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Psycho-Social and Economic Problems Faced by Parent's of Children with Epilepsy

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ABSTRACT

Parents of epilepsy children face various issues that are neglected by the society. On a regular basis an epilepsy child needs care so parents take away their time for other commitments, leisure and personal care. Unfortunately this issue has drawn very little attention, so the present study is to examine the problems faced by parents of children with epilepsy. The study was conducted at The Neurology Department of The Children's Hospital & the Institute of Child Health Multan, Pakistan from 1st March 2018 to 30th August 2018. A structured interview schedule was administered to parents of 100 children aged between 01-12 years and having epilepsy disease for more than 6 month period. Of the 100 respondents majority of the respondents were male 71(71.0%) while 29(29%) of the respondents were female. About 50(50%) of respondents were aged between 25-35 years. About 37(37.0%) respondents' family monthly income was 15000-25000/- PKR. High levels of depression (42%), and anger (31%) were found among parents. A majority (77%) of parents admitted that their social life was disturbed due to child's epilepsy. Their psychological condition was also disturbed due to child's epilepsy. Economically they faced multiple problems like the cost of drugs (96%) doctor fees (83%) and hospitalization charges (22%). The study concluded that parents' daily life and social activities significantly were exaggerated; they had been experiencing depression, frustration, guilt, helplessness and had decreased visiting their friends and relatives, and watched less TV and fewer videos. Results indicated that parents of children with epilepsy had faced many hitches. Appropriate interventions are required to sustenance these parents so that they might advance their economic and societal conditions.

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1. Introduction

Epilepsy is one of the most common neurological chronic disorders and requires prolonged treatment and medicines (Fisher et al., 2014). The prevalence rate of epilepsy is 4-7 per 1000 which is higher in developing countries (Kotsopoulos et al., Knottnerus, 2002; Fiest et al., 2017). According to the World Health Organization (WHO) epilepsy not only affects the individual but also has a deep impact on family members and society in general. Around the world approximately 50 million people are affected by the disease of epilepsy. In the developed countries neurologists/ epileptologists have developed guidelines for the epilepsy patients' management (Austin, 1988). Various studies have been carried out across several countries and report the negative impacts of epilepsy on families and caregivers. Deficits in communication, depression, low self esteem, fear, social and employment restriction, financial constraints, poor family social support are reported among the families of children with epilepsy (Hoare, 1993; Thompson & Upton, 1992). Parents of an epileptic child have an average of 4.5 hours of sleep per night and have to get frequent awakenings which badly affect their health (Smith, Wagner, Andrews, Austin, Mueller, Carter & Griesemer, 2014; Ohaeri, Awadalla & Farah, 2009). Trainings programs and useful interventions which are important to improve the coping skills and to reduce the stress of parents regarding the management of epilepsy patients (Rodenburg, Meijer, Deković, & Aldenkamp, 2007).

Thomas and Bindu (1999) found that parents of a child with epilepsy faced high levels of depression, guilt, anger, helplessness and frustration. Austin (1988) identified the low level of self esteem and higher level of stress among the families with epilepsy children as compared to those families of children with asthma. Greer (1972) found that about 20% of mothers, who had epileptic children, had a history of nervous breakdowns compared with the other chronic group conditions. Persistent issues arise from many of the families that they seek more information and advice about epilepsy because information plays a very important role in term of diagnosis, every day care, coping with the condition (Hartshorn, & Byers, 1994; Hoare and Kerley, 1992). The majority of the families report that they are offered very little information from clinical doctors (Chappell & Smithson, 1998). Studies point out that the epilepsy disease of child may cause the stress, poor self esteem, restriction of social activities, stress, stigmatization and psychiatric morbidity and marital problems for family members. Commonly it is assumed that major causes of child behavior problems occur due to negative family environment. So, family environment plays a very important role in the psychological development of chronic illness like epilepsy. Behavioral problems are found to be higher in epileptic children as compared to the other chronic disease children (Beech, 1992; Davies, Heyman & Goodman, 2003). Parents of a child with epilepsy suffer from stigma, limitations and prejudice which might compromise their quality of life, self esteem, social integration and social life (ILAE, 2003). In developing countries, stigma regarding epilepsy is very frequent (Fernandes, Salgado, Noronha, Barbosa, Souza, Sander, & Li, 2007). Child diagnosed with epilepsy might have negative consequences for families (Yang, Wang, Snape, Chen, Zhang, Wu, & Jacoby, 2011). Some families hide the diagnosis of their child from relatives and society. So parents who have a child with epilepsy faced many difficulties adopting social norms, finding employment and facing society (Bellon, Walker, Peterson & Cookson, 2013).

In Pakistan, one neurologist is working for 1.4 million (14 lac) people as compared to the United States, where one neurologist is working for 26 thousand people. The disease of epilepsy is widely misunderstood and carries a vicious stigma. Epilepsy has varied etiologies and affect in all age groups. It is treatable with anti-epileptic drugs which mostly medicines are easily available in the markets. In Pakistan, knowledge about the disease of epilepsy and its treatment is very low. The vast majority of the people with epilepsy are treated wrongly and inadequately. Due to needing to regularly care for

these epileptic children their parents take away their time for leisure, private care and other promises eroding their mental and physical fitness. Even in the developed countries, support systems available for parents is limited (Thomas and Bindu, 1999). Parents of an epileptic child leave their jobs or use the elderly relative services to take maintenance of such children so this indicates to great social and economic restraints. Inappropriately these matters have drawn slight attention.

Social and cultural practices vary from region to region even within the same country. For the child's psychological development related to chronic illness, family environment plays the very important role. Behavioral problems are found in child with epilepsy at a higher rate as compared to the child with other chronic conditions (Davies, Heyman & Goodman, 2003). Dealing a child with epilepsy can be stressful for the whole family, though the stress level may vary over time. Studies showed that families of children with epilepsy face more difficulties and disrupted environment as compared to the families of child with other chronic diseases (Rodenburg, Marie Meijer, Deković, & Aldenkamp, 2006). Parents face many difficulties with an epileptic child because of the disorder's unpredictable nature, associated cognitive difficulties, and potential for injury (Gilliam, Kuzniecky, Faught, Black, Carpenter & Schrodt, 1997). Childhood epilepsy conditions vary from person to person because some children have no problems and others experience uncontrolled seizures and development delay, so parents respond differently to their epilepsy child with some faced more difficulties in coping than others (Cramer, 1997). The major responsibilities of parents are to manage epileptic child and his or her treatment, dealing with the child having this seizure condition. So for these challenges, parents need a healthy adjustment to the epilepsy themselves. For these parents interventions are needed to facilitate this accomplishment. Epilepsy is strongly associated with the social stigma that reduces patient's quality of life and has substantial social and economic impact on caregivers and society (Ribeiro, Mendonga & Martins da Silva, 1998; Jacoby & Austin, 2007). Parents reduce their social interactions due to child epilepsy and isolate themselves for fear of their child's having a seizure (Smeets, van Lierop, Vanhoutvin, Aldenkamp & Nijhuis, 2007). So at primary care level there is a need to adopt the guidelines for the management of epilepsy patients, and to standardize epilepsy care on a National level.

2. Methods

The study was conducted at the Out Patient Department of Neurology of The Children's Hospital & the Institute of Child Health Multan, Pakistan from 1st March 2018 to 30th August 2018. A structured interview schedule was administered to the parentages of 100 children aged between 01-12 years and having epilepsy for more than 6 months period. Descriptive and inferential statistics was performed by using Statistical Package for Social Science (SPSS) version 24. Parents of children with epilepsy participated in this study. Before data collection, formal consent was taken from the parents of epilepsy children. Parents of children with epilepsy aged between 1-12 years old receiving treatment from the Department of Neurology CH&ICH were included. Those with other associated diseases like renal failure, diabetes, cardiac disease hypertension, and physical deformities were excluded.

3. Results

Table I. Demographic information of the respondents (n=100)

Variables	Frequency (%)	Variables	Frequency (%)
Gender		Residential area	
Male	71(71.0%)	Rural	55(55.0%)
Female	29(29.0%)	Urban	45(45.0%)
Age of the respondents		Family size	
25-35	50(50.0)	1-4	2(2.0%)
36-45	32(32.0)	5-8	85(85.0%)
46-55	18(18.0)	9-12	13(13.0%)
Education level of the respondents		Family Type	
Illiterate	61(61.0%)	Joint	59(59.0%)
Matriculation	20(20.0%)	Nuclear	41(41.0%)
Intermediate	19(19.0%)	Family monthly income	
Residence		15000-25000 PKR	37(37.0%)
Owned	87(87.0%)	26000-35000 PKR	32(32.0%)
Rented	6(6.0%)	36000-45000 PKR	19(19.0%)
Other	7(7.0%)	46000-55000 PKR	12(12.0%)

Table I showed the demographic information of the respondents. Among the 100 respondents, majority 71(71.0%) of the respondents were male while 29(29.0%) of the respondents were female. Similarly 50(50.0%) respondents were aged between 25-35 years while 32(32.0%) of the respondents were aged between 36-45 years and 18(18.0%) of the respondents were aged between 46-55 years. The majority 61(61.0%) of the respondents were illiterate while 20(20.0%) of the respondents were matriculation and 19(19.0%) of the respondents were intermediate. So the greater part of the respondents was illiterate. Of the 100 respondents, 87(87.0%) had their own home while 6(6.0%) respondents were living in a rented home. About 55(55.0%) respondents lived in rural areas and 45(45.0%) of the respondents lived in an urban area. As for the respondents' family size, about 2(2.0%) respondents had family members 1-4 while majority 85(85.0%) of the respondents had of 5-8 family members and 13(13.0%) of the respondents had 9-12 family members. Of the 100 respondents, 59(59.0%) respondents were living in joint family system while 41(41.0%) of the respondents were living in a nuclear family system. A question was asked to the respondents about their family regular income. Out of 100 respondents, 37(37.0%) reported that their family monthly income was 15000-25000 PKR, while 32(32%) respondents shared that their family monthly income was 26000-35000/-PKR, 19(19%) indicated that their family monthly income was 36000-45000/-PKR and 12(12%) respondents reported that their family monthly income was 46000-55000/-PKR. So majority of the respondents indicated that their family monthly income was 15000-25000 per month which was insufficient to run the family.

Table II. Psychological Effects of Child with Epilepsy on Parents (N=100)

Ranks	Statements	N	Always	Occasionally	Rarely	Mean	Std
1	Did your spouse sustenance you by helping in the care of child?	100	93%	07%	0%	2.93	.256
2	Did your spouse support you by providing emotional support?	100	77%	19%	04	2.73	.529
3	How often has your child's illness cooperate your personal care?	100	51%	41%	08%	2.43	.640
4	How often has your child illness compromised your sleep?	100	44%	54%	02%	2.42	.535
5	How often has your child illness conceded your food habits?	100	41%	49%	10%	2.31	.647
6	Are you depressed due to child illness?	100	42%	47%	11%	2.31	.662
7	Are you frustrated due to child's illness?	100	32%	59%	9%	2.23	.601
8	Are your ever angry due to child's illness of epilepsy?	100	31%	53%	16%	2.15	.672
9	Have you ever felt guilt due to epileptic child?	100	15%	53%	32%	1.83	.667
10	How often do you end up arguing with your spouse because of your child's illness?	100	11%	56%	33%	1.78	.629
11	Are you ever feel hopeless because of child disease?	100	4%	20%	76%	1.28	.533

Scale=Always=1; Occasionally=2; Rarely=3

Table II. Described the emotional difficulties faced by parents of children with epilepsy. The respondents were asked multiple questions regarding the emotional problems faced by parents of children with epilepsy. A question was asked to the respondent if their spouse supported them by helping in the child care. The majority 93% of the respondents reported that 'Always' their spouses support them for the care of epileptic child, while 7% reported that their spouses 'Occasionally' supported them by helping the care of epileptic child ($\mu=2.93$). Of the 100 respondents, the majority 77% of respondents expressed that 'Always' their spouses supported them by providing emotional support and 19% expressed that their spouses 'Occasionally' supported them by providing emotional support and only 04% of respondents showed that 'Rarely' their spouses supported them in care of epilepsy child ($\mu=2.73$). Similarly 51% of the respondents reported that 'Always' their child's illness compromised their personal care, while 41% of respondents reported that 'Occasionally' their personal care was compromised due to child's care and only 08% of respondents showed that 'Rarely' their personal care compromised because of children's illness ($\mu=2.43$). Of the 100 respondents, 44% expressed that they 'Always' compromised their sleep because of their epilepsy child illness while 54% of respondents expressed that the 'Occasionally' compromised their sleep because of child's epilepsy disease 02% of respondents reported that 'Rarely' they compromised their sleep because of child's epilepsy disease ($\mu=2.42$). About (41%) of respondents expressed that 'Always' their child's illness compromised their food habits while 49% showed that 'Occasionally' their child's illness compromised their food habits and 10% of respondents expressed that 'Rarely' their food habits were compromised

($\mu=2.31$). A question was asked to the respondents if they were depressed due to child's disease. About 42% respondents reported that 'Always' they remained depressed because of child's epilepsy while 47% shared that 'Occasionally' they were depressed and 11% expressed that 'Rarely' they felt depressed because of their epileptic child ($\mu=2.31$). About 32% of respondents reported that they 'Always' were frustrated due to child's illness while 59% of respondents reported that they 'Occasionally' were frustrated due to their child's epilepsy and 09% of respondents expressed that they were 'Rarely' frustrated because of child epilepsy disease ($\mu=2.23$). A question was asked to the respondents that if they were ever angry due to child's epilepsy disease. About 31% of respondents showed that they 'Always' were angry due to child's disease while 53% of respondents reported that they 'Occasionally' were angry because of their child's disease and 16% of respondents reported that 'Rarely' they were ever angry due to child's disease with epilepsy. About 15% of respondents expressed the feelings that they 'Always' felt guilt due to their epileptic child while 53% of respondents expressed that 'Occasionally' they felt guilt due to epilepsy child and 32% of respondents reported that 'Rarely' they felt guilt due to epileptic child ($\mu=1.83$). About 11% of respondents reported that they 'Always' ended up fighting with their spouses because of child's illness while 56% of respondents reported that they 'Occasionally' ended up quarreling with their spouse's because of child disease and 33% of respondents reported that they 'Rarely' ended up quarrelling with their spouses because of their child's illness ($\mu=1.78$). About 4% reported that they 'Always' felt hopeless because of their child's disease while 29% of respondents expressed that 'Occasionally' they felt hopeless because of child's disease and 76% of respondents reported that they 'Rarely' felt hopeless because of child's disease ($\mu=1.28$).

Table III. Parents Social Activities after Child Epilepsy Disease (N=100)

Ranks	Statements	N	Increased	Decrease d	Unchange d	Not applicable	Mean	Std
1	Watching TV or Video	100	04%	79%	16%	01%	2.14	.472
2	Visiting Friends or relatives	100	09%	62%	26%	03%	2.23	.649
3	Celebrating social functions in your places	100	08%	79%	9%	04%	2.09	.570
4	Visiting Holy Places	100	85%	10%	0%	0%	1.20	.512
5	Going to a movie	100	0%	79%	10%	11%	2.32	.665

Scale= Increased=1; Decreased=2; Unchanged=3; Not applicable=4

Of the 100 respondents, the majority 79% reported that after their child's diagnosis of epilepsy they 'Decreased' watching TV or Videos ($\mu=2.14$). Similarly 62% of respondents expressed that they 'Decreased' visiting friends or relatives due to child epilepsy disease ($\mu=2.23$). Likewise 79% respondents shared that they had 'Decreased' their social activities due to child's epilepsy disease ($\mu=2.09$). About 85% of respondents accepted that they had 'Increased' visiting Holy places ($\mu=1.20$) and 79% of respondents expressed that they had 'Decreased' their visits for going to a movie ($\mu=2.32$).

Table IV. Economic Problems faced by parents of child with epilepsy (N=100)

Ranks	Statements	N	Yes	No	Mean	Std
1	Has your social status deteriorated after your child's developed epilepsy?	100	77%	23%	1.23	.423
2	Do you receive financial assistance from others for the child's care?	100	33%	67%	1.67	.473
3	Did you have to make any special arrangements for your child's travel to school because of epilepsy?	100	76%	24%	1.24	.429
4	Has the child's illness increased your financial burden?	100	89%	11%	1.11	.314
5	Travel	100	95%	5%	1.05	.219
6	Clinical investigation	100	96%	04%	1.04	.197
7	Doctors Fee	100	83%	17%	1.17	.378
7	Hospitalization charges	100	22%	78%	1.78	.416
8	Cost of Drugs	100	96%	04%	1.04	.197
9	Have you taken extra care of your epilepsy child?	100	89%	11%	1.11	.314
10	Do you take leave without pay to attend your epilepsy child?	100	79%	21%	1.21	.409
11	Do you require a job transfer to attend your epilepsy child?	100	93%	07%	1.07	.256
12	Do you quit (resign) your job because of child's epilepsy disease?	100	60%	40%	1.40	.492

Of the 100 respondents, the majority 77% indicated that their social status deteriorated after child's diagnosis of epilepsy disease while 23% of respondents reported that their social status did not deteriorate because of child's disease. The majority of the respondents (67%) reported that they did not receive any financial assistance from other sources for the treatment of their epileptic child while 33% of respondents shared that they got financial help from other sources of Pakistan Bait-ul-mal, Zakat Funds and through patient's welfare society funds. The majority of the respondents discussed that they made special arrangements for epilepsy child's travel to school while 24% shared that they did not make special arrangements. A vast majority 89% of the respondents shared their experiences that their child's illness increased the financial burden, while 11% shared that their child's illness does not increase any financial burden. The vast majority 95% of respondents discussed that they traveled a lot because of their epileptic child while 96% of respondents reported that they paid too much for clinical investigation of their epilepsy children. Similarly, 83% of respondents reported that the doctors charged high fees for medical checkups. About 22% of respondents expressed that they paid the hospitalization charges while majority of the respondents 78% could not pay the hospitalization charges. The majority 96% of respondents reported that they purchased the drugs for their epileptic child on their own. About 89% of respondents expressed that they took extra care of their epileptic child. Mostly 79% of respondents expressed that they took consent without pay to join to the epileptic kid. About 93% of respondents indicated that they required a job transfer to attend to the epileptic child. About 40% of respondents quit or resigned their jobs because of epileptic child, while 60% could

not resign because they indicated that they were the only earner in the family.

4. Discussion

The study addressed the psychosocial and economic problems faced by parents of children with epilepsy. A structured interview schedule was adopted to collect the information from the parents. The main reason for using a structured interview schedule was that the majority of the parents were illiterate and were unable to fill out the questionnaire. This was the first study conducted at Out Patient Department of the Children Hospital & the Institute of Child Health Multan, Pakistan. During the study, it was observed that there were no organized services for the therapy of parents, or day care centre for epilepsy child at CH&ICH Multan and psychosocial aspects were totally neglected. Of the 100 respondents, the majority of the respondents (71%) were fathers while (29%) of the respondents were mothers. In our study (32%) parents reported that they were always frustrated while (59%) respondents reported that they were occasionally frustrated because of child's epilepsy disease and only (9%) respondents reported that they were rarely frustrated because of child disease. A study was conducted by Thomas, & Bindu (1999) showed that (52%) parents were found frustrated due to their child epilepsy disease. In our study (31%) respondents expressed that they were ever angry due to child's epilepsy disease while (53%) respondents reported that they occasionally were angry due to child's disease and (16%) respondents expressed that they were rarely angry due to child's epilepsy. These results correlated with the study conducted by (Thomas et al, 1999) that (38%) parents were found angry because of child epilepsy disease. In our findings about (15%) respondents expressed their feelings that they felt guilt due to having epileptic child while (53%) respondents showed that they occasionally felt guilt and (32%) respondents reported that they rarely felt guilty because of epilepsy child. Similarly another study conducted by (Thomas et al, 1999) that (12%) parents admitted that they felt guilty because of epilepsy child. In the present study (44%) respondents reported that they always compromised their sleep because of child's illness while (54%) reported that they occasionally compromised their sleep and only (2%) respondents showed that they rarely compromised their sleep. Similarly in our study it was found that (90%) respondents reported that they had little time for meals because of child's epilepsy. Similar results were found in a study conducted by Thomas and Bindu (1999), showed that (82%) parents admitted that they slept poorly and (76%) showed that they had little time for meals. Our study results showed that (51%) parents always compromised their personal care while (41%) respondents occasionally compromised their personal care and only (8%) identified that they compromised their personal care due to child's epilepsy. A study conducted by Spangenberg and Lalkhen (2006) showed that (74%) parents compromised their personal care. In this study, (93%) respondents reported that their spouses supported them for the helping of epileptic child. These results correlated with the study conducted by Coulter and Koester, (1984) that 96% of spouses supported their partners for caring for epilepsy children. Our findings highlighted that majority (79%) parents took leave without pay to attend their epileptic children. A similar study was conducted by Ostendorf, and Gedela (2017) that (47%) parents had to take unpaid leave to attend their epilepsy children. In our study, the majority (89%) of the respondents reported that their children illness had increased the financial burden. In another study conducted by Aziz, Akhtar, and Hasan (1997) which results showed that (60%) of parents claimed financial hardships due to their child's illness. A question was asked to the respondents if they received any financial assistance from other sources, and (67%) respondents reported that they did not received any financial assistance from other sources but (33%) accepted that they received financial support in the form of medicines for the epilepsy child. In our study majority (95%) of the respondents expressed that due to regular visits to hospital for the epilepsy child their travel expenses increased. Similar results were found in another study conducted by (Devinsky et al, 1999) that their travel cost (36%) increased due to frequent hospital visits.

5. Conclusion

The study concluded that parentages of children with epilepsy had faced numerous difficulties regarding their psychosocial health, social and economic conditions. Parents' daily life and social activities significantly had been exaggerated; they had been experiencing frustration, depression, guilt and helplessness, decreased visiting with friends and relatives, and decrease leisure such as watching videos or TV. The results indicated that parents of children with epilepsy had faced many glitches. Suitable intervention is required to sustenance these parents so that they can recover their social life. The diagnosis of epilepsy generally made when more than once seizures occur without any reason such as injury or fever. When a child experienced an unprovoked seizure then it needs immediate emergency medical treatment. After initial treatment, patient must visit to pediatric neurologist who manages seizures and epilepsy. The treatment of epilepsy usually begins with medicines. A child should never stop taking medicines unless it is recommended by neurologist. So it is very important that parents should help their children to maintain a healthy lifestyle and ensure regular medical visits.

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