

Burden and Quality of Life among Caregivers to Children with Epilepsy

Samia M. Abd El-Mouty*, Nagwa M. Salem

Community Health Nursing, Faculty of Nursing, Mansoura University, Egypt

*Corresponding author: yohaahmed12@yahoo.com

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Abstract Background: Epilepsy is one of the chronic illnesses that have a great impact on the life of the epileptic children, their family caregivers and society in general. About 50 million people worldwide have epilepsy, and nearly 80% of epilepsy occurs in developing countries. Caregivers, usually family members or friends, who are responsible for making treatment judgments, providing livelihood, and managing daily activities. **Aim of the study is** to assess quality of life and burden among caregivers of children with epilepsy. **Setting:** Neurological Outpatient's clinics of Pediatric Hospital of Mansoura University. **Design:** A cross sectional descriptive design was used in this study. **Tools:** data was collected using the following three tools: first, socio-demographic data sheet, second, Zarit caregiver burden inventory (BI) and third, Short-Form Health Survey (SF-12) to assess caregiver quality of life. **Results:** There is significant difference between two categories of the study sample on the variables (Burden index score, Emotional role, Vitality, Mental health) at significant level 5%. **Conclusion:** A negative correlation presented between the burden index score and QOL of the caregivers to children with epilepsy. **Recommendations:** Caregiver burden and problems in caring of epileptic children should be discussed and counseled with health care providers through broad health educational program related to nature of disease, compliance to medication, follow-up, referral besides making emotional and economic support.

Keywords: caregiver, children, epilepsy, burden, quality of life

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1. Introduction

Epilepsy is one of the world's oldest recognized conditions, with written records dating back to 4000 BC. However, epilepsy is one of the chronic illnesses that have a great impact on the life of the epileptic children, their family caregivers and society in general. About 50 million people worldwide have epilepsy, and nearly 80% of epilepsy occurs in developing countries. [1,2]

Epilepsy affects 0.5% to 1% of children and is the most frequent chronic neurologic condition in childhood. Incidence rates appear to be declining in high-income countries. There is a lack of updated information about incidence and prevalence. Knowledge about the overall disease burden of childhood epilepsy is also insufficient. [3] Fear, misunderstanding, discrimination and social stigma have surrounded epilepsy for centuries. This stigma still present in many countries and impact on the quality of life for people with the disease and their families. [2,4]

Seizure episodes are a result of excessive electrical discharges in a group of brain cells. Different parts of the brain can be the site of such discharges. Seizures can vary from the briefest lapses of attention or muscle jerks to severe and prolonged convulsions. Seizures can also vary

in frequency, and one seizure does not signify epilepsy (up to 10% of people worldwide have one seizure during their lifetime). Meanwhile, epilepsy is defined as having two or more unprovoked seizures. [2,5]

However, the appearance of a disease in a family member especially young requires countless changes in the family structure. Various aspects of family life can be altered and affected as results of epilepsy condition. In general, different professionals focus on the sick patients, while relatives/caregivers are seen as helpers in the care process, without being acknowledged as people who are going through an emotional upsets, a painful process, need help and support. [6,7]

Family caregivers play a critical role in our health and long term care system by providing a significant proportion of the care for both the chronically ill and healthy individual; they provide care to individuals with a variety of conditions. [8,9] They experience a chronic stressor, and often experience negative psychological, behavioral, and physiological effects on their daily lives and health. Also, they are at increased risk for poor quality of life (QOL). [10,11] WHO has defined QoL as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns". [12]

It seems obvious that epilepsy can affect negatively on many aspects of the child and his or her family life such as, emotional, psychological, and academic problems that children experience with epilepsy, as well as issues of self-esteem, stigma, and social interactions. Long-term caregiving families have many needs. They need connections with resources to get their questions answered; they need to know where they can obtain needed information and where they can receive support and encouragement to convey on their role into his or her life. [13,14]

There are many different definitions of the burden of taking care of the chronically sick persons in the literature: burden, strain, stress, distress. Pearlin and colleagues (1990) refer to them as physical, mental, emotional, social and financial problems, associated with families that care for patients. [15,16] Caregiver burden is a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience. [17]

Nurses have become increasingly involved in overseeing the management of patients with complex medical conditions, including those with epilepsy. CHN can play a central role in providing optimal care, education, and support to their patients and allied families with epilepsy. [18]

Caregiver burden (CB) in epilepsy constitutes an understudied area. Here we attempt to identify the magnitude of this burden, the factors associated with it, and its impact on caregivers' quality of life (QOL). [14]

2. Aim of the Study

To assess quality of life and burden among caregivers of children with epilepsy.

2.1. Research Questions

1. What is the quality of life of caregivers of children with epilepsy?
2. What are the factors contribute to caregiver's burden?

3. Subject & Methods

Design: A cross sectional descriptive design was used in this study

Setting: The study was conducted at neurological outpatient department of pediatric university hospital in Mansoura.

3.1. Subject

3.1.1. Sample Size

Based on the data obtained from the study of Westphal-Guitti AC et al, (2007), [19] a sample size of 267 caregivers is required to determine the effect of caregiving to a patient with epilepsy on the QoL of the caregiver with precision/absolute error of 5% and at type 1 error of 5%.

The required number of patients to be included in the study will be calculated based on the following formula (Thompson, 1987). [20]

$$n = \frac{[DEFF * Np(1-p)]}{\left[d^2 / Z^2_{1-\alpha/2} * (N-1) + p*(1-p) \right]} = 323$$

As: Population size (for finite population correction factor) (N): 2000

Hypothesized % frequency of outcome factor in the population (p): 50% +/- 5

Confidence limits as % of 100 (absolute +/- %) (d): 5%

Design effect (for cluster surveys-DEFF): 1

3.1.2. Tools: Three Tools Were Used in This Study

Tool I: Socio-demographic data questionnaire:

A structured socio-demographic data questionnaire was developed by the researchers to collect data from the caregivers of children with epilepsy which included (age, gender, religion, employment, education, marital status and time spent for child care in hours per week).

Tool II: The Brazilian version of the Burden Interview (BI) Scale (Zarit caregiver burden inventory (1987)). [21,22]

The Zarit caregiver burden inventory (BI) assesses the burden on caregivers of individuals with chronic diseases. It is the most widely used standardized, validated scale to assess caregiver burden, administered previously in various neurological disorders, including epilepsy. It is usually self-administered, but in this study the questions were read to the participants, and the oral responses were scored by the interviewers. The interview is composed of 22 items, which explore negative effects on caregivers in relation to physical and mental health, reflecting areas of concern such as health, personal and social life, emotional status, personal relationships, and economic resources. Each question is evaluated on a Likert-type scale with five possible responses: never (0), rarely (1), sometimes (2), quite frequently (3), and nearly always (4). The degree of burden is computed from the frequency of each item, and scores range from 0 to 88, with 0 indicating lack of burden and 88 the maximum level of burden. The scale is further divided into bands: under 21 = lack of burden or minimum burden, 21–40 = mild or moderate burden, 41–60 = moderate to severe burden and 61–88 = severe burden.

Tool III: Health-related QOL was assessed by administering Short-Form Health Survey (SF-12), (1996):

The 12-item Short-Form Health Survey (SF-12) [23] is an instrument derived from the longer 36-item Short-Form (SF-36), [24] which was designed to measure general health functioning. The SF-12 items measure eight domains which include physical or emotional limitations, physical functioning, pain, general health, vitality, social functioning, and mental health problems. It provides 2 summary scores, the Physical Component Summary (PCS) and the Mental Component Summary (MCS). Scores are standardized; the mean score in the population is 50 with a standard deviation of 10 points. Higher scores indicate better functioning in each domain. Therefore, any score <50 for any health dimension and component scale falls

below the general population mean and each point represents 1/10 of a standard deviation. This allows direct comparison among different populations. [25] and has established precedence in epilepsy caregiver research.

3.2. Methods

3.2.1. Phase I: Administrative Process

An official letter was issued from the Faculty of Nursing, Mansoura University to the Director of outpatient department of pediatric university hospital in Mansoura to permit the researchers to carry out the study.

Ethical consideration:

- An approval was obtained from research ethics committee of Faculty of Nursing, Mansoura University.
- Consent was obtained from the participants caregivers. The researchers introduced themselves and a simple explanation about the objectives of the study was given to them. They were assured that their participation in the study is voluntary and that collected data was treated confidentially and only used for the purpose of the study. Participants were informed that they have the right to withdraw at any time from the study without giving any reason.

3.2.2. Phase 2: Development of Study Tools

- After reviewing the literatures, the socio-demographic data questionnaire was developed, and Zarit caregiver burden inventory, [22] and the 12-item Short-Form Health Survey (SF-12), [23] were adopted.

Face validity of the developed tools tested by conducting pilot study to 27 of caregiver who considered as a 10% from (267) of the study sample. Accordingly; any required modification was done.

3.2.3. Phase 3: Data Collection

Data were collected in March to May 2016. Socio-demographic information was obtained from caregivers by researchers. Caregivers burden and QoL assessment was done using tool II and III. The time spent for each interview ranged between 20 and 30 minutes in waiting room of outpatient department of pediatric hospital at Mansoura University.

3.3. Statistical Analysis

All statistical analyses were performed using SPSS for windows version 20.0 (SPSS, Chicago, IL). Continuous data were expressed as mean \pm standard deviation (SD), while categorical data were expressed in number and percentage. The continuous data were compared using independent sample t test for comparison between two groups or one way ANOVA test for comparison among more than two groups. The correlation between the variables with continuous data was performed using the correlation co-efficient test. Statistical significance was set at $p < 0.05$.

4. Results

Table 1 shows sociodemographic characteristics of the caregivers and the children with epilepsy, 93.3% of the

caregivers were females with mean age of 35.7 ± 10.9 . Concerning the educational level, 69.7% of them were educated. However, 79.8% of caregivers spent all of their times caring of epileptic child. Regarding the child data, 61.8% of them were male with mean age of 6.7 ± 4.9 . The mean of frequency of fits in past 6 months was 6.1 ± 5.3 .

Table 1. Socio-demographic characteristics of the caregivers and the children with epilepsy (n=267)

Items	N (%)
Caregivers	
Age (years) Mean \pm SD	35.7 \pm 10.9
Sex	
Female	249 (93.3)
Male	18 (6.7)
Relation to child	
Mother	246 (92.1)
Father	16 (6)
Sister/brother	5 (1.9)
Educational level	
Non educated	81 (30.3)
Educated	186(69.7)
Marital status	
Single	3 (1.1)
Married	247 (92.5)
Widow	11 (4.1)
Divorced	6 (2.2)
Working	78 (29.2)
Time spent in care	
All time	213 (79.8)
Most of time	54 (20.2)
Children with epilepsy	
Age (years)	6.7 \pm 4.9
Sex	
Female	102 (38.2)
Male	165 (61.8)
Having brothers/sisters	183 (68.5)
Duration of epilepsy (years)	4.6 \pm 3
Frequency of fits in past 6 months	6.1 \pm 5.3

Table 2, shows the correlation of the burden index score and quality of life (QOL) score with the age of caregivers and age of children. The results showed a negative significant correlation between age of the caregiver and physical functioning. There was a negative correlation between duration of epilepsy and bodily pain. On the other hand there was a negative correlation between frequency of fits in past 6 months and emotional role with statistically significant (0.039).

Table 3: Shows the mean difference in scores of quality of life and Burden index score according to the gender of the caregiver, from the table it was clear that mean of the value of Burden Index score was 36.9 with standard deviation 13.9 for mother caregiver and 29.9 with standard

deviation 13.8 for father caregiver. There was significant difference between two categories of the study sample on the variables (Burden index score, Emotional role, Vitality, Mental health).

with the epileptic child of the caregiver and the scores of quality of life and Burden index score. There was significant difference for Burden index score, general health, Physical functioning, emotional role, and mental health.

Table 4: Shows the mean difference of the times spent

Table 2. Correlation of the burden index score and quality of life score with the age of caregivers and age of children, duration of epilepsy and frequency of fits

	Age of the caregiver		Age of the child		Duration of epilepsy		Frequency of fits in past 6 months	
	R	P	R	P	R	P	R	P
Burden index score	0.110	0.073	0.100	0.105	0.033	0.593	0.063	0.308
Quality of life score	-0.027	0.660	-0.026	0.673	0.006	0.922	-0.029	0.663
Short-Form Health Survey (SF-12)								
General health	-0.112	0.067	-0.054	0.384	-0.031	0.620	-0.086	0.159
Physical functioning	-0.134	0.028	-0.039	0.525	-0.047	0.445	-0.035	0.569
Physical role	-0.085	0.164	-0.044	0.470	-0.045	0.460	-0.051	0.410
Emotional role	-0.114	0.062	-0.018	0.770	-0.049	0.424	-0.127	0.039
Bodily pain	-0.106	0.083	-0.027	0.655	-0.161	0.008	-0.042	0.495
Social functioning	-0.110	0.072	-0.017	0.781	-0.040	0.515	-0.044	0.469
Vitality	-0.104	0.090	-0.036	0.556	-0.043	0.487	-0.026	0.678
Mental health	-0.119	0.053	-0.025	0.681	-0.045	0.460	-0.034	0.579

Table 3. Mean difference in scores of quality of life and Burden index score according to the gender of the caregiver

	Mother Caregiver	Father Caregiver	T test	
	Mean ±SD	Mean ±SD	T	P
Burden index score	36.9 ±13.9	29.9 ±13.8	2.064	0.040
Quality of life score	29.5 ±6.6	26.4 ±5.5	1.930	0.055
Short-Form Health Survey (SF-12)				
General health	51.1 ±16.3	46.1 ±15.5	1.277	0.203
Physical functioning	56.1 ±15.7	51.5 ±15.7	1.206	0.229
Physical role	54.5 ±15.2	52.4 ±16.1	0.507	0.569
Emotional role	46.7 ±13.4	39.2 ±13.7	2.290	0.023
Bodily pain	60.4 ±16.2	55.6 ±15.1	1.228	0.221
Social functioning	51.5 ±11.3	46.4 ±11.4	1.834	0.068
Vitality	51.5 ±15.8	43.7 ±15.4	2.026	0.044
Mental health	49.7 ±16.4	41.3 ±15.6	2.105	0.036

Table 4. Mean difference of the times spent with the patients of the caregiver and the scores of quality of life and Burden index score

Items	All time	Most of time	T test	
	Mean ±SD	Mean ±SD	T	P
Burden index score	36.9 ±14.1	31.5 ±12.8	2.559	0.011
Quality of life score	29.7 ±6.6	27.7 ±6.4	1.944	0.053
Short-Form Health Survey (SF-12)				
General health	47.4 ±14.5	52.3 ±15[=.3	2.193	0.029
Ph. Functioning	51.4 ±16	58.7 ±14.8	3.039	0.003
Physical role	54.9 ±15.4	52.4 ±14.6	1.070	0.286
Emotional role	41.9 ±13.6	46.1 ±13	2.045	0.042
Bodily pain	60.6 ±16.4	57.9 ±15.4	1.087	0.278
So. Functioning	51.3 ±11.3	50.5 ±11.4	0.496	0.620
Vitality	49.9 ±15.9	48.3 ±15.2	0.689	0.491
Mental health	44.2 ±16.6	49.3 ±15.4	2.045	0.042

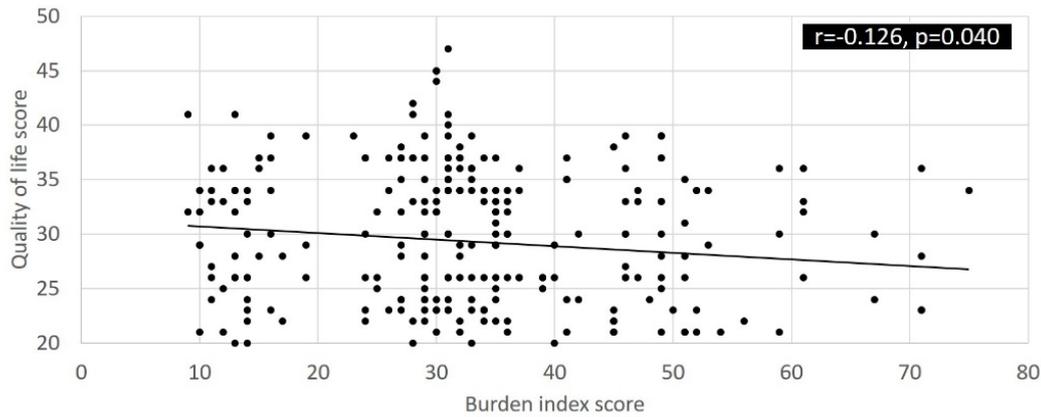


Figure 1. The correlation between the burden index score and quality of life QOL of the caregivers for a child with epilepsy

Figure 1: Shows the correlation of the burden index score and quality of life (QOL) score, there was negative correlation between the burden index score and QOL of the caregivers for a child with epilepsy, with correlation coefficient value ($r = -0.126$), with statistically significant (0.040).

5. Discussion

Epilepsy can affect the lives of all family members besides the patient. The caregivers of persons with epilepsy encounter severe emotional, economic and physical burden due to the nature, chronicity, disability, and stigma attached to the illness. [26,27]

Regards the socio-demographic characteristics, the study illustrated that the majority of the study sample were females who represents mothers as a caregiver, and near one third of study sample were not educated. This was in line with study in Port-Said by (Mohamed MA, et al. 2018) which stated that most family caregivers were females and about one third of them were illiterate. [11]

The present study showed that most of study sample were married with only one third were working. This may be due to caring of epileptic children takes a long time beside that in our society, mothers are the predominated in caring for their children protect and provide them with their needs especially ill children. Due to the difficulty to reconcile care and work activities, which impact negatively in caregivers daily life and their health dimension. [6] Studies were in the same line wherever demonstrated that, when one children has chronic illness, employment contracts are broken due to the need for planning to caring for their children and follow up in addition to, caring for another family members and house activities [13,14,27].

Present study showed correlation of the burden index score and QOL score with the age of caregivers and age of children, As it shows correlation between age of the caregiver and physical functioning. Moreover, there is a negative correlation between duration of epilepsy and bodily pain. This may be due to many of Egyptian society viewed that house hold activities, raring of children, caring for older family members.....etc.,) are the role of married women. Also prolonged caring can affects on caregivers physical and psychological health. [27] With

long period of married and caring for their children especially if one or more of them chronically ill , with prolonged care time and all this can affects on their health and experience of continuous bodily pain and deteriorate their emotional and physical role and this increase in older age caregivers. [28,29]

In this context, finding (Opara, 2017) indicated that older carers tended to experience impact on physical functioning and adding that women serving as caregivers had lower in their scores in emotional role, mental health, and vitality and reported a greater burden on their life. [17]

As regards the duration of disease and frequency of seizures, the current study showed that frequency of seizures was negatively correlated with burden index scores and affect quality of life domains of caregivers emotional role. This indicated to long duration of disease which required more care for patient in providing medication, caring in different aspects, protection and this need more effort and developed fatigue for caregivers (mothers). These can resulting in lowering physical functioning and emotional distress. [19,26,29]

Additionally, worrying about patients due to recurrency or occurrence of seizure from time to another, however long duration of treatment and worrying from forgetting the time of medication or any intrupption can lead to deterioration in patients' condition which resulting in more burden and worsening caregivers QOL. [30]

The study was disagreed with (Westphal, A.C, etal, 2007) who stated that caregiver have a decrease in QOL and developed mild to moderte burden regardless of the frequency and duration of the disease. [19]

The present study show increasing in burden and decreasing in quality of life regarding caregiver time spent with epileptic child to the following four domains; general health, physical functioning, emotional role, mental health. The results agreed with a study involving caregivers to young epilepsy patients using the Burden Interview Zarit and the SF-36, found a negative and statistically significant correlation among: general perceived health, mental health and emotional role functioning in the SF-36 and the caregiver burden. [19]

The finding of this study revealed that there was negative correlation between the burden index score and QOL of the caregivers for a child with epilepsy. At the same line, the correlation score which showed a

significant negative correlation between the caregivers level of coping among patients with epilepsy with coping strategies. In other words when the caregivers level of burden increases, the coping level decreases. [13]

The Indian study conducted to explore association between quality of life, depression and caregiver burden in epileptic patients revealed significant positive correlation between Beck depression inventory and Zarit burden interview. Duration of disease was not significantly correlated with Quality of life and Zarit burden interview. It was also found that emotional wellbeing is most affected domain in quality of life. [31]

However, families and parents of children with chronic conditions are at greater risk for increased stress and decreased quality of life (QL) compared to families of typically developing children. [14,31]

6. Conclusion

It can be concluded that the caregiver of epileptic children suffer from a lot of burden and consonantly their quality of life were affected in many aspects as, physical functioning, bodily pain, emotional role and general health in relation to age of caregiver, duration of disease, frequency of seizures and time spent with epileptic child. A negative correlation presented between the burden index score and QOL of the caregivers to child with epilepsy.

7. Recommendations

1. Caregiver burden and problems in caring of epileptic children should be discussed and counseled with health care providers through broad health educational program related to nature of disease, compliance to medication, and follow up, referral besides making emotional and economic support.
2. Increasing parent's awareness about ways of improving their quality of life during health an illness.
3. The government should adopt the epilepsy problem in our society, especially children. By activating the role of visual, audio media and means of social communication to announce about the disease stigmatization and its management
4. Develop school program to overcome learning difficulties among epileptic children through parent, teachers and colleges meeting.
5. Further studies are recommended to assess the different factors contributing to epilepsy in childhood.

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