

The Socio-Personal Effects of Epilepsy on Adolescents in the Metropolitan City, Karachi

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Abstract

Introduction: Epilepsy is characterized by uncontrolled, recurrent seizure attacks in one or more body parts of a person. It is related to abnormal brain activity which can be genetic, can be caused by drugs or infections or may even be idiopathic in nature. Epilepsy is a widely stigmatized disease in Pakistan which affects a person's mental and social wellbeing but the socio-personal effects of the disease have not been discussed immensely in this part of the world.

Methodology: The following article is a cross-sectional study conducted at the National Epilepsy Centre, Karachi from June, 2018 to March, 2019 for a span of 10 months after prompt approval from the institutional review board. Parents of 70 adolescents were handed out a questionnaire devised on the basis of Rutter-Parent Questionnaire and GHQ-30. The final data was analyzed by mean of Statistical package for Social Sciences (SPSS) version 22 using descriptive statistics and Pearson-correlation test. A p-value of <0.05 was considered significant.

Results: Out of the 70 adolescents, 46 (64.8%) attended school while 24 (35.18%) did not. Out of the 46 who attended school, males were 35 (50%) while females were 11 (15.7%). 14 (20%) had received primary education, 21 (30%) had received secondary education, 12 (17.1%) received higher education and 3 (4.3%) went to religious schools. 44 adolescents (62.8%) took active parts in sports, 8 (11.4%) never played sports, 35 (50%) faced difficulties in school, 35 (50%) had a good school life despite the disease. Teachers of 42 (60%) and peers of 36 (51.4%) children supported them in the process. Around 60 (85.7%) children made friends easily. 14 (20%) children were the reason for arguments in the family while parents of 44 (62.8%) children denied any family quarrels due to their children. 29 (40%) children had a good sleep free of nightmares due to their seizures, while 22 (31.4%) children complained of bad dreams.

Conclusion: Approximately a quarter of the total number of parents who took part in the study perceived epilepsy to be a burden for the healthy social and mental well-being of their children whereas the remaining parents were hopeful about their child's disease. Further studies need to be done city-wide to study the psychosocial effects of the disease not only on the children but also the family.

Keywords: Psychosocial • Epilepsy • Adolescents • Anxiety • Depression

Introduction

Epilepsy is a chronic disorder, the hallmark of which is recurrent, unprovoked seizures. A person is diagnosed with epilepsy if they have two unprovoked seizures (or one unprovoked seizure with the likelihood of more) that were not caused by some known and reversible medical condition like alcohol withdrawal or extremely low blood sugar [1]. It is the 4th most common neurological condition and affects more than 65 million people worldwide [2]. Epilepsy can occur in people with abnormal development of brain and disease like encephalitis, meningitis and abscess or in people, who take illicit drugs, sometimes people can have a family history and sometimes no cause can be found.

The indeterminate, uncalled for and unpredictable nature of epilepsy together with the stigma attached to it around the globe, gives rise to a spectrum of psychosocial difficulties in epileptic subjects [3-8]. People with this condition have lower self-esteem and higher levels of anxiety and depression compared to the general population [9]. In most individuals with epilepsy, the condition

is clinically benign but in many cultures, however, the dishonour associated with having epilepsy can have a negative effect on the social personality of people with the disorder, particularly for those living in third-world, resource-poor countries like Pakistan. The general opinion tends to overlook the psychological and social disruptions epilepsy creates in people's lives.

Aziz H et al. in 1997 conducted a nation-wide study to evaluate the degree of stigmatizations like avoidance of school and negligence by friends and neighbours and the effect of epilepsy on education and marriage [10]. However, no substantial research on the subject has been done in our setup in the past 15 years which compelled us to examine the socio-personal effects of this disorder on adolescents in Karachi, one of the largest cities in Pakistan with a huge inflow of epileptic patients to hospitals regularly.

Research Methodology

This research is a cross-sectional study, conducted between June, 2018 and March, 2019 for a span of 10 months at the National Epilepsy Centre (NEC) Karachi after prompt approval from the institutional review board of the institute. Parents of 70 epileptic adolescents presenting to the out-patient department in the age range of adolescence (defined by WHO to be 10-19 years) were interviewed employing a well-structured questionnaire for the psychosocial assessment of their children [11]. This proforma was devised on the basis of Rutter Parent Questionnaires [12] and the GHQ-30 [13]. The sample size was taken out purposively under 95% confidence interval using Open Epi version 3.03, under an estimated prevalence for adolescent epilepsy of 23 per 1000 [14]. The numbers were chosen based on empirical considerations (number of eligible cases seen during routine outpatient visits). The questionnaire was

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converted into the local language to remove any ambiguity in interviewing the individuals and subsequently to avoid bias. The questionnaire was pilot-tested amongst 15 parents to check for any errors.

The questionnaire was divided into two parts. It started with the demographics of the participants which included gender, age, educational level, marital status, duration of epilepsy and the time since the last attack. The second part comprised of sub-sections which included the description of the person's daily activities, behaviour at school with teachers and peers, emotional behaviour, social attitude, the effect on sleep and lastly the relationship with siblings and parents at home. The missing data were handled using the list-wise deletion method. The data was shifted to the Statistical package for Social Sciences (SPSS) version 22 (IBM,NY,USA) and analysed utilizing descriptive statistics and Pearson-correlation test was applied for ordinal variables like 'often', 'sometimes' and 'never'. A p-value of less than 0.05 was considered significant.

Results

Population characteristics

Out of 70 adolescents, 46 (64.8%) attended schools while 24 (35.18%) did not. The male adolescents who attended school were 35 (50.0%) while females were 11 (15.7%) in number. 30 (42.9%) adolescents suffered from epilepsy for a duration greater than 1 year but lesser than 5 years while 24 (34.3%) had it for less than a year. 16 (22.8%) participants had been having this disease for more than 5 years. The level of education received by these children was also assessed and it was found that only 15 (21.4%) out of 70 participants had not received any kind of education while others had been schooled to a certain grade. 14 (20.0%) of them had received primary education (till grade 5), 21 (30.0%) had received secondary education (till grade 10), 12 (17.1%) had gone to college while 3 (4.3%) had attended a religious institution. Remaining 5 (7.1%) children were taught in a school for children with special needs (Tables 1-3).

Hindrance of daily activities and school

Parents of 44 adolescents (62.8%) admitted that their children often took an active part in sports while 8 (11.4%) children never took part in any sport in

school. 35 (50%) adolescents faced difficulties in school due to their disorder while 35 parents did not complain of epilepsy interfering with the school life. 18 (25.7%) of those who were affected mostly faced attendance issues, 9 (12.9%) complained of decreased concentration during lectures, 2 (2.9%) ended up having bad grades while 7 (8.57%) registered all three factors to be interfering with their school performance. The teachers of around 42 (60%) adolescents had been supportive through these times. 36 (51.4%) children had also been supported by their peers who acknowledged the disease their colleagues suffered from, making it easy for around 39 (55.7%) children to be actively participative in school's extra-curricular activities.

The behavior of children in society and at home

It has been noted that around 60 (85.7%) out of 70 children have had no hesitation in making friends. Parents of 44 (62.8%) adolescents agreed to their child's disorder never being a bone of content in the house while 14 (20%) parents complained of usual disturbances in the house due to the epileptic child and 12 (17.1%) complained of occasional quarrels. They (74.3%) also rejected any ideas of their child being a reason for financial issues in the house. 41 (58.6%) parents were also positive about never having treated their epileptic child any different from their other children. 29 (40%) parents did not complain about their child waking up due to nightmares while 22 (31.4%) children had often been victims of nightmares whenever they had the seizure attack. Tables 4 and 5 tell us about the questions the parents answered (Figure 1).

Discussion

Our study focused on the changes in the overall quality of life of the adolescent children suffering from epilepsy reported by their parents. Most of the parents, as the results indicate, were affirmative about their children not being rigorously affected by epilepsy in most aspects. However, some aspects of their child's life were severely affected as per the data. Parents were concerned about the stigma attached to the disease and the resultant effect on their children.

A positive finding in our study was that most of the children even though suffering from epilepsy and belonging to the tertiary setup received secondary education while handling their disease side by side. This had been previously endorsed by Aziz et al. [10] who found 51% epileptics who participated in

Table 1. Number of children who attended/did not attend school with epilepsy.

Gender			Total number of male/female students
	Attended school	Did not attend school	
Male	35 (50.0%)	18 (26.0%)	53 (76.0%)
Female	11 (15.7%)	6 (8.6%)	17 (24.0%)
Total number of attendees/non attendees	46	24	70

Table 2. Duration of epilepsy in adolescents.

Duration of epilepsy	Frequency of adolescents	Percent
<1 Year	24	34.3%
1-5 Years	30	42.9%
5-10 Years	8	11.4%
>10 Years	8	11.4%
Total	70	100.0

Table 3. Level of education of epileptic adolescents.

Level of education	Frequency of adolescents	Percent
None	15	21.4
Primary	14	20.0
Secondary	21	30.0
Intermediate	12	17.1
Madrasah	3	4.3
Special Needs	6	7.5
Total	70	100.0

Table 4. Questions asked related to behavior at home and at school.

Questions	Number of children (%)		
	Often	Sometimes	Never
Does your child participate in sports or household chores?	44 (62.8%)	18 (25.7%)	8 (11.4%)
How often does your child volunteer for extra-curricular activities?	36 (51.4%)	21 (30.0%)	10 (14.3%)
How often has your child talked to you or someone in the family about his/her issues or problems related to his disorder?	22 (31.4%)	31 (44.3%)	16 (22.9%)
Has your child ever complained about not able to do things as well as most other people?	15 (21.4%)	20 (28.6%)	35 (50%)
How often does your child get nervous in a public place or environment?	18 (25.7%)	19 (27.1)	33 (47.1)
How often your child got into a fight?	14 (20%)	12 (17.1%)	40 (57.1%)
How often does your child get wake up in the middle of the night due to his disorder?	20 (28.6%)	23 (32.9%)	27 (38.6%)
Has your child ever complained of nightmares?	22 (31.4%)	20 (28.6%)	29 (40%)
Has the child's disorder caused economic problems in the house?	3 (4.3%)	15 (21.4%)	52 (74.3%)
Has the child's disorder been a reason of conflict amongst family members?	1 (1.4%)	17 (24.3%)	52 (74.3%)

Table 5. Interference of epilepsy with school performance.

Questions	Number of students (%)	
	Yes	No
Does epilepsy interfere with school performance?	35 (50%)	19 (27.1%)
How do they react?	42 (60%)	28 (40%)

Type of affect of epilepsy on school

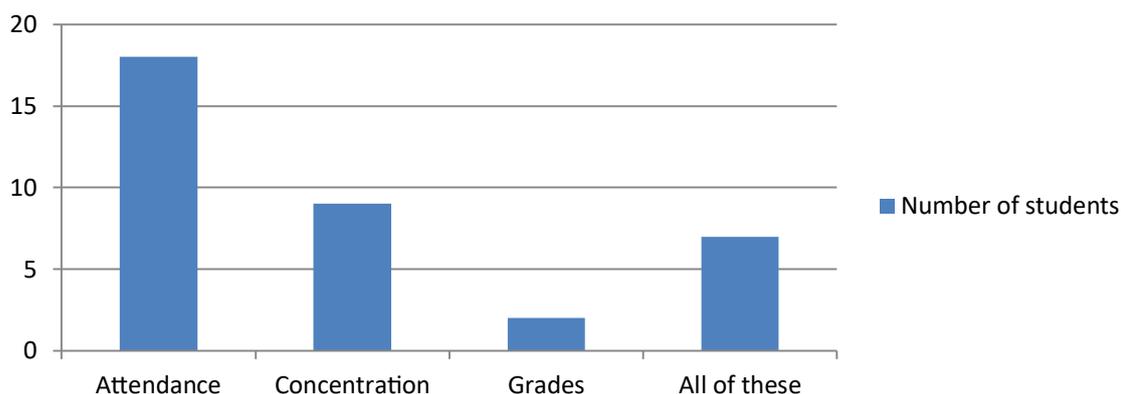


Figure 1. The type of effect of epilepsy on school.

their study to have received higher education. This shows that although going through a chronic disease that requires immense mental and physical fortitude, adolescents and their parents were steadfast in their quest of education. Epilepsy did not seem to be a matter of distress for the children who pursued sports and other group activity; instead many of them actively took up different sports. It has been reported in the literature that even though sports is largely discouraged in all setups in epileptic disorders but exercise and sports have proven to decrease seizure frequency in epileptics to a certain extent [15-17]. Gotze W showed that exercise, sports and other activities that boost a person physically reduce epileptiform discharges on electroencephalography (EEG) and increase the seizure threshold of a person, thus reducing the attacks overall [18].

Epilepsy can affect cognitive functions in people with epilepsy and impair memory, decrease concentration and provoke forgetfulness. Frequent seizure attacks impair learning as the person becomes unaware of the surrounding for a considerable period during an attack [19]. There was a further endorsed as participants in our study complained of bad results and poor grades due to decreased concentration and impaired learning. Teachers and peers play an important role in such a scenario to help a child enhance his school performance. Both of them were found to be supportive in our study. Demet et al. [20] by their study showed that the quality of life (QOL) was better in people

who were lent psychological support from friends and family as compared to people who were not.

Parents of epileptic adolescents in our study denied any domestic conflicts in association with these children. Studies [21,22] show that children who had diseased brothers or sisters took extra care of these siblings and paid attention to their needs and kept their needs above their own many at times. In our study, parents denied any sibling rivalry, jealousy or hatred due to extra care received by epileptic siblings. Epilepsy at times hinders the social interactions of affected individual directly and indirectly that of his or her family members. Moreover, it results in general anxiety in the family about the child's health and life expectancy [23]. In our study, most of the parents were adamant about their child not being a factor of interruption in any family members' work; however, some parents were concerned, as a natural rule, about their children's health.

Limitations

The first limitation to our study was that some parents were hesitant to open about their children's disease so we could only assess the situation to a certain extent. Our second limitation was that we had only covered a single epilepsy institute as compared to the mass presentation at different neurology

wards city-wide. Thirdly, there was a difficulty in comparing our findings to those of the other studies that used different scales to assess the quality of life (QoL) in children, adolescents and their parents.

Conclusion

It is safe to say that according to our findings, a quarter of parents perceived epilepsy to be a burden on the socio-personal lives of their children while the remaining were convinced that their diseased children can live a standard life, achieving everything a normal child can. Further studies need to take place on a large scale in our setup to study the psychological and social aspects of epilepsy on affected children, their siblings, and their parents, encompassing a complete family unit so that epilepsy is not only treated in the future as a medical disease with means of drugs but also as a psychologically demanding disease that needs psychological therapy and counselling for both affected children in their prime and their parents.

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