

A Pilot Study on Psychological and Social Impact of Epilepsy on Quality of Life of Adolescents

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ABSTRACT

Background of the Study: The impact of epilepsy on the quality of a teenager's life cannot be overestimated. Epilepsy affects a teenager's peer interactions, social life, education, career decisions, driving ability and much more. Communication with the teenager in regards to the effects of epilepsy may have on these issues is vital. While treating the seizures and all of the ramifications of the diagnosis is challenging, most teenagers can achieve the main goals of therapy - freedom from seizures and a high quality of life.

Aims: The aim of the study was to assess psychological and social impacts of epilepsy on quality of life of adolescents.

Objectives

- To assess the self-esteem level of adolescents with epilepsy
- To assess the depression level of adolescents with epilepsy
- To assess the social avoidance and distress level of adolescents with epilepsy
- To determine the quality of life of adolescents with epilepsy
- To determine the correlation between quality of life with self-esteem level, depression level and social avoidance and distress level
- To explore the association between self-esteem level, depression level, social avoidance and distress level with selected demographic level

Methodology: This was pre experimental descriptive study design. The population involved in this study was 30 adolescents with

epilepsy who is attending neurology OPD at selected hospitals and purposive sampling technique was used for the study. Data was collected using quality of life scale (QOLIE-48), Rosenberg Self-esteem scale, Birlerson Depression scale, and David Watson and Ronald Friend Social avoidance and distress scale. Tools were administered to 30 adolescents with epilepsy who fulfilled the sample criteria. For 45-60 minutes. Data were analyzed by using descriptive and inferential statistics in terms of frequency distribution, percentage, mean, mean percentage, Standard Deviation, and Karl Pearson correlation was used to correlate quality of life with depression, self esteem and social avoidance and distress.

Results: the outcomes of Karl Pearson correlation between the quality of life, self esteem, depression and social avoidance and distress of adolescents with epilepsy shows that the correlation between quality of life with self-esteem ($r=0.489$, $p<0.05$), depression ($r=-0.395$, $p<0.05$) and social avoidance and distress ($r=-0.393$, $p<0.05$) were significant, Hence, the null hypothesis was rejected and research hypothesis was accepted. It evidenced there was significant linear correlation between quality of life, self-esteem, depression, social avoidance and distress.

Conclusion: The pilot study revealed that there was significant correlation between quality of life and self-esteem, depression and social avoidance and distress among adolescents with epilepsy further; it will be examined in main study with large sample. It also revealed that the tools for self-esteem, depression, social

avoidance and quality of life are reliable and the study is feasible and practicable

Key Words: Epilepsy, depression, Distress, social avoidance, Self esteem, Quality of Life, JPMR Effectiveness, Interventional Package, clinical variables and Socio-demographic variables.

INTRODUCTION

More than 3% of the total population will suffer from epilepsy at some time during their lives. One quarter of newly diagnosed cases worldwide are children. With optimal treatment, around 70% will enter remission. In the long run, antiepileptic drugs can be discontinued in almost half of affected individuals. Most patients with epilepsy undergo normal cognitive development. This relatively good prognosis contrasts with persistent public stigma surrounding the condition.

The prevalence of epilepsy in childhood is approximately 0.5%. In industrialized countries, an average of about 50 per 100 000 children newly develop epilepsy each year. Children account for 25% of all new cases of epilepsy¹

Epilepsy is the most frequent neurological disorder in adolescence and around 2% of the adolescent population will experience the disorder. For these adolescents, epilepsy has an incredible impact on this stage of their lives. Often times, the seizures are not preceded by any symptoms and may occur at any time.

Leisure, sport, and free time are not triggers for a seizure, but a person in their adolescent years may be frightened that these activities might provoke a seizure. The belief can only worsen the situation. A teenager might feel that they have no control over their own life and on a number of occasions may demonstrate poor behavior and thoughts to their fellow students, with friends, at work, or with family members. Doing so will have an impact on their person, work, and social situation Hence researcher has planned to undertake "Psychological and Social

impacts of epilepsy on quality of life of adolescents"²

MATERIALS AND METHOD

Study Design and Participants
Present study was a pre experimental descriptive design. Conducted between November and December 2021, A purposive sampling technique was used to select the 30 subjects for the present study. Epileptic adolescents with anti-epileptic treatment and on follow up for the minimum six months at the time of data collection, Able to communicate English, Kannada, and Those subjects who are willing to participate in the study are selected for the study.

Instruments:

Rosenberg Self-Esteem Scale: Self esteem was assessed using Rosenberg Self-esteem scale. This is a 10 item self report measure. Scores are calculated as follows: For items 1, 2, 4, 6, and 7:(Strongly agree = 3, Agree = 2, Disagree = 1, Strongly disagree = 0) For items 3, 5, 8, 9, and 10 (which are reversed in valence, Strongly agree = 0, Agree = 1, Disagree = 2, Strongly disagree = 3) The scale ranges from 0-30. Scores between 15 and 25 are within normal range; scores below 15 suggest low self-esteem.

Birleson Depression Scale: Depression was assessed using Birleson depression scale This is an 18 item self report measure. Scores are calculated as follows items 1, 2, 4, 7, 8, 9, 11, 12, 13 and 16 'mostly' scores 0, 'sometimes' scores 1 and 'never' scores 2. For items 3, 5, 6, 10, 14, 15, 17 and 18 'mostly' scores 2, 'sometimes' scores 1 and 'never scores 0. Higher scores indicate stronger depressive tendencies and the maximum score is 36. The scale ranges from 0-36, score 0 suggests no depression, scores 1-18 shows sometimes depression and scores 19-36 shows always Depression.

Watson and Friend's Modified Social Avoidance and Distress Scale: social avoidance and distress was assessed using

Watson and Friend's Modified Social Avoidance and Distress Scale This is a 28 item self report measure. Watson and Friend divided their sample in to high, average and low scorers as follows: Low 0 to 1 .Average 2 to 11, High 12 and up.

Quality of life scale (QOLIE-48): Quality of life of adolescents with epilepsy was assessed by using qolie -48 scales. It contains 48 self reported statements and its divided based on subthemes like General health, Physical function, School behavior, Social support, Epilepsy Impact, Stigma and attitude. The overall maximum score was 240 and interpreted as score 42-92 was poor QOL, 93-144 was average quality of life, 145-192 was good QOL and score above 193 indicates very good quality of life.

Scales were translated to Kannada and then back translated to English. The reliability of the test was found out by using Karl Pearson's co-efficient of correlation formula.

Data Collection Procedures Prior permission was taken from relevant institutions before the beginning of data collection procedure. The study participants were indentified during the study period. Every adolescents with epilepsy was fulfilled the inclusion criteria was approached for data collection. Assent and Consent was obtained by the interviewers before participants underwent the structured interview which lasted approximately 45 to 60 minutes. All the information collected was based on patient's self report.

Data Analysis: Data analyses were performed using SPSS v25. Description of sample characteristics was done using frequency and percentages. Karl Pearson correlation test was used to access correlation between the quality of life, self esteem, depression and social avoidance and distress of adolescents with epilepsy.

Since the sample size is small as per pilot study the chi square test for association

was not worked out. This will be done for major study.

RESULT

Section -1: Description of background c variables of adolescents with epilepsy

Description of socio-demographic of adolescents with epilepsy. Percentage wise distribution of adolescents with epilepsy according to their age group reveals that majority of the adolescents with epilepsy (46.7%) were in the age group of 15- 17yrs, majority of the adolescents with epilepsy (56.7%) were female, most of the adolescents with epilepsy (50%) were having education of 11-12 and all are living with parents majority (36.7%) were residing in rural area. majority (90%) of adolescents with epilepsy are from nuclear family and majority (53.3%) were having income of 20001 to 30000, and majority (93.3%) care givers are mother.

Description of Clinical and Diagnostic variables of adolescents with epilepsy:

majority of the adolescents (83.3%) were having generalized seizures, majority (60%) having visual aura, majority (93.3%) of the adolescents informed epilepsy causes as Unknown and majority (70%) reported post ictal phase, majority (86.7%) of adolescents reported as age of diagnosis was 10-14 years and most of the adolescents (66.7%) with epilepsy reported as epilepsy was diagnosed by subsequent diagnosis.

Description of Treatment variables of adolescents with epilepsy:

currently majority of the adolescents (83.3%) were in mono therapy, most of the adolescents with epilepsy (96.67%) were not having any complaint on treatment and majority (73.3%) undergone counseling and majority (53.3%) were taking treatment since 13-24 months.

Description of status of epilepsy of adolescents with epilepsy:

All the samples (100%) reported that presently epilepsy controlled and 66.6% of adolescents

experienced 1-4 seizures in the last 6 months and 33% of samples seek hospital admission once since last 6 months, majority (36.7%) reported that they missed school more than 11 days due to epilepsy and majority (73.3%) reported that they feeling same as earlier.

Section-2: Assessment of Self esteem Depression, social avoidance and distress (SAD) and Quality of life of adolescents with epilepsy

Table 2.1: Frequency and percentage distribution of adolescents with epilepsy according to level of self esteem, n=30

Sno	Level of Self esteem (Max. score=30)	Adolescents with epilepsy	
		Frequency	Percentage
1	Low (0-1)	4	13.3
2	Normal (15-25)	23	76.7
3	High (26-30)	3	10.0
4	Over a ll	30	100

The above table depicts the frequency and percentage of adolescents with epilepsy according to level of self -esteem... Of the sample, a majority 23(76.7%) of them had normal regarding self -esteem , 4(13.3%) had low self- esteem and 3(10.0%) had high self- esteem.

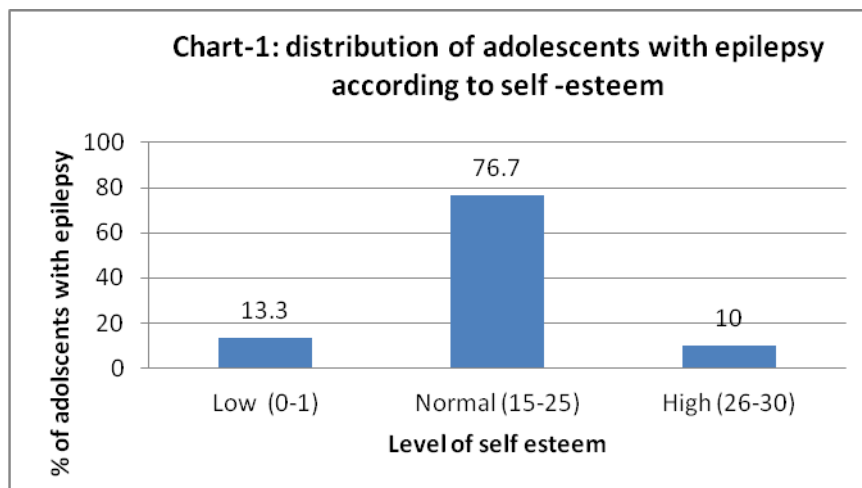


Table 2.2: Frequency and percentage distribution of adolescents with epilepsy according to level of depression. n=30

Sno	Level of depression (Max. score=36)	Adolescents with epilepsy	
		Frequency	Percentage
1	Non depression (0)	-	-
2	Some times (1-18)	29	96.7
3	Depressive (19-36)	1	3.3
4	Over a ll	30	100

The above table 2.2 presents the frequency and percentage of adolescents with epilepsy according to level of depression... Of the sample, a majority 29(96.7%) of them were found to be some times depressive, 1(3.3%) was found always depressive and none of them was with no depression.

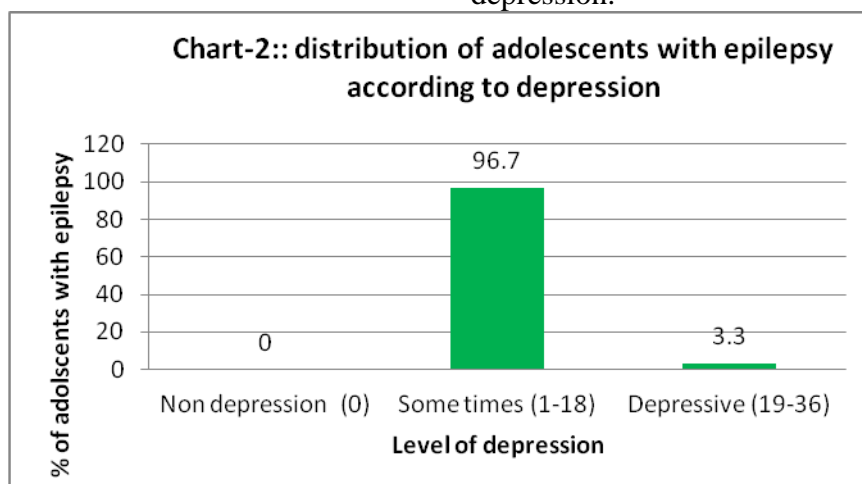


Table 2.3: Frequency and percentage distribution of adolescents with epilepsy according to level of social avoidance and distress (SAD). n=30

Sno	Level of social avoidance and distress (Max. score=28)	Adolescents with epilepsy	
		Frequency	Percentage
1	Low distress (0-1)	-	-
2	Average (2-11)	18	60.0
3	High (12-28)	12	40.0
4	Over a ll	30	100

The above table 2.3 presents the frequency and percentage of adolescents with epilepsy according to level of social avoidance and distress... Of the sample, more than half 18(60.0%) of them were found to be average distress, 12(40.0%) were found to be with high distress and none of them was with low distress.

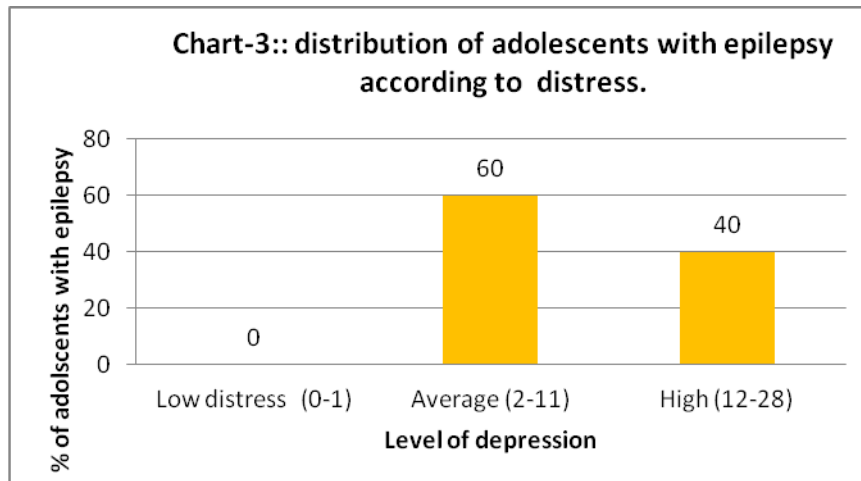


Table 2.4: Frequency and percentage distribution of adolescents with epilepsy according to level of quality of life. n=30

Sno	Quality of life (Max. score=240)	Adolescents with epilepsy	
		Frequency	Percentage
1	Poor (42-92)	-	-
2	Average (93-144)	2	6.7
3	Good (145-192)	28	93.3
4	Very good(193-240)	-	-
	Over a ll	30	100

The above table 2.4portrays the frequency and percentage of adolescents with epilepsy according to level of quality of life. Of the sample, a majority, 28(93.3%) of them were found to be with good quality of life, 2(6.7%) were found to be with average quality of life and none of them was with poor or very good quality of life..

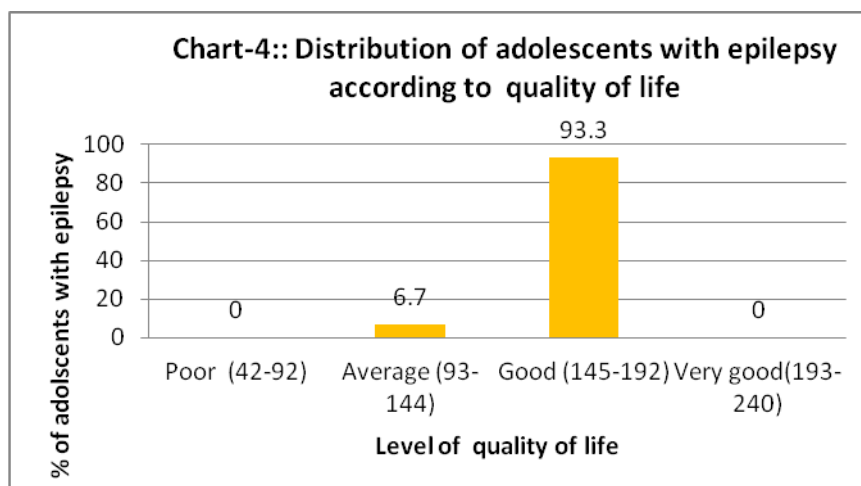


Table 2.5:: Mean, standard deviation of self-esteem, depression and social avoidance of adolescents with epilepsy. n =30

S.no.	Variables	Max score	Pre test			
			Range	Mean	SD	Mean %
1.	Self-esteem	30	14-28	18.60	3.69	62.0
2.	Depression	36	5-20	11.07	3.94	30.6
3	Social avoidance and distress	28	4-24	12.27	4.60	43.8

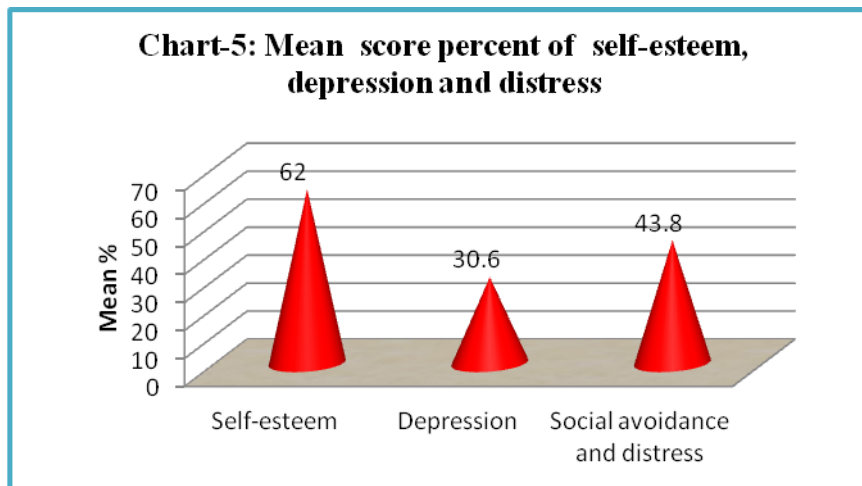
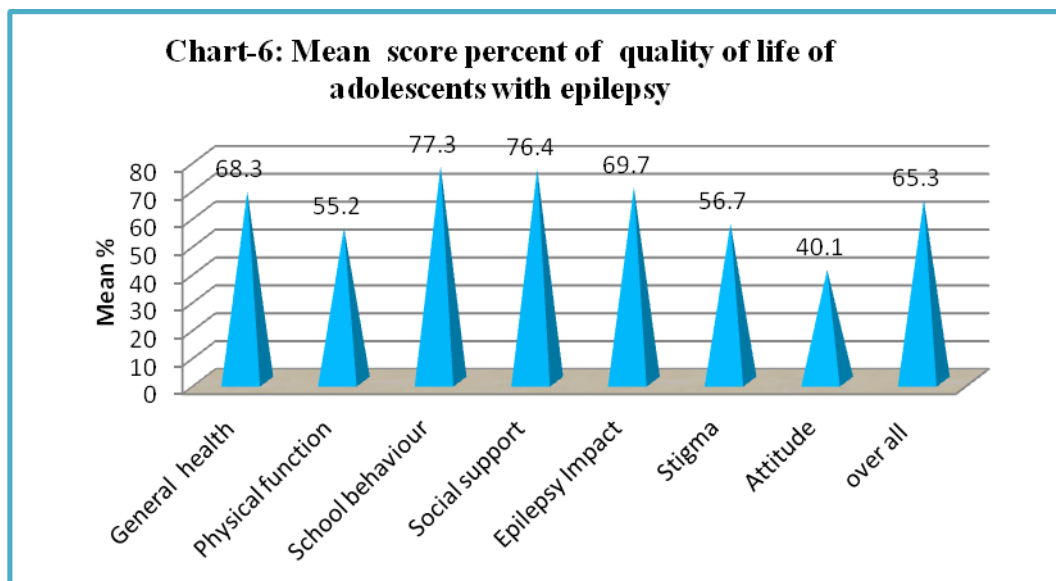


Table 2.6:: Mean, standard deviation of quality of life of adolescents with epilepsy. n =30

S.no.	Quality of life	Max score	Pre test			
			Range	Mean	SD	Mean %
1.	General health	10	5-9	6.83	1.11	68.3
2.	Physical function	35	13-28	19.33	3.46	55.2
3	School behaviour	60	39-53	46.40	3.98	77.3
4	Social support	20	9-20	15.27	2.80	76.4
5	Epilepsy Impact	60	35-48	41.80	3.11	69.7
6	Stigma	30	14-22	17.00	1.85	56.7
7	Attitude	25	6-15	10.03	2.32	40.1
	Over all	240	135-174	156.67	8.56	65.3



Section -3: Correlation between self-esteem, depression, social avoidance and distress and quality of life of the adolescents with epilepsy.

Table-3.1: correlation between the self-esteem, depression, social avoidance and distress and quality of life of the adolescents with epilepsy.

Sno	Correlation matrix	Self esteem	Depression	Social avoidance and distress	Quality of life
1	Self esteem	1	-0.358	-0.178	0.489*
2	Depression	-0.358*	1	0.403*	-0.395*
3	Social avoidance and distress	-0.178	0.403*	1	-0.393*
4	Quality of life	0.489*	-0.395*	-0.393*	1

*-denotes significant at 5% level (p,0.05)

The table 3.1 presents the correlation between self esteem, depression, social avoidance and distress and quality of life. The Karl Pearson correlation was worked

out to find the correlation between these variables. It was found that the correlation between self-esteem and depression ($r = -0.358$) was negative and significant ($p < 0.05$). It implied that increase in self-esteem has decrease in depression. Similarly, the correlation between self-esteem and social avoidance and distress (SAD) was found to be negative ($r = -0.178$) but not statistically significant ($p > 0.05$). The correlation between self-esteem and quality of life was found to be positive ($r = 0.489$) and significant ($p < 0.05$). It evidenced that higher the self-esteem higher the quality of life. The correlation between depression and social avoidance and distress ($r = 0.409$) was found to be positive and significant ($p < 0.05$). It implied that higher the depression lower the quality of life. Similarly, the correlation between social avoidance and distress (SAD) ($r = -0.393$) was negative and significant ($p < 0.05$). It implied that higher the social avoidance and distress (SAD) lower the quality of life. The following scatter plots depicts the pattern of relationship between the variables.

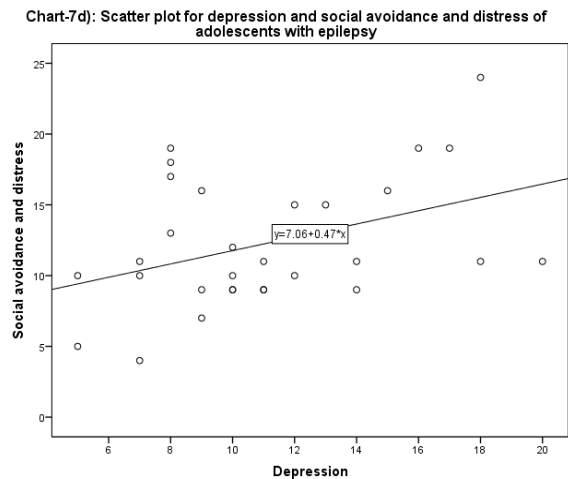
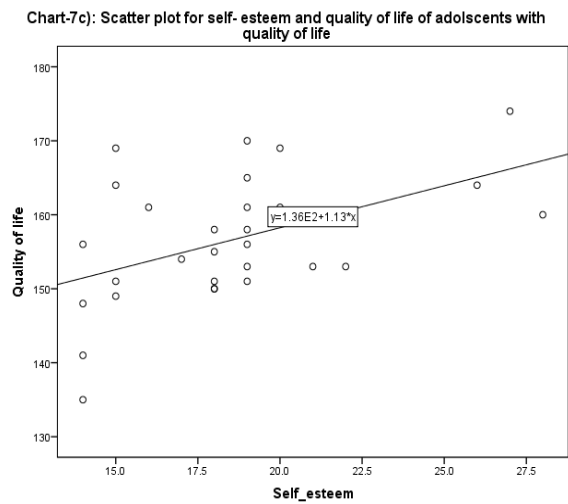
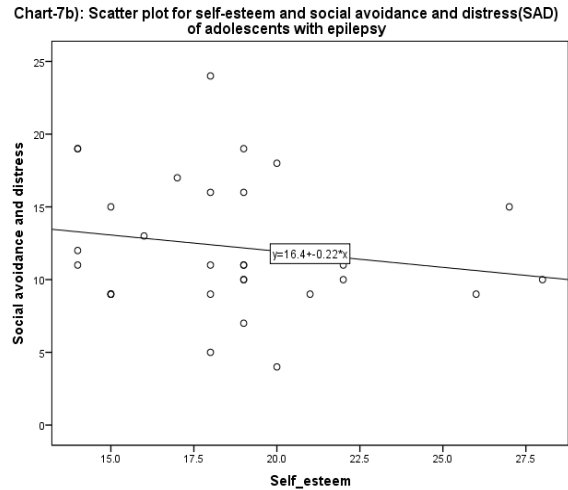
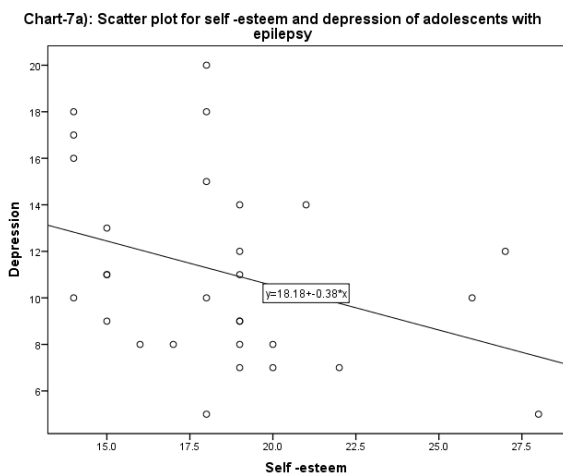


Chart-7e): Scatter plot for depression and quality of life of adolescents with epilepsy

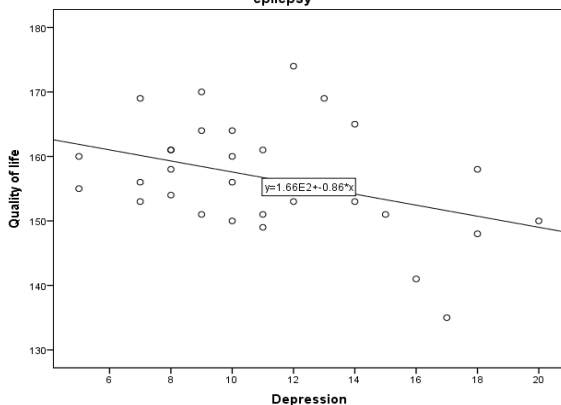
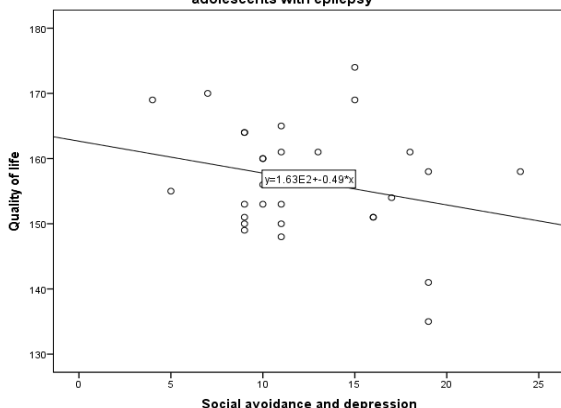


Chart-7f): Scatter plot for social avoidance and distress and quality of life of adolescents with epilepsy



Testing of hypothesis-1:

H₀: There is no significant correlation between quality of life with self-esteem level, depression level and social avoidance and distress level

Vs

H₁:- There is significant correlation between quality of life with self-esteem level, depression level and social avoidance and distress level

The table 3.1 presents the outcomes of Karl Pearson correlation between the quality of life, self esteem, depression and social avoidance and distress of adolescents with epilepsy. The correlation between quality of life with self- esteem ($r=0.489$, $p<0.05$), depression ($r= -0.395$, $p<0.05$) and social avoidance and distress ($r= -0.393$, $p<0.05$) were significant, Hence, the null hypothesis was rejected and research hypothesis was accepted. It evidenced there was significant linear correlation between

quality of life, self-esteem, depression, social avoidance and distress.

CONCLUSION

The pilot study revealed that there was significant correlation between quality of life and self-esteem, depression and social avoidance and distress among adolescents with epilepsy further, it will be examined in main study with large sample. It also revealed that the tools for self – esteem, depression, social avoidance and quality of life are reliable and the study is feasible and practicable.

Ethical Consideration

The study was approved by the Institutional Ethical Clearance Committee, Karnataka College of Nursing Bangalore and Tejasvini Nursing Institute, Mangalore.

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Conflicts of Interest: There are no conflicts of interest.

Acknowledgement: None

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2. Synopsis: The adolescent stage of life is hard and complex to understand and it becomes a delicate time as well when a person has epilepsy, available online from <https://www.disabled-world.com/health/neurology/epilepsy/adolescents.php>

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