

**Burden and coping strategies among caregivers
having children with epilepsy**

Thesis

Submitted for Partial Fulfillment of Requirements of
the Master Degree

In

Psychiatric Mental Health Nursing

By

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Summary

Epilepsy is a common medical and social disorder characterized by epileptic seizures. These seizures occur due to disruptions of electrical signals in the brain. Epilepsy also characterized by the neurobiological, cognitive, psychological, and social consequences of this condition. These disruptions cause temporary communication problems between nerve cells, leading to seizures (*Osman et al., 2017*).

A chronic disease such as epilepsy can be often causes multiple stressors, adjustment related problems and disturbances in family relations and inability to deal with the condition can bring psychological difficulties and emotional discomfort . From the caregivers view the diagnosis of epilepsy riser a change in their perception and anxiety about the future in the community with apprehension about getting a job or starting a family (*irari et al., 2014*).

It is important that the type of seizure and epilepsy is identified and classified in order for healthcare professionals, especially the nurses, to facilitate ongoing child and family education to optimize long-term management, and to promote self-care for young children and appropriate healthy lifestyle choices (*Lewis, Noyes, and Mackereth ,2010*).

Caregivers often think that their epileptic child is abnormal and therefore tend to show negative attitudes toward them, either by being overprotective and thus hindering them from living a normal life like other children of the same age, or by being ignorant about the extra care that is needed for these children with epilepsy. These caregivers may manifest a disorder known as generalized parental anxiety due to their overprotective parenting, which impedes their children from being independent (*Arulsamy & Shaikh, 2016*).

Aim of the Study:

This study was aimed to assess the burden and coping strategies among caregivers having children with epilepsy through the following:

- Assess knowledge of caregivers about epilepsy
- Assess burden of caregivers having children with epilepsy .
- Assess coping strategies of caregivers having children with epilepsy.
- Assess the relationship between knowledge of caregivers about epilepsy with their burden and coping strategies.

Research Questions:

The current study answered the following questions:

- What are the knowledge of caregivers about epilepsy?
- What are the burden facing caregivers of children with epilepsy?
- What are the coping strategies of caregivers with their epileptic children?
- Is there any relationship between knowledge of caregivers about epilepsy with their burden and coping strategies?

Subjects and Methods:

A-Research Design:

A descriptive research design was conducted in the study.

B- Research Setting:

The study was conducted at Abbasia Psychiatric Mental Health Hospital and Fayoum university hospital in Neurological pediatric outpatient clinics.

C- Subjects:

Purposive sample was used and included selected caregivers of their epileptic children who fulfilled these criteria (age group from 3 -18 years old, duration of the diagnosis of epilepsy at least one year and diagnosis is made by a specialist or consultant in neurology).

D- Tools of Data Collection:

Data were collected through using the following tools:

I- A Structured Interviewing Questionnaire :

It was developed by the researcher after reviewing related literature, it was designed in a simple Arabic language to suit level of understanding of caregivers and it includes the following parts:

-First Part:

A- Socio-demographic characteristics of caregivers as age, sex, educational level, occupation.

B-Characteristics of children with epilepsy such as age, sex, illness and educational level.

-Second Part:

It was concerned with caregiver's knowledge about childhood epilepsy such as symptoms of epilepsy, causes, types, emergency and maintenance management.

II- Caregivers burden scale (Zarit et al,1980).

It was developed by **(Zarit et al,1980)** to assess burden of caregivers having children with epilepsy, it measured the extent to which the caregivers emotional and physical health, social life and financial status were affected by caring for their child with epilepsy, it is formed of 29 statements.

III-Coping Pattern Scale (Jalowiec and Powers, 1991).

This scale was developed by **(Jalowiec and Powers, 1991)** to assess adaptive attitude of the caregivers had children with epilepsy , it contains 35 coping behavior , problem - focused coping and emotion – focused coping behavior , they are grouped into subscales 15 problem –focused behavior and 20 emotion focused coping .

Results

The Finding of the Current Study Can be Summarized as:

- As regards characteristics about children with epilepsy it was found that , the mean age of the children is 16.67 ± 4.023 years and less than two thirds of children(63%) are males , and two fifth of children(40%) ranking as second . As regards the educational level of children showed that, less than half of children(48%) in primary school .
- As regards characteristics about caregivers had children with epilepsy it was found that, the mean age is 35.29 years , as regards the mothers educations ,more than one third(36%) had secondary education .As regards the mothers occupation ,more than three quarters (85%) of mothers are housewife.
- Less than two third (62%) of caregivers had unsatisfactory knowledge about the disease.
- Less than half (45%) of sample had severe physical burden ,(46%) suffering from severe psychological burden, (52%) had severe social burden and (43%) had severe financial burden .
- As regarding coping pattern among caregivers had epileptic children ,more than one third (40%) of caregivers had low

coping , while (35%) had moderate coping and (25%) of them had high coping.

- There was highly statistical significant relation between coping pattern among caregivers and their total level of knowledge with ($X^2=28.023$ and $P\text{-value} \leq 0.001$).
- There was statistical significant relation between level of caregivers burden and total level of knowledge ($X^2=23.332$ and $P\text{-value} \leq 0.001$) .
- There was statistical significant relation between caregivers burden and their level of coping ($X^2=19.553$ and $P\text{-value} \leq 0.001$) .
- There was statistical significant relation between mothers age and their level of knowledge with($X^2=8.586$ and $P\text{-value} =0.014$), there was significant relation between mothers education and level of knowledge ($X^2=13.895$ and $P\text{-value} =0.016$) . And there was statistical significant relation between mothers residence and their level of knowledge with ($X^2=6.338$ and ($P\text{-value} =0.012$).
- There was significant relation between caregivers level of education, family history of epilepsy with their coping pattern with ($P\text{-value} \leq 0.001$),there was statistical relation between caregivers age with their total coping.with ($X^2=11.339$ and $P\text{-value}=0.023$).

Summary

- There was significant relation between caregivers level of education and family history of disease with their burden , (p-value <0.001).
- There was significant relation between caregivers burden with their age with (p-value= 0.008).
- There was highly statistical positive correlations between caregivers knowledge related to epileptic disease and their coping pattern (p-value= <0.001**).
- There was statistical negative correlations between caregivers burden and their coping pattern (p-value= <0.001**).
- There were negative correlation between caregivers knowledge about disease and their burden (p-value= <0.001**).

Conclusion

In the light of the present study findings, it can be concluded that:

The caregivers of children with epilepsy have unsatisfactory knowledge about epilepsy, caregivers facing several burdens resulting from epilepsy they are continually worried about the child diagnosis, long-term costs of treatment, follow-up and low income in the family. Caring for

children with epilepsy is really challenging and associated with enormous burden. These burdens include all aspects of life as physical, social, psychological and financial burden. Also caregivers have low coping pattern with their epileptic children. There was negative relation between caregiver's burden and their coping pattern, there was negative relation between caregiver's burden and their level of knowledge. Meanwhile, there was positive relation between coping pattern among caregivers and their level of knowledge.

Recommendations

Based on the findings of the present study, the following suggestions are recommended:

For caregivers:

- Emphasize the importance of availability and distributions of pamphlets and booklet containing the basic knowledge for caregivers about epilepsy.
- Caregivers should be encouraged to attend scientific meeting and conferences and educational program to gain updated knowledge about their children disease.
- Increase caregiver's awareness toward their children disease regarding emergency and maintenance management

by implementation educational training program in outpatient clinics.

- Develop systematic guidance programs to ensure positive coping strategies that contribute to reducing their burdens and stressors for caregivers.
- Planned programs and campaigns should be conducted in the form of mass society education for caregivers toward their epileptic children.
- Periodic meetings parent of children with epilepsy to talk about their experience and acquire new information from each other, which will decrease the symptoms of anxiety and depression for them
- **For Future researches:**
- Future research is required to examine the role of different models of care and insurance programs in protecting against economic hardship for this condition, particularly in low and middle income settings
- The impact of social and economic conditions on the families had children with epilepsy and their relation to anxiety and depression.
- The impact of child with epilepsy on brothers and fathers and the extent of their adaptation to the surrounding environment.

- Barriers that affect negatively on parents coping abilities toward their epileptic children.