SUMMARY

Epilepsy is the commonest serious chronic disease of the nervous system. One in 200 people has epilepsy and one person in 50 will develop epilepsy at some time in their life. Twenty five percent of people newly diagnosed with epilepsy are under the age of 20 and it affects on quality of life for those children.

Aim of the study:

The aim of the study is to improve the quality of life for children with epilepsy, through:

1- Identifying children's and mothers' knowledge and practice regarding epilepsy.

2- Identifying factors affecting on quality of life for epileptic child.

3- Designing and implementing a health educational intervention for mothers to improve quality of life for their children with epilepsy.

4- Evaluating the effect of the educational intervention on mothers' knowledge and practice to improve quality of life of their children with epilepsy.

Subjects and Methods:

A) Setting:

This study was conducted at the Student School Health Insurance in Benha, which is the only established known place in Kaliubia that provides care to such children.

B) Sample:

A sample of convenience 100 mothers and their children with epilepsy from both sexes, aged 6-15 year and their accompanying mothers recruited for the conduction of the study

Tools and Technique of Data Collection:

Data collection was done through the following tools:

1- Questionnaire format: Appendix (II)

It was designed by the researcher under the guidance of supervisors, written in Arabic language and composed of two parts in the form of open ended and closed questions, it includes

Part (1): a- Characteristics of the children as age, educational level and gender.

b- Past history of the children, as previous hospitalization and previous illness.

c- Present history of the disease, as age during the first seizures, how much seizures occur and complication of epilepsy.

d- Characteristics of the mother and family, as age, occupation, and education.

Part (2): It covered the following items.

A- Mothers' knowledge regarding epilepsy as concept, causes, and clinical manifestation.

b - Knowledge regarding practice of the mothers with children during seizures

c - Seizure severity questionnaire about events before, during, and after typical seizures.

Scoring system:

A scoring system was followed to obtain the outcome of mothers' knowledge.

- Knowledge contents were divided into 7 questions and each question was assigned a score

- The total score of questionnaire responses was 30, accordingly, more than 75% was considered good knowledge, 60 – <75 was considered average knowledge and less than 60% was considered poor knowledge

2- Practice Assessment Sheet: Appendix (III)

Designed by the researcher under the guidance of supervisors, it aimed at assessing the practice of the mothers toward the seizures. It was presented in (3) scales according to mothers' responses. Their practice was divided into either competent or incompetent, it included good, average, and poor.

Scoring system:

Each scale question was assigned a score (3) if the participant response is good, score (2) if average, and score (1) if poor. The total score of the practice is (27). Accordingly 27-17 was considered competent practice and less than 17 was considered incompetent practice.

3- Epilepsy Quality of Life Scale: Appendix (IV)

Adopted from ***Cramer (2003)*** it was modified by the researcher under the guidance of supervisors, to assess the impact of epilepsy on quality of life. It include daily activity, mental activity, medication effect, seizures' worry, and overall quality of life.

Scoring system:

A scoring system was followed to obtain the outcome of impact of epilepsy on quality of life for children.

- Quality of life contents were divided into 6 parts, physical, psychological and mental, social and activity of daily living, medication effect, seizure effect, and over all quality of life. Each question was rated from 0-10 marks. The child was asked to put a circle around one mark only, which represents what he/ she is feeling. If the participant obtained 0-3 was considered mild score, while was 4-7 considered moderate score, and 8-10 was considered as a sever score of questionnaire responses was 430, accordingly it was evaluated mild score from: 0 -< 258, moderate from: 258- <323, sever from: 323- ≤ 430. When the QOL was more than 75% it is considered sever score quality of life, while 60 – <75 was considered moderate score quality of life and less than 60% was considered mild score quality of life.

4- Educational program:

It was designed by the researcher under the guidance of supervisors after reviewing of the related literature and according to needs of children and their mothers.

Proposed management program

This program was designed to enhance quality of life for children with epilepsy through improving mothers' knowledge and practice regarding caring for their children. It was designed in the form of handouts. It consists of providing the mothers with the essential information about epilepsy (definition, causes, signs & symptoms, first aid during seizures and how to deal with child during seizure).

Program implementation

The program was conducted through five sessions the time of each session was be verified 60 minutes according to the mothers' & children's needs and condition. At the beginning of the first session, mothers were oriented regarding the program content, its purpose, and its impact on their children's condition. Mothers were informed about the time of the next session at the end of the setting.

Each session was started by a summary about what has been discussed in the previous one and presenting the objectives of the new session, using simple Arabic language, also the session ended by a summary of its content and feedback from the mothers was obtained to ensure that they got the maximum benefit.

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Program evaluation

An effect of the program on children's quality of life was done through comparing the pre and post assessment scores of the mothers regarding their knowledge and practice toward seizures of their children, and quality of life. This evaluator phase was taken two times; an evaluation taken immediately after finish the implementation phase, then after three months, the second evaluation was done to assess retention of knowledge gained.

Main finding of this study can be summarized as follows:

- The mean age for studied mothers was 34.00 ± 6.09 years, 44% of them has family history of disease, and for 67% of them there is consonqunty relation between mother and father.
- As regards mothers' educational level 57% of them were illiterate, and 72% were housewives

- The mean age for children was 11.39 ± 2.19 years and 69% of them were males.

-As regards children's education 80% of them were from preparatory schools.

- Slightly more three fifths of studied children (61%) have history of hospitalization, and none of them had surgical management for epilepsy.

- Regarding children's and mothers' knowledge assessment, there were significant improvement in knowledge scores for mothers and children with epilepsy post program than pre program.

-Considering mothers' practice there were significant improvements in their practice during seizures as scores of post test were better than pre program. The majority (80%) of studied mothers having incompetent practice before program implementation, after program all of them (100%) of them have competent practice.

- Regarding children QOL there were significant improvements in their quality of life scores in post test than pre test score. Half of studied children had sever score quality of life preprogram implementation. While after three month of program implementation most (90%) of them had mild score quality of life.

- There was a statistically significant correlation between mothers' age and their knowledge immediately after program implementation.

- There was a significant correlation between mothers' occupation and their knowledge.

- There was a statistically significant correlation between children's educational level and their total quality of life

- There was a statistically significant correlation between children's' age and their total quality of life.

-There were statistically significant correlations between children's age and their educational level, and their total knowledge.

CONCLUSION:

The mothers' knowledge and practice related to epilepsy was deficient as none of them pre–program had good knowledge or competent practice. The program succeeded in improving the mothers' knowledge and practice regarding to epilepsy. After three months of implementation of the program, the mothers' knowledge and practice declined but were still higher than before the program in relation to all items about knowledge and practice. As regards QOL of children, by comparing the results in the pre- and after three months of program implementation, they showed improvements in all domains of the QOL; in relation to physical, psychological, mental, social and activities of daily living, as well as in drug effects, seizures' effects and total QOL post program than pre program.

Recommendations

Based on the findings of the current study, the following recommendations are proposed;

- Educational training program for school teachers about caring for children having epilepsy, and giving him specific information about epilepsy and how to deal with those children during a seizure to improve their QOL.

- Provide mothers of children with epilepsy by updated pamphlets, posters and an Arabic booklet about epilepsy, which contain an action plan suitable for children's nature in order to facilitate improving mother's knowledge as they considered the main member in children's care plan

- Periodical educational training program for mothers caring for their children having epilepsy to improve their QOL.