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Perceived Loneliness Among Patients with Epilepsy

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KEYWORDS

Perceived loneliness, Epilepsy patients, Psychological Distress, Psychological Challenges, Neurological Disorder.

ABSTRACT:

Introduction:

BACKGROUND:

Epilepsy is a chronic neurological condition often associated with significant psychological challenges. Individuals living with epilepsy frequently experience elevated levels of perceived loneliness (PL) due to unpredictable seizure episodes, social stigma, lifestyle limitations and reduced support systems. Understanding these psychological burdens is essential for guiding mental-health interventions and improving patient's wellbeing.

Objectives:

1. To determine the level of perceived loneliness among the patients with epilepsy.
2. To find out the association of demographic variables-age, gender and occupation with perceived loneliness among the patients with epilepsy.

Methods: A descriptive cross-sectional study design was used with convenience sampling to select 70 reported patients with Epilepsy from neurology and neurosurgery outpatient department's (OPDs) from hospitals and registered neuroclinics in Belagavi city. Perceived Loneliness Scale was employed to measure perceived loneliness. Percentage method and Chi-square were applied.

Results: *:* Majority of the participants with epilepsy (70%) reported extremely high to high level of perceived loneliness. Age and occupation were significantly associated with perceived loneliness ($p<0.05$).

CONCLUSION: Most patients with epilepsy experience high level of perceived loneliness and there is a significant association between Age and occupation and perceived loneliness.

1. Introduction

Health is the most important aspect of life as it directly influences physical, psychological and social well-being of people'. When health is compromised, it can have profound effects on almost every aspect of life, limiting an individual's ability to engage in daily activities, build relationships and experience life fully. One such health condition is epilepsy, a neurological disorder that affects approximately 2% of the global population. [1]

Epilepsy is 'an occasional, excessive and a disorderly discharge of nerve tissue'.

An epileptic attack (or seizure) happens when there's a sudden burst of unusual electrical activity in a part of the brain. These bursts cause the symptoms of a seizure. [2]

Clinical varieties of epileptic attack or seizure are Generalized seizures, Partial seizures, Special types of epilepsy and Status epilepticus. [3]

Symptoms are loss of blood in haemorrhage, inadequate venous return to the heart, the circulatory system itself may be primarily at fault, when fainting occurs in Stokes-Adams attacks resulting from heart block and in disturbances of cardiac rate or rhythm such as paroxysmal tachycardia and atrial flutter. [3]

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Epilepsy in adult life can be caused due to the intracranial tumors, cerebral atherosclerosis (especially after the age 50), head injury (particularly penetrating injuries), alcohol withdrawal, cysticercosis (especially in those with tropical exposure). [4] Alongside these biological causes, epilepsy is strongly associated with multiple comorbidities that affect behavioural, cognitive and psychological functioning. Common behavioural and cognitive comorbidities include memory impairments, reduced attention, slower processing speed, executive dysfunction and difficulties in social cognition such as interpreting emotions or social cues. **Mula & Sander (2016)** [5]

Psychological comorbidities particularly depression, anxiety, low self-esteem and increased vulnerability to social stigma are also highly prevalent and often emerge due to the chronic nature of the condition and its social burden. [6] These comorbidities collectively contribute to significant consequences in the lives of people with epilepsy. Over time, these consequences can impair social participation, reduce quality of life and exacerbate psychological difficulties, creating a cycle of emotional and social disadvantage for individuals living with epilepsy.

Beyond the direct physical risk posed by seizures, individuals living with epilepsy often face persistent psychological and social problems. The unpredictable nature of seizures, coupled with fears of embarrassment, social stigma, and discrimination can lead to perceived loneliness.[7]

Perceived loneliness is an affective and cognitive discomfort or uneasiness arising from the perception of being alone or solitary. [8]

Understanding the interplay between physical health, health-related behaviours and psychological well-being is crucial for improving outcomes in epilepsy. Health-compromising behaviours such as inadequate sleep, poor stress management, avoidance of physical activity and social withdrawal can exacerbate both seizure frequency and emotional distress.[9] These behaviours may also contribute to social isolation, reduced self-esteem and non-adherence to treatment, further worsening psychological health.

Conversely, health-enhancing behaviours like regular physical activity, adequate sleep, stress-reduction techniques, medication adherence and social engagement can improve both seizure control and mental well-being. Evidence suggests that lifestyle modification and psychosocial support significantly reduce overall distress in epilepsy patients. [10]

Promoting such behaviours is therefore essential for improving the holistic health of individuals with epilepsy. Understanding their psychological burden provides valuable insight for designing targeted interventions aimed at improving overall quality of life and treatment outcomes.

In this context, the present investigation was carried out to measure Perceived loneliness and examine how the demographic factors were associated with PL.

2. Objectives:

1.To determine the level of perceived loneliness among the patients with epilepsy.

2.To find out the association of demographic variables-age, gender and occupation with perceived loneliness among the patients with epilepsy.

3. Methods

Research Design:

Descriptive Cross-sectional

***Sampling technique*:**

Convenience sampling

***Sample size*:**

A sample of 70 reported patients diagnosed with Epilepsy was determined by using Cochran's formula.

Inclusion Criteria:

1.Patients diagnosed with epilepsy experiencing seizures from neurology and neurosurgery OPDs from hospitals and registered neuroclinics in Belagavi.

2.Patients with epilepsy Aged between 18- 55 years.

Exclusion Criteria:

1. Patients with epilepsy currently on psychotropic medications (Antidepressants, Anxiolytics, Antipsychotics, Mood Stabilizers and Valproate) were excluded from study.

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2. Female patients with epilepsy who were pregnant or had a recent childbirth.

Measure used:

Perceived Loneliness Scale of Dr. Praveen Kumar Jha.

***Procedure*:**

The present study was conducted on 70 clinically diagnosed patients with epilepsy selected from neurology and neurosurgery outpatient departments from hospitals and neuroclinics in Belagavi, Karnataka through convenience sampling after obtaining ethical clearance from the Jawaharlal Nehru Medical College Ethics Committee for Human Subjects' Research and permission from the authorities of the concerned hospitals and clinics.

Informed Consent was obtained from the patients after ensuring confidentiality and questionnaire was administered on the patients one to one with clear instructions by the researcher. Doubts (if any) raised by the patients were cleared by the researcher.

Once, the questionnaires were filled completely, they were collected back and produced for scoring and statistical analysis.

***Analysis of Results*:**

Percentage method and Chi-square were used to measure the level of perceived loneliness and association of demographic factors with PL among the patients with Epilepsy.

4. Results

Table No.1: Showing the Distribution of Participants Demographic Characteristics wise.

Demographic characteristics	**Number**	**%**
Age groups		
<=20yrs	10	14.29
21-30yrs	26	37.14
31-40yrs	14	20.00
>=41yrs	20	28.57
Gender		
Male	33	47.14
Female	37	52.86
Occupations		
Business	5	7.14
House wife	20	28.57
Student	22	31.43
Employed	8	11.43
Self employed	15	21.43
Total	70	100.00

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Table No. 2: Showing the Levels of Perceived loneliness among the patients with Epilepsy.

Levels of Perceived loneliness	Number	%
Extremely lonely	22	31.43
High	27	38.57
Above average	9	12.86
Average	7	10.00
Not lonely	5	7.14
Total	70	100.00

Graph No. 1: Showing the level of Perceived loneliness among the patients with Epilepsy.

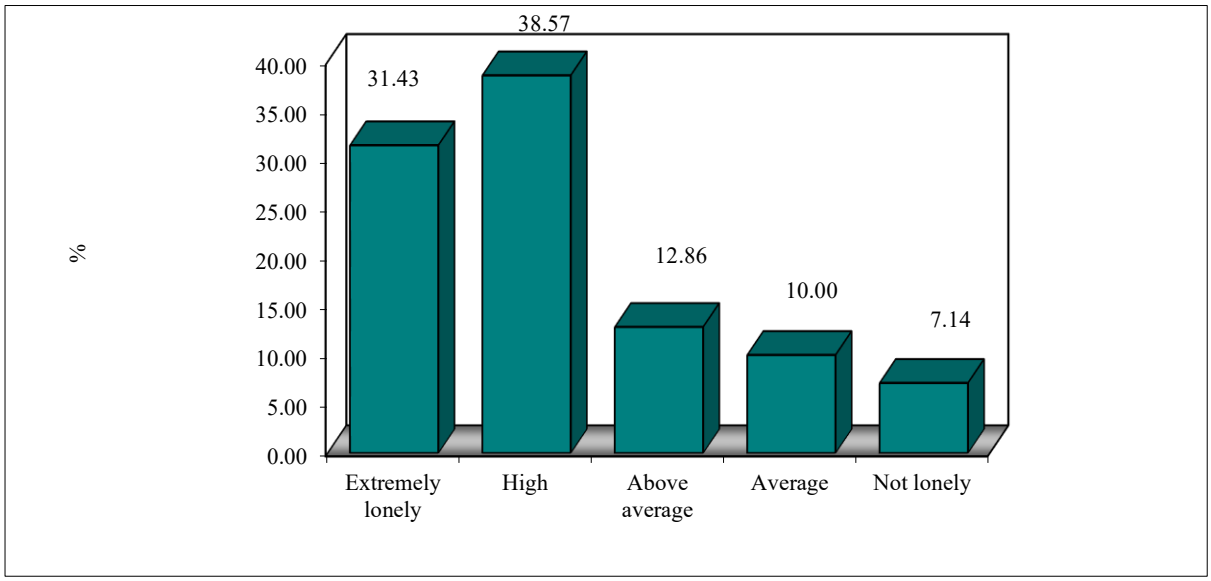

Table no. 3: Showing the association of demographic characteristics with perceived loneliness.

Characteristics	Extremely lonely	%	High	%	Above average	%	Average	%	Not lonely	%	χ^2	p-value
Age groups												
<=20yrs	5	50.00	3	30.00	2	20.00	0	0.00	0	0.00	21.6430	**0.0420***
21-30yrs	14	53.85	9	34.62	1	3.85	1	3.85	1	3.85		
31-40yrs	0	0.00	7	50.00	3	21.43	2	14.29	2	14.29		
>=41yrs	3	15.00	8	40.00	3	15.00	4	20.00	2	10.00		

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Gender												
Male	11	33.33	14	42.42	3	9.09	1	3.03	4	12.12	6.2000	0.1850
Female	11	29.73	13	35.14	6	16.22	6	16.22	1	2.70		
Occupation												
Business	1	20.00	2	40.00	0	0.00	0	0.00	2	40.00	34.5230	**0.0050***
House wife	2	10.00	9	45.00	5	25.00	4	20.00	0	0.00		
Student	14	63.64	3	13.64	3	13.64	1	4.55	1	4.55		
Employed	1	12.50	5	62.50	0	0.00	1	12.50	1	12.50		
Self employed	4	26.67	8	53.33	1	6.67	1	6.67	1	6.67		
Total	22	31.43	27	38.57	9	12.86	7	10.00	5	7.14		

***p<0.05**

5. DISCUSSION

Health is a multidimensional concept that goes beyond mere absence of disease. It is important because it allows individuals to live actively, work towards their goals, enjoy daily activities and maintain positive relationships. When a person is healthy, s/he can manage responsibilities, cope with challenges and experience a better quality of life. Without good health, even success and opportunities lose their meaning because one cannot fully enjoy them. **Smith & Lee (2018)** [11]

Engel (1977) described that this emphasizes the interconnectedness of physical, mental and social factors, highlighting that overall well-being depends on balance among them. [12]

Psychological health, a critical component of overall health, refers to a state of mental well-being, where individuals can cope with psychological problems, maintain fulfilling relationships and adapt to life challenges. [13]

However, when people experience a chronic illness such as epilepsy, their psychological stability can begin to deteriorate. The state of sickness often reduces an individuals' psychological resources, affecting their ability to manage emotional challenges and maintain healthy social interactions; as coping capacity declines, the person may experience increased emotional vulnerability, leading to behaviours such as withdrawal or avoidance. Gradually, this emotional strain can disrupt relationships and contribute to feelings of disconnection from others. At this point, many individuals begin to experience perceived loneliness.

Perceived loneliness, the subjective feeling of social isolation, is frequently experienced by individuals with epilepsy. Loneliness not only affects emotional well-being but can also worsen anxiety, depression and stress levels, creating a cycle of psychosocial difficulties. **Seid et al. (2019) and Tekle et al. (2021)** [14]

In this regard this study was carried out on this population of epileptic patients.

Among the total participants of the study, the majority of patients (37.14%) belonged to 21–30 years of age group followed by 28.57% from 41 years and above. In terms of gender factor, majority of the participants were female (52.86%); with regard to occupation, the highest proportion (31.43%) of participants were students and 28.57% were housewives. This distribution suggests that the study population mainly consisted of young adults and adults, who were majorly engaged in either pursuing education or engaged in household responsibilities, followed by participants who were self-employed,

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employed and a business. Majority of the patients participated in the study were females.

The results of objective 1 are presented and discussed as follow.

In reference to the results presented in Table No. 2, it is observed that 31.43% of the participants reported feelings of extremely lonely, while 38.57% had high loneliness, 12.86% showed above-average loneliness, 10.00% had average levels and only 7.14% of the participants reported not lonely. Overall, these findings indicate that the levels of loneliness are predominantly high and extremely high, suggesting compromised emotional well-being, possibility of experiences of Distress, and Anxiety, and reduced quality of life among a large proportion of the participants.

These results confirm the findings of previous research, which shows that individuals with epilepsy commonly experience significant psychosocial difficulties that contribute to feelings of isolation and loneliness. **Seid et al. (2019)**[15]

In reference with Table No. 3, among all age groups, extremely high loneliness was seen in 53.85% of the participants belonging to 21–30 years group, followed by 50.00% from ≤20 years group and 15.00% from the ≥41 years group, and 50% from the 31–40 years group reported higher PL compared to other groups. Calculated chi-square with p-value indicate that age group was significantly associated with perceived loneliness (χ^2 = 21.6430, p = 0.0420).

These results confirm the findings of early research, which reported that young adults (aged 21–30 years) showed higher levels of loneliness compared to older adults. **Child et al. (2017)** [16]

In respect to gender, although males showed slightly higher loneliness (42.42%) compared to females (35.14%) and extreme loneliness was almost equal in both male (33.33%) and female (29.73%), this similarity may reflect that chronic illnesses like epilepsy affect social participation equally among both genders, reducing social confidence and increasing isolation.

Calculated chi square and p value (χ^2 = 6.2000, p = 0.1850) reveal that the association was not statistically significant with respect to gender.

This confirms the findings of previous research that loneliness in chronic illness populations shows no significant gender difference because social stigma and reduced interaction affect everyone similarly**. Theeke L et al. (2019)** [17]

Referring the occupational status, 63.64% of students demonstrated extremely high perceived loneliness and 26.67% of self-employed individuals reported extremely high loneliness; while greatest proportion of participants (62.50%) who were employed showed high PL followed by 45.00% of housewives and business participants (40.00%). In contrast, 40.00% of business participants reported as not lonely, indicating comparatively lower perceived loneliness in this group. Overall, the calculated chi-square value with its p-value (χ^2 = 34.5230, p = 0.0050) indicate that occupational status was significantly associated with perceived loneliness at the level of 0.005.

This also confirms the findings of previous research that reported a higher magnitude of loneliness among students with epilepsy compared with other groups, indicating students are particularly vulnerable to loneliness. **Zahedi et al. (2022)** [18]

The evaluation of overall findings of the study demonstrated that patients with epilepsy experienced high perceived loneliness. The results clearly showed that among the demographic characteristics, only age group and occupational were significantly associated with perceived loneliness. This indicates that perceived loneliness varied based on life stage, social roles and functional responsibilities.

6. CONCLUSION

The following conclusion is made based on the findings.

1. Patients with epilepsy experience high perceived loneliness.
2. Age and Occupation were significantly associated with perceived loneliness.

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LIMITATIONS OF THE STUDY

1.Study was limited to the Belagavi city and the sample size was comparatively small.

2. Study included only male and female participants and did not include transgenders.

SUGGESTIONS

1. Further qualitative investigations have to be conducted to understand the personal experiences, emotional struggles and coping patterns of patients with epilepsy.

2. Psychoeducation models or materials have to be developed and utilized for patients and their families about emotional wellbeing, seizure management and mental-health awareness to reduce distress.

3. Stress-management techniques such as relaxation training, breathing exercises, mindfulness and coping-skills programs and awareness programmes have to be part of treatment and management of epilepsy.

4. Regular psychological screening for mental health concerns has to arranged in hospitals and neuroclinics for epilepsy patients.

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