Quality of Life of Caregivers of Epileptic Children, Using Zarit Burden Scale

Allah Rakha,1 Munazza Saduf,2 Saba Aziz,3 Anjum Razzaq,4 Tahir Mahmud5

Abstract

Objective: To assess the subjective quality of life of caregivers of epileptic children and to figure out recommendations to improve it.

Method: This descriptive study was conducted at The Children's Hospital and Institute of Child Health Lahore in collaboration with Institute of Public Health (IPH), from January 2018 to March 2018. Convenient purposive sampling was done to obtain a sample size of 85. Data collection tool employed was a predesigned questionnaire. Data were analyzed using SPSS version 20.0. Frequency tables were generated for all possible variables. Chi square test was used to compare categorical variables. Ethical considerations were born in mind including confidentiality and consent.

Results: Results of the study show that majority of caregivers had mild to moderate and moderate to severe burden. The mean age of caregivers was 34.69 years and all were females. Analysis of data showed that age and gender of children had no significant effect on level of stress on caregivers. However, frequency of seizures, duration since last episode of seizures, type of drug therapy, compliance with treatment and associated co-morbidities had statistically significant (p value < 0.05) effect on degree of burden on caregivers.

Conclusion: Epilepsy imparts remarkable stress on caregivers. It is recommended that increased awareness about dealing with epileptic children and physiological and psychological rehabilitation of caregivers must be established.

Keywords: Caregiver burden, epilepsy, quality of life.


DOI: https://doi.org/10.51273/esc22.251819

Introduction

Epilepsy is one of the commonly occurring neurological disorders with a prevalence of 0.5-1%. It affects people of all nations, and races.1 It is one of the most prevalent non-communicable diseases which evolves spontaneously and gives rise to a lot of neurologic and psychosocial implications affecting people of all age groups.2 Children are more vulnerable to epilepsy and its complications.3 Epilepsy has adverse implications not only for the patients but also for the caregivers as many are prone to an increased risk of spontaneous un-predicted fatality linked to epilepsy.4 The clinical hallmark of epilepsy is termed as seizures resulting from abnormal excessive or synchronous neuronal brain activity. Epilepsy can be diagnosed if at least two reflex seizures happen in excess of twenty-four hours apart and confirmed on electroencephalogram.5 Epileptic seizures occur spontaneously or triggered by fatigue, fever, stress or a specific recognizable precipitant such as flashing light, a sudden noise or cognitive activity. Epilepsy can result from various underlying brain disorders. Genetics is involved in a substantial part of cases of epilepsy.6 In many cases, the
underlying cause of epilepsy is unknown or poorly known. In Pakistan about more than two million people suffer from epilepsy and social stigma related to epilepsy and treatment gaps are very high. The implications in epilepsy for a person’s life depend on physiological repercussions of the epileptic episodes, their impacts on social status and their mental impact. Epilepsy is also linked to a greater risk of co-morbid conditions.

In children, normal development and school performance may decline and parents may become very protective, which interferes with normal social functioning, self-esteem and independency. Early life epilepsy inevitably will also affect the future. People having seizures have to struggle with all these medical, social and psychological aspects of their condition in daily life, usually resulting in a reduced quality of life. Childhood epilepsy is an elevated hazard for poor psychological outcomes and impacts on quality of life of children but also has a great effect on family functioning. Care provision is a tough experience which can drastically ruin the physiological & the psychological health of caregivers. Caregivers of epileptic children have been labeled as forgotten-patients & it was asserted that care provider’s signs like mood swings, fatigability, headaches, arthralgia & myalgia, marital and family rivalries, and monetary issues can be indicators of care provider’s strain in taking care of epilepsy subjects. Zarit-Burden score interview is a famous care-giver self-report tool employed by numerous geriatric organizations. Every question in the Zarit’s is a problem-statement which the care-giver is required to answer. It consists of twenty-two questions regarding how the care givers feel about themselves, their concerned sick relative and whether their relation with the concerned relative negatively affects their life and he caregiver is asked to rate the burden they feel regarding the care of the concerned relative employing a five-point scale. Every question is rated from 0 (never) to 5 (almost always). Total score is interpreted as follows.

- **a. No or minimal burden: 0-20**
- **b. Mild to moderate burden: 21-40**
- **c. Moderate to severe burden: 41-60**
- **d. Severe burden: 61-88.11**

The merits of Zarit Burden Scale include it being a relatively quick measure that is easy to administer and can be completed less than 10 minutes. The demerits include the self-checklist format which can be limiting, positive aspects of caregiving that might reduce feelings of burden being not explored. There is paucity of literature on the quality of life of caregivers, as in Pakistan most of studies include measurement of the quality of life of care providers and epileptic patients only. The study is an attempt to identify the magnitude of physical, psychological, social and economic effect on the quality of life of the caregivers of epileptic children because very less work has been done on caregivers in developing countries like Pakistan. This study will help patients, caregivers, healthcare providers and policy makers to take measures to improve the quality of life of caregivers.

**Material and Method**

Descriptive cross-sectional study was conducted in The Children’s Hospital and Institute of Child Health Lahore in collaboration with Institute of Public Health (IPH), after approval by internal review board of Institute of Public Health and The Children Hospital, Lahore. We recruited 85 caregivers of epileptic patients from outpatient department of Paediatric Neurology by convenient purposive sampling technique. Caregivers with psychological and psychiatric health problems were excluded. Data were collected with the help of pre-designed questionnaire after informed consent maintaining privacy and confidentiality. Study variables for caregivers were identified including age, gender, religion, education, marital status, occupation, family type, place of residence and monthly income were recorded. Study variables for epileptic children were also recognized including age, sex, schooling, type of seizures, frequency of seizures, drug therapy, comorbidities, compliance and duration of treatment. Zarit Caregiver Burden Scale (CBS) was used to assess the burden of caregivers of epileptic children. Data were analyzed using SPSS version 20.0. Frequency tables were generated for all possible variables. Means and other parameters of central tendency were calculated for continuous data and categorical data was analyzed by chi square test.

**Results**

Mean age of caregivers was 34.69 years and all were females. About 54.1% caregivers were literate while 45.9% were illiterate. Among 85 caregivers, 1.2% had little or no burden (group 1), 51.8% mild to moderate burden (group 2), 32.9% had moderate to severe burden (group 3) while 14.1% had severe burden (group 4) as shown in Fig-1.
Table 1 shows that as far as sociodemographic and medical history of epileptic children in relation to burden on caregivers is concerned, age and gender of children and duration of epilepsy has no significant effect on level of stress on caregivers. While schooling, frequency of seizures in last four weeks, epilepsy control, associated comorbidities, compliance with treatment, duration since last episode of seizures and type of drug therapy had statistically significant (p value < 0.05) effect on degree of burden on caregivers.

Table-1: Sociodemographic and medical history of epileptic children in relation to burden on caregivers

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Category</th>
<th>Group1 count</th>
<th>Group2 count</th>
<th>Group3 count</th>
<th>Group4 count</th>
<th>X²</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schooling of children</td>
<td>No</td>
<td>0</td>
<td>10</td>
<td>10</td>
<td>11</td>
<td>19.94</td>
<td>0.000*</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>1</td>
<td>34</td>
<td>18</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Seizure frequency past 4 weeks</td>
<td>&lt;5</td>
<td>1</td>
<td>43</td>
<td>15</td>
<td>3</td>
<td>33.36</td>
<td>0.000*</td>
</tr>
<tr>
<td></td>
<td>≥5</td>
<td>0</td>
<td>1</td>
<td>13</td>
<td>9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Epilepsy control</td>
<td>Poor</td>
<td>0</td>
<td>0</td>
<td>18</td>
<td>12</td>
<td>56.85</td>
<td>0.000*</td>
</tr>
<tr>
<td></td>
<td>Good</td>
<td>1</td>
<td>44</td>
<td>10</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comorbidities</td>
<td>No</td>
<td>0</td>
<td>16</td>
<td>23</td>
<td>11</td>
<td>22.22</td>
<td>0.000*</td>
</tr>
<tr>
<td></td>
<td>Good</td>
<td>1</td>
<td>44</td>
<td>19</td>
<td>7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Compliance</td>
<td>Poor</td>
<td>0</td>
<td>0</td>
<td>9</td>
<td>5</td>
<td>19.40</td>
<td>0.000*</td>
</tr>
<tr>
<td>Duration since last seizures</td>
<td>&lt;1 week</td>
<td>0</td>
<td>3</td>
<td>19</td>
<td>12</td>
<td>47.90</td>
<td>0.000*</td>
</tr>
<tr>
<td></td>
<td>≥1 week</td>
<td>1</td>
<td>41</td>
<td>9</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drug therapy</td>
<td>Monotherapy</td>
<td>1</td>
<td>40</td>
<td>18</td>
<td>3</td>
<td>22.60</td>
<td>0.000*</td>
</tr>
<tr>
<td></td>
<td>Polytherapy</td>
<td>0</td>
<td>4</td>
<td>10</td>
<td>9</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Statistically significant.
be contributed by support of spouse and social pressures in divorced or widowed.

In our study, age and gender of children has no significant effect on level of stress on caregivers. While frequency of seizures 4 weeks prior to interview, epilepsy control, associated comorbidities, compliance with treatment, duration since last episode of seizures and type of drug therapy had statistically significant (p value <0.05) effect on degree of burden on caregivers. These findings are in line with the work of Samia and coworkers as well as Riechmann and coworkers. It may be due to the possibility that deterioration of health of child and prolonged treatment is tedious work and creates a significant burden for the caregivers. Westphal and coauthors, however stated that burden on caregivers is not dependent on severity or duration of illness.

**Conclusion**

An analysis of the results shows that most of the caregivers of children with epilepsy experienced remarkable burden associated with demographic and clinical characteristics of caregivers and patients.

**Conflict of Interest:** None

**References**


**Authors Contribution**

RA, SM, MT: Conceptualization of Project
RA, SM: Data Collection
RA, SM: Literature Search
AS, RA: Statistical Analysis
RA, SM: Drafting, Revision, writing