	2	1	2	2	2	1	2	62.68	65	88	65	80.28	72.23	95	78.89	60	2

183	2	1	2	5	2	2	2	2	2	1	2	2	2	2	2	62.68	72.5	72	35	76.95	72.23	95	73.04	56	2
184	3	1	2	5	2	2	3	2	2	1	2	2	2	2	2	90	82.5	92	90	100	91.66	95	93.04	68	2
185	3	2	2	3	5	2	1	2	2	1	2	1	2	2	2	62.68	72.5	84	30	57.21	72.23	95	68.91	54	2
186	2	2	2	3	5	1	1	2	2	1	2	2	2	2	2	72.68	77.5	88	65	80.28	72.23	95	81.44	61	2
187	2	2	2	4	5	2	1	1	2	1	2	2	2	2	2	62.68	77.5	88	65	80.28	72.23	95	80.64	61	2
188	1	2	2	5	5	2	1	1	2	1	2	2	2	2	2	62.68	67.5	92	80	76.95	83.33	90	80.02	61	2
189	3	2	2	3	5	1	1	2	2	2	2	2	2	2	2	79.34	82.5	92	90	100	83.33	100	92.98	68	2
190	1	1	1	5	2	2	3	2	1	1	2	2	2	2	1	62.68	77.5	84	75	76.95	83.33	95	80.67	61	2
191	1	1	1	5	2	2	3	1	2	1	1	2	2	2	2	79.34	87.5	96	75	100	100	100	92.99	68	2
192	1	2	2	5	5	2	1	1	2	1	2	2	2	2	1	28.32	55	52	35	64.71	83.33	75	57.67	47	1
193	3	1	2	3	4	2	2	3	2	1	2	1	2	2	2	79.34	77.5	88	80	96.66	91.66	95	88.77	66	2
194	1	2	2	5	5	2	1	2	2	1	2	2	2	2	2	69.34	72.5	72	50	96.66	91.66	95	81.27	61	2
195	1	1	1	4	3	2	1	1	2	2	3	2	2	2	2	95	87.5	100	95	100	91.66	100	96.99	71	2
196	3	1	2	4	4	2	3	2	2	1	2	2	2	2	2	66	77.5	92	80	100	88.9	100	90.19	67	2
197	1	2	2	4	5	2	1	2	2	1	2	2	2	1	2	6.66	60	40	35	73.88	91.66	37	49.58	42	1
198	3	1	2	4	4	2	2	2	2	3	2	1	2	2	2	50.32	77.5	84	80	71.38	69.43	100	79.42	60	2
199	2	2	2	4	5	1	1	2	2	1	2	2	2	2	2	78.34	82.5	84	80	90	80.56	95	86.67	65	2
200	2	2	2	4	5	2	1	1	2	2	2	2	2	2	2	74.34	87.5	92	90	83.33	100	100	89.28	66	2
201	3	2	2	3	5	1	1	2	2	1	2	1	2	2	2	72.68	65	76	75	100	91.66	90	83.95	63	2
202	1	1	1	4	3	2	1	1	2	2	1	2	2	2	1	67.68	72.5	56	50	100	91.66	100	80.7	61	2
203	1	2	1	4	3	2	1	1	2	1	2	2	2	2	2	95	87.5	92	95	100	100	100	96.05	70	2
204	1	2	2	5	2	2	3	1	2	1	3	2	2	2	2	95	87.5	92	80	90.28	77.76	100	90.95	67	2
205	2	2	2	5	5	2	1	2	2	1	1	2	2	1	2	15.66	77.5	80	70	100	100	95	82.45	62	2
206	1	1	1	1	3	1	1	1	2	2	2	1	2	2	2	38.68	40	72	95	93.33	91.66	62	71.84	56	2
207	1	1	1	5	3	2	1	1	2	3	1	2	2	2	2	67.68	72.5	64	60	100	91.66	100	83.1	62	2
208	2	2	2	5	2	2	1	2	2	1	1	2	2	1	2	61.34	60	68	35	39.71	63.9	43	49.36	41	1
209	1	2	2	3	5	1	1	1	2	1	2	2	2	1	2	10.66	30	28	30	10	8.33	22	20.41	24	1
210	2	1	2	6	2	2	4	2	1	1	2	2	2	1	2	95	60	52	30	45.55	19.43	87	58.54	48	1
211	1	2	1	3	3	1	1	1	2	1	2	2	2	1	2	74.34	87.5	92	90	83.33	100	100	89.28	66	2
212	1	1	1	4	2	2	1	1	2	2	1	2	2	2	2	86	87.5	92	90	73.61	100	100	87.6	65	2
213	1	1	1	4	3	2	1	1	2	1	1	2	2	2	2	32.32	32.5	32	20	61.38	61.1	53	43.86	38	1
214	1	1	1	3	3	2	1	1	2	1	2	2	2	2	2	76.66	50	92	80	68.61	80.56	80	74.26	57	2
215	2	2	2	5	5	1	1	2	2	1	1	2	2	2	2	72.68	82.5	92	80	96.66	88.9	100	90.51	67	2
216	1	1	2	5	2	1	3	1	2	1	2	2	2	2	2	52	55	56	45	80.28	77.76	95	69.61	54	2
217	2	2	2	5	5	2	1	2	2	1	1	2	2	2	2	79.34	82.5	92	80	86.95	100	100	88.76	66	2
218	3	1	2	3	3	2	1	1	2	4	2	1	2	1	2	80	67.5	76	45	61.38	66.66	61	64.02	51	1
219	2	2	2	4	4	2	3	1	2	2	2	2	2	2	2	95	87.5	92	80	90.28	77.76	100	90.95	67	2
220	2	1	2	2	4	1	1	2	2	1	2	2	2	2	2	78.34	70	92	80	80.28	72.23	95	83.24	62	2
221	1	1	1	5	2	2	2	1	2	1	1	2	2	2	2	68.68	82.5	92	80	96.66	88.9	100	90.19	67	2
222	3	1	2	4	2	2	3	2	2	1	2	2	2	2	2	78.34	70	92	80	80.28	72.23	95	83.24	62	2
223	2	1	2	4	4	2	3	2	2	1	2	2	2	2	2	57	60	72	80	100	72.23	95	82.47	62	2
224	1	1	1	3	3	2	1	1	2	1	2	2	2	2	2	76.66	50	92	80	68.61	80.56	80	74.26	57	2
225	1	1	2	2	3	1	1	1	1	2	2	2	2	2	1	20	32.5	52	40	83.33	52.76	60	55.42	45	1
226	2	2	2	1	5	1	1	2	2	1	2	2	2	2	1	69.34	50	44	75	25	100	85	55.74	46	1
227	3	1	2	5	1	2	2	2	2	2	1	2	2	2	2	85	87.5	100	100	83.33	100	91	92	68	2
228	3	1	2	4	4	2	2	1	2	2	1	1	2	2	2	86	55	68	80	88.33	88.9	95	80.83	61	2
229	2	2	2	1	5	1	2	2	2	1	2	2	2	2	2	85	87.5	100	100	100	100	100	97.05	71	2
230	3	1	2	4	4	1	1	2	2	1	2	1	2	2	2	47	70	72	25	34.16	38.9	57	49.71	42	1
231	3	2	2	4	5	2	1	2	2	2	1	2	2	2	2	95	77.5	68	85	100	100	100	89.85	67	2
232	2	2	2	1	5	1	2	2	2	1	2	2	2	2	1	32.32	70	68	80	30.28	83.33	90	75.24	57	2
233	1	2	2	3	5	2	2	1	2	2	2	2	2	2	2	88.34	82.5	84	80	100	69.43	90	88.79	66	2
234	3	1	2	5	4	2	1	2	2	2	2	1	2	2	1	32.32	50	52	65	56.38	61.1	52	53.15	44	1
235	3	1	2	3	4	1	2	2	2	2	2	2	2	2	1	48	65	88	80	76.11	72.23	62	71.46	55	2
236	2	2	2	5	5	2	2	2	1	1	2	2	2	2	2	53.68	70	84	80	91.66	80.56	80	80.24	61	2
237	1	1	2	4	4	1	1	1	2	1	2	2	2	1	1	43	50	52	40	26.38	38.9	56	43.08	38	1
238	3	1	2	4	2	2	1	2	2	1	2	2	2	2	2	84.34	50	76	45	80.28	61.1	65	67.69	53	2
239	1	1	2	4	2	2	2	1	2	1	2	2	2	2	2	95	87.5	92	90	100	100	100	95.45	70	2
240	3	1	2	4	4	2	2	2	2	1	1	1	2	2	2	95	87.5	88	90	100	100	100	94.85	70	2
241	2	1	2	4	4	1	1	2	2	1	2	2	2	2	2	67.68	65	72	60	77.5	83.33	85	73.77	57	2
242	3	2	2	4	5	2	1	2	2	1	2	2	2	2	1	49.32	55	72	75	66.11	61.1	85	68.96	54	2
243	1	1	1	5	2	2	2	1	1	1	1	2	2	2	1	44	60	52	20	73.61	63.9	86	61.96	49	1
244	2	2	2	6	5	2	2	1	1	1	1	2	2	2	2	27.34	55	84	60	62.21	88.9	68	63.41	50	2
245	2	1	2	6	4	2	2	1	1	1	2	1	2	1	1	0	22.5	44	10	6.66	33.33	37	21.5	24	1

246	1	1	1	4	1	2	1	1	2	1	2	2	1	2	2	64.32	70	84	100	61.11	66.66	63	71.25	55	2
247	1	1	1	4	2	2	2	1	2	1	2	1	2	1	2	22.66	65	40	50	86.66	41.66	53	58.67	48	1
248	3	1	2	3	2	1	2	2	1	2	1	1	2	2	2	67.68	70	88	60	65.28	72.23	61	68.2	53	2
249	3	2	2	1	5	2	2	2	2	2	1	1	2	2	2	95	87.5	92	85	100	100	100	94.85	70	2
250	2	1	2	5	4	2	2	2	2	1	2	2	2	2	1	24.66	37.5	32	25	36.38	61.1	29	32.76	32	1
AVG																58.8273	67.2996	75.072	65.78	78.9324	72.09752	82.4	74.1076	56.88	
ST.DEV.																25.7557	16.916	20.6650143	23.1147	23.4832	25.07013784	22.04177851	18.748828	11.4613	