

Controlled Study of Distress in Parents of Children with Epilepsy

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Research

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Abstract

Background

Childhood epilepsy can have a significant impact on family functioning with high rates of parent anxiety and depression being reported.

Objectives

To demonstrate the frequency of depression, anxiety and distress among the parents of epileptic children.

Patients and Methods

A cross sectional study design was carried out on 100 children and their parents attending the outpatient clinics in Minia University Hospital, arranged in two groups, Group (A) consisted of 50 epileptic children and their caregivers. On the other hand, Group (B) consisted of 50 age- and sex matched controls. Comprehensive Assessment was carried out. A well-prepared sheet had been used for the evaluation of subjects of the study. Twenty-one item Depression Anxiety Stress Scale (DASS-21), Hamilton Anxiety Scale (HAM - A) and Hamilton Rating Scale for Depression (HRSD) were used for interviewing the parents of the epileptic children to screen for depression, anxiety, stress in those parents. This process preceded by full explanation of all the previous tools.

There was statistically significant difference between the parents of the epileptic group and the control group regarding DASS score, and HAM-A score. There was no statistical significance between the 2 groups regarding the HRSD. The parents group of generalized fits shows to have a higher score of DASS (9.5 ± 4.7), HDRS (5.1 ± 3.3). In contrast to the focal fits group. On the other hand, the parents of group of generalized fits shows to have lower score of HAM-A (6.7 ± 4) in contrast to the focal fits group but not statistically significant.

Compliant group shows to have higher score of HAM-A, HDRS score in contrast to non-compliant group. These correlations were not statistically significant.

Conclusions

Parents of the epileptic children had more anxiety, depression and stress than the control. Lower parental education was associated with more distress and anxiety.

Poly-therapy increased parent anxiety and depression. Compliance on treatment decreased parent distress but increased parent anxiety and depression.

Introduction

A community based study was conducted by Khedr et al., (2013) in Egypt. According to this study the crude lifetime prevalence rate (CPR) of epilepsy is 12.67/1000 while, the prevalence rate is 9.3/1000 and

the incidence rate is 1.5/1000. The CPR is higher in rural, illiterate group than urban and literate populations (17.7/1000, 9.56/1000 and 12.02/1000, 9.94/1000, respectively). The highest prevalence rate is recorded in the early and late childhood group (69.78/100,000 and 43.78/100,000).

Children with epilepsy display more attention problems and internalizing problems (withdrawal, somatic complaints, anxiety, and depression symptoms) than they do externalizing problems such as acting out and conduct problems (Caplan et al, 2004).

Childhood epilepsy has serious and far-reaching psychosocial sequelae for the patient and his/her family. In this regard the family practitioner can play an invaluable role by providing useful knowledge, guidance and support. Without a collaborative relationship of mutual trust between the family practitioner, the parents and the child, compliance is compromised and treatment outcome is often less successful (Jan et al, 1983). Especially while the child is still young, the parents are the essential source of collateral information and feedback about the number and severity of seizures, the efficacy of medication and its side effects.

Parents attach great value to advice and suggestions from their family practitioner, who should therefore form a key component of the family's support system throughout. Parental anxiety may interfere with their ability to comprehend and recall information and instructions about treatment (Ziegler et al, 2000).

Participants & Methods

A. Setting of the Study:

The study has been held in the Neurology and Psychiatry outpatient clinic of Minia university hospital; which is considered as a tertiary healthcare facility. It includes specialized subunits for child psychiatry, adult psychiatry and neurophysiology unit.

B. Participants of the Study & Size of the Sample:

Number of subjects and classification: The total study sample was 100 children and their parents arranged in two groups,

Group (A) consisted of 50 epileptic children and their caregivers. On the other hand, Group (B) consisted of 50 age- and sex matched controls.

- **The Inclusion criteria:**

1- The age ranges from 4-18 years old.

2- The diagnosis of epilepsy in the children is based on history from a reliable eye witness account, the patient's account and the EEG findings.

3- The elapse of minimum six months from the diagnosis of the disorder.

4- Informed consents from parents of the studied children.

(B) Exclusion criteria:

- Children with apparent intellectual disabilities (IQ less than 75).
- Children with history of neurological illness other than epilepsy.
- Other major co-morbid non-neurological disorders that would have an impact on quality of life (e.g., asthma requiring daily medication, renal failure.... etc).
- Death of child during the study.

(C) Study Tools:

1- A well-prepared sheet was used for the evaluation of subjects of the study. This sheet included several parts investigating for

(1) Socio-demographics, (2) Family Atmosphere, (3) Negative consequences of epilepsy on school performance and psychiatric health status as well as the quality of life. (4) The occurrence of seizures

2-Twenty one item Depression Anxiety Stress Scale (DASS-21)

3-Hamilton Anxiety Scale (HAM - A)

4- Hamilton Rating Scale for Depression (HRSD)

F. Study Variables:

1. Socio-demographic characteristics:

For the purposes of this study, the socio-demographic variables used were age, gender, marital status, working status, educational level, residence, number of siblings, birth order & parental marital status.

2. Negative consequences of childhood epilepsy on family, school & work.

G. Data Analysis:

Data analysis was done by the Statistical Package of Social Sciences (SPSS) Version 16.0 for Windows. Frequencies and percentages were calculated for categorical variables, while means and standard deviations were calculated for continuous variables. Descriptive statistics of the study participants were conducted. T-tests were used to compare the epileptic group with control group on continuous variables while Chi square tests were used in comparing the two groups on categorical variables. Correlations were conducted to study the magnitude, nature and significance of the relationship between independent study variables (socio-demographics, illness characteristics) & dependent variables (psychiatric presentations) as well as to establish the relative predictive importance of the independent variables on the dependent variables.

Results

I. Comparison between the parents of the epileptic children group and the control group:

- Socio-demographic characteristics of the parent in the epileptic group in comparison to the control group.
- HDRS, HAM-A and DASS-21 `S characteristics in epileptic and control group.

II- Correlation between independent variables and different parameters:

- Socio-demographic characteristics:
- The correlations between Anxiety, depression (assessed by HDRS, HAM-A and DASS-21) and different variable in the epileptic children as Type of seizure, the used Antiepileptic drugs and compliance.

I. Comparison between the parents of the epileptic children group and the control group:

A. Socio-demographic characteristics of the parent in the group with seizures in comparison to the control group.

Table (1): Socio-demographic characteristics of the parent in the epileptic group in comparison to the control group.

| | Parents of the epileptic group (n=50) | Parents of the control group (n=50) | P value |
|---------------------------|---------------------------------------|-------------------------------------|---------|
| Parental age | | | 0.474 |
| Range | (20-59) | (20-50) | |
| Mean ± SD | 37.7±8.6 | 36.7±5.9 | |
| Parental Sex | | | 0.001* |
| Male | 16(32%) | 33(66%) | |
| Female | 34(68%) | 17(34%) | |
| Occupation | | | <0.001* |
| Not working | 36(72%) | 15(30%) | |
| Working | 14(28%) | 35(70%) | |
| Parental Education | | | 0.001* |
| Illiterate | | | |
| Primary | 27(54%) | 16(32%) | |
| Preparatory | 0(0%) | 0(0%) | |
| Secondary | 5(10%) | 0(0%) | |
| Higher | 17(34%) | 23(46%) | |
| | 1(2%) | 11(22%) | |

Independent sample t test for parametric quantitative data between the two groups

Chi square test (if number per cell ≥5), Fisher Exact test (if number per cell <5) for qualitative data between the two groups: Significant difference at P value < 0.05*

B. DASS score, HAM-A and HDRS characteristics in the parents of the epileptic and control group.

Table (2): DASS different domains characteristics in the parents of the epileptic and control group.

| | Parents of the epileptic group (n=50) | Parents of the control group (n=50) | P value |
|-------------------------|---------------------------------------|-------------------------------------|----------|
| DASS depression | | | 0.001* |
| Normal | 23(46%) | 39(78%) | |
| Mild | 15(30%) | 7(14%) | |
| Moderate | 12(24%) | 2(4%) | |
| Severe | 0(0%) | 1(2%) | |
| Extremely severe | 0(0%) | 1(2%) | |
| DASS anxiety | | | < 0.001* |
| Normal | 12(24%) | 33(66%) | |
| Mild | 11(22%) | 6(12%) | |
| Moderate | 20(40%) | 7(14%) | |
| Severe | 5(10%) | 2(4%) | |
| Extremely severe | 2(4%) | 2(4%) | |
| DASS stress | | | 0.508 |
| Normal | 43(86%) | 46(92%) | |
| Mild | 5(10%) | 2(4%) | |
| Moderate | 2(4%) | 1(2%) | |
| Severe | 0(0%) | 1(2%) | |
| Extremely severe | 0(0%) | 0(0%) | |
| DASS total Score | | | 0.001* |
| Range | (0-20) | (2-28) | |
| Mean ± SD | 9.6±4.9 | 6.9±5.4 | |

Fisher Exact test for qualitative data between the two groups

*: Significant difference at P value < 0.05

Table (3): HAM-A and HDRS score characteristics in the parents of the epileptic and control group.

| | Parents of the Epileptic Group (n=50) | Parents of the Control Group (n=50) | P value |
|--------------|---------------------------------------|-------------------------------------|---------|
| HAM-A | | | <0.001* |
| Range | (0-18) | (0-12) | |
| Mean ± SD | 7±4.2 | 4.1±2.4 | |
| HDRS | | | 0.370 |
| Range | (0-14) | (0-19) | |
| Mean ± SD | 5.2±3.4 | 5.9±3.9 | |

Mann Whitney test for non-parametric quantitative data between the two groups*: Significant difference at P value < 0.05

II-Correlation between independent variables and different parameters:

Socio-demographic characteristics (parental education):

Table (4): Correlation between parental education and DASS score, HAS and HDRS

| | Parental education R | P value |
|------------|-------------------------|---------|
| DASS Score | 0.118- | 0.414 |
| HAS | 0.186- | 0.196 |
| HDRS | 0.046 | 0.749 |

Table (5): summarizes the correlations between type of seizure and HDRS, HAM-A and DASS.

| | Type of seizure | | P value |
|------------|-----------------------|----------------|---------|
| | Generalized (n=45) | Focal (n=5) | |
| DASS score | (2-20) | (0-12) | 0.893 |
| Range | 9.5±4.7 | 8.4±5 | |
| Mean ± SD | | | |
| HAM-A | (1-18) | (0-14) | 0.435 |
| Range | 6.7±4 | 8.2±5.6 | |
| Mean ± SD | | | |
| HDRS | (0-14) | (0-7) | 0.842 |
| Range | 5.1±3.3 | 4.4±3.2 | |
| Mean ± SD | | | |

Mann Whitney test for non-parametric quantitative data between the two groups

Independent sample t test for parametric quantitative data between the two groups

**: Significant difference at P value < 0.05*

N.B. there was a case with absence seizure which excluded due to small sample size

Table (6) Correlations between the poly-therapy and DASS, HAM-A and HDRS.

| | Poly Therapy | |
|------------|--------------|---------|
| | R | P value |
| DASS score | -0.014 | 0.926 |
| HAM-A | 0.220 | 0.125 |
| HDRS | 0.197 | 0.169 |

- *Non-parametric Spearman's rho correlation*
- **: Significant correlation at P value <0.05*

Table (7) Correlations between compliance on the therapy and DASS, HAM-A and HDRS

| | Compliance | |
|------------|------------|---------|
| | R | P value |
| DASS score | -0.123 | 0.395 |
| HAM-A | 0.032 | 0.828 |
| HDRS | 0.091 | 0.532 |

- *Non-parametric Spearman's rho correlation*: Significant correlation at P value <0.05*

In the present study. A total 100 children and their caregiver were included. Fifty children diagnosed clinically as epileptic (group A). Another 50 age and sex matched control (Group B). Forty five children diagnosed as having generalized fits while five children had focal fits. Within the epileptic group, 34 subjects (68%) were on mono-therapy of antiepileptic drugs while 16 subjects (32%) were on poly-therapy. Thirty one subjects (62%) were compliant on treatment while 19 (38%) were noncompliant.

Regarding parents, they also classified into two groups. Parents of epileptic children and parents of the control. There was a statistical significance between the 2 groups regarding parent sex where 16 parents at epileptic children group (32 %) were males who attended the interview in contrast to 33 parents (66 %) in the control group. There was also a trend to statistically significance between the 2 groups regarding

parent occupation where 36 parents (72%) were not working at the epileptic children group in contrast to 15 parents (30%) were not working at the control group ($p < .001$).

There was also a trend to statistical significance between the 2 groups regarding the parental education where 27 parents (54%) were illiterate in contrast to 16 parents (32%) within the control group ($p < .001$).

There was no statistically significant difference between the parents of the epileptic group and the control group in their socio-demographic characteristics other than the previously described.

Also, there was a statistically significant difference between the parents of the epileptic group and the control group regarding DASS score with a mean of 9.6 ± 4.9 at the epileptic group, in contrast to a mean of 6.9 ± 5.4 in the control group ($p < .001$).

There was a statistically significant difference between the parents of the epileptic group and the control group regarding DASS score (depression and anxiety) ($p < .001$). On the other hand, there was no statistically significant difference between the two groups regarding DASS stress score ($P = 0.508$).

There was a statistically significant difference between the parents of the epileptic group and the control group regarding HAM-A score with a mean of 7 ± 4.2 at the epileptic group, in contrast to a mean of 4.1 ± 2.4 in the control group ($p < .001$). There was no statistical significance between the 2 groups regarding the HDRS.

However, there was a negative correlation between parental education and DASS score and HAS but not statistically significant. While there was a positive correlation between parental education and HDRS score but also not statistically significant.

The parents of the group of generalized fits had a higher score of DASS (9.5 ± 4.7), HDRS (5.1 ± 3.3). In contrast to the focal fits group.

The group of generalized fits shows to have a lower score of HAM-A (6.7 ± 4) in contrast to the focal fits group. All of these correlations were not statistically significant.

Moreover, the poly-therapy group shows to have less depression, anxiety and stress in their parents measured by DASS score.

The complaint group shows to have a lower score of (DASS), in contrast to the non-complaint group. These correlations were not statistically significant.

The compliant group shows to have a higher score of HAM-A, HDRS score in contrast to the non-compliant group. These correlations were not statistically significant.

Discussion

It should be noted here that absence of significant difference in socio-demographic characteristics between the 2 groups adds more to the reliability of the comparison between them regarding other variables that will be discussed below; i.e. the epileptic group serves as an age and sex matched group to the control group.

Regarding the parents between the 2 groups, there was a trend to statistical significance between the 2 groups regarding parent occupation where 36 parents (72%) were unemployed at epileptic children in contrast to 15 parents (30%) were unemployed in the control group. This may reflect the effect of childhood epilepsy on the function of the parents. This does not correlate with Reilly et al (2018) who stated that there are no differences in the working hours of the parents of the epileptic group but coincides with Ramsey et al (2016).

On the other hand, there was also a trend to statistical significance between the 2 groups regarding the parental education where 27 parents (54%) were illiterate in contrast to 16 parents (32%) within the seizure free group. This may be due to cultural factor and most patients were from rural areas.

Regarding the Depression, Anxiety Stress Scale (DASS), there was statistically significant difference between the parents of both group (anxiety and stress) with a mean of 9.6 ± 4.9 at seizures group, in contrast to a mean of 6.9 ± 5.4 in the group without seizures ($p = 0.001$). This reflects the impact of childhood epilepsy on the parents. This may be explained by the stigma of childhood epilepsy or may be due to financial factors (cost of treatment).

Reilly et al (2018) stated that the DASS score is very high in the parents of the epileptic children in comparison to other neuro-disability group with a mean of 18.12 ± 11.48 at the epileptic group in contrast to a mean of 10.33 ± 6.82 .

The depression and anxiety according to Hamilton scale, there was statistically significant difference between the epileptic group and the control group regarding HAM-A score with a mean of 7 ± 4.2 at seizures group, in contrast to a mean of 4.1 ± 2.4 in the control group ($p < 0.001$). There was no statistical significance between the 2 groups regarding the HDRS. This may have attributed to the impact of childhood epilepsy on their parents.

Yong et al (2008) used the Hospital anxiety and depression scale in the parents of the epileptic children and stated that higher anxiety is seen among the parents of the epileptic children.

There was a trend to statistical significance between the 2 groups regarding family history of seizure where 12 subjects (24%) had a family history of seizure in seizure group in contrast to 2 (4%) had a family history of seizure the control group.

Higher parental education is associated with higher score (better quality of life) in the epileptic children ($p = 0.012$). This coincides with Iqbal et al, (2016) who found that there is statistical significance impact of the maternal level of education on the overall quality of life of the epileptic children.

The compliance on therapy in the complaint group shows to have a lower score of (DASS). In contrast to non-complaint group. These correlations were statically significant ($p = 0.001$).

Regarding the correlation between the quality of life of the epileptic children depression as well as anxiety in their parents assessed by HDRS and HAM –A respectively. It shows that better quality of life of the epileptic children shows to have less depression and anxiety in their parents ($p = 0.003, 0.007$ respectively). This can conclude that psychosocial interventions as well as targeting adherence to antiepileptic drugs may improve the parent anxiety and depression. This was coincided with Ferro et al, (2011) who stated that a poor quality of life of the epileptic children can have a negative effect on parental emotional status.

Conclusion

Parents of the epileptic children had more anxiety, depression and stress than the control. Lower parental education was associated with more distress and anxiety. Ploy-therapy increased parent anxiety and depression. Compliance on treatment decreased parent distress but increased parent anxiety and depression.

Recommendations

1. Selection of cases from multiple sites that provide service epileptic children and their parents.
2. Further studies to prove the high association between the childhood epilepsy and lower quality of life in the affected children and family.
3. Further studies of other adverse psychiatric effects of childhood epilepsy on their parents.

Limitations

1. The sample size was relatively small and this did not permit an assessment of actual frequencies of depression and anxiety in the parents of the epileptic children, hence prevented generalization of the results. This also might be the reason that many of the correlations in the current study are not statistically significant.
2. The exclusion of other neurodevelopmental disabilities from the study prevented us from studying the suspected increased risk of depression and anxiety as well as the stress in the parents of the epileptic children.
3. The use of the subject or witness descriptions for determining the presence of seizures.

List Of Abbreviations

| | |
|---------|---|
| DASS-21 | Twenty-one item Depression Anxiety Stress Scale |
| HAM - A | Hamilton Anxiety Scale |
| HRSD | Hamilton Rating Scale for Depression |
| SPSS | Statistical Package of Social Sciences |

Declarations

Acknowledgements

Ethics approval and consent to participate

An oral and written consent approved from parents (Mother or father) of children included in this research. Approval to conduct this study was obtained from the local ethical committee of Minia Faculty of Medicine.

Consent for publication:

"Not applicable" in this section.

Availability of data and materials:

Not applicable.

Competing interests:

"The authors declare that they have no competing interests" in this section.

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Authors' contributions

All authors participated in a meaningful way in the preparation of the manuscript; MAN had chosen the tools, wrote and revised the manuscript, MAH has analyzed the data and wrote the manuscript after data analysis, MH had wrote and revised the Manuscript. All authors read and approved the final manuscript."

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