



A STUDY ON THE PROBLEMS FACED BY THE PARENTS IN HANDLING THE EPILEPTIC CHILDREN IN CHIKKAMAGALURU DISTRICT

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Abstract

Epilepsy is a long-term chronic disease that causes repeated seizures due to abnormal electrical signals produced by damaged brain cells. A burst of uncontrolled electrical activity within brain cells causes a seizure. Family is the main source of support for the children with disabilities in any societies. Families of epileptic children with experience a great deal of physical, psychological and social-economic issues. This study aimed to assess the impact of epilepsy on the family caring burden of epileptic children and knowledge of the parents in relation to epilepsy. The study results revealed that negative perception about epilepsy more among rural parents of epileptic children and educated parents have more awareness than the uneducated parents of the epileptic children, the study also explored that majority of the parents experience more social stigma, low-confidence, inferiority poor social interaction and variety of psychosocial issues due to their epileptic children. Further, it is also found that the low income is the major stressor for the family due to their children's medical condition.

Key words: Epilepsy, Burden, Psycho-Social issues

1.0. Introduction

Epilepsy is a group of non-communicable neurological disorders characterized by recurrent epileptic seizures. Approximately 50 million people are suffering from epilepsy worldwide. It is characterized by recurrent seizures, which are brief episodes of involuntary movement that may involve a part of the body (partial) or the entire body (generalized) and are sometimes accompanied by loss of consciousness and control of bowel or bladder function.

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, from less than one per year to several per day.

One seizure does not signify epilepsy (up to 10% of people worldwide have one seizure during their lifetime). Epilepsy is defined as having two or more unprovoked seizures. Epilepsy is one of the world's oldest recognized conditions, with written records dating back to 4000 BCE. Fear, misunderstanding, discrimination and social stigma have surrounded epilepsy for centuries. This stigma continues in many countries today and can impact on the quality of life for people with the disease and their families.

Epilepsy can have adverse effects on social and psychological well-being. These effects may include social isolation, stigmatization, or disability. They may result in lower educational achievement and worse employment outcomes. Learning disabilities are common in those with the condition, and especially among children with epilepsy. The stigma of epilepsy can also affect the families of those with the disorder.

People with epilepsy are more likely to have psychological problems especially Psychosis, depression, anxiety disorder and aggression, Emotional Disturbances, intellectual Disabilities and behaviors problems. Similarly, the risk of premature death in people with epilepsy is up to three times higher than in the general population, with the highest rates of premature mortality found in low- and middle-income countries and in rural areas. These Problems may be a result of difficulties dealing with the condition itself as well as medication side effects, but even people with well-controlled epilepsy are at increased risk.

Problems Faced By Parents of Children with Epilepsy

Whether the special needs of the child are minimal or complex, the parents are inevitably affected. They may receive assistance from family, friends and the community or the paid caregivers but it is difficult task of maintaining balance in the home. Parents with special children go through psychological, emotional, spiritual and physical trauma all throughout during their lifetime. There are various problems faced by parents of such Epileptic children.

1. **Acceptance:** When the parents are informed by the child specialist, doctor or a counselor, they are not ready to accept that the child is special. It is too painful for most parents to accept. Since many of them find it difficult to accept, they live in a phase of denial and try to find solution or cure for this incurable problem by visiting many doctors or sometime they may also go to the black magicians or fortune tellers to find out why it has happened to them or whether they have any solution for the problem. Their dreams and aspiration for their child is shattered once they come to know that they cannot do anything rather they need to accept the fact that their child is a special child.

2. **Self- blame:** Most of the parents develop guilt and sometime they start thinking whether they have committed any mistake that their child has to suffer. They wonder if God is punishing them for their past sins.

Sometime they may also get into depression if they think that their sins are the reason for their child to suffer.

3. **Social Stigma:** Having mentally retarded or special child in the family is something to be ashamed. Many parents do not go out for any public gathering or celebrations by the family as they fear that the neighbors, relatives and other known people might make cruel remarks about the child or may make them feel more with their sympathies targeting the condition of the child. This sometimes make the parents feel guilty about their past and might feel isolated and without any support from the family, relatives or the community.
4. **Behavior Problems:** Special children are unable to concentrate, aggressive in nature and stubborn and parents of such children find it difficult to hand such behavior problems of the children. Patience can wear thin for parents especially mothers who have to manage both household chores and outside jobs. Children of such intelligence will not know why the parents are angry with his/her behavior.
5. **Socio –Economic Problems:** Socio economic problem faced by the parents like low social status, stigma, social isolation negligence, lack of facilities, low financial status, lack of social contact, independence. Children with disabilities are often not seen as full citizens of society. They are unfit to do any jobs in the society and so they are considered as burden to the society or useless and unwanted persons in society. These problems bring down the coping ability of the parents. Raising a child with a mentally retarded may be more expensive than raising a typical child. These expenses can arise from medical equipment and supplies, medical care giving expenses, private education tutoring, adaptive learning equipment or specialized transports.
6. **Marital/Family Problems:** Having a child who is epilepsy places greater strain on a family. Due to the extra tasks that have to be done to take care of the child, stressed out and unhappy. The marital relationship can become strained if the parents have different approaches in dealing with the child or if one parent has to take care of the child all the time. Sometimes the mothers might feel that they are not getting enough support from their husbands in taking care of the child and fathers might feel that the wives are unnecessarily worried and too protective of their child.
7. **Helplessness:** Helplessness of the parents comes both from a lack of knowledge regarding the epilepsy and a lack of information about the resources available for epilepsy. Many parents find it difficult to take care of the child and they are not aware of the assistance by the Government and various NGO's for the welfare of the epilepsy and other mentally illness children. Helplessness also arises from insensitive handling of the case by the mental health professionals who might not have enough time to assistance the families and give them psycho-education.
8. **Emotional Problems:** Parents of epileptic children face lot of emotional problems like stress, fear of taking care of their children after their death, fear of losing them, fear of the people who make these children victim of abuse sexually or physically. Some of the parents commonly experience a gamut of emotions over the years. They often struggle with guilt and sometimes they may feel that they are reason for their child to be the victim of their selfishness. This guilt can harm the parents' emotional health if it is not dealt properly. Most of the parents have dreams of their child before it is born. They want their child to be a star in the competitive world but

when they see the child with inabilities their dreams are shattered and they cannot compromise with the reality. Such parents either become protective of their child or develop a total neglect towards that child.

9. **Worry about the future:** one of the main concerns of parents with epileptic children is about how their child will be taken care of when they die. They feel that no one else can take care of their child with same love and care that they have and they are scared about how their child will be able to manage to survive in the world. Sometimes they try to accumulate the wealth in the name of the child but that does not take the worry they have about the future of the child.

10. **Unrealistic expectations:** some times, parents of epileptic child are dissatisfied with the slow progress their child is making in learning new things like any other normal child. They try to push harder to force the child to learn quicker and try to be on par with other children. However, the child can only learn to the best of his/her ability and not more than that. When parents have unrealistic expectations of what their child can achieve, it leads to disappointment not only for them but also in the child who does not understand what he/she is doing wrong.

11. **Societal attitude and responses:** Somewhat stereotyped view of epilepsy by the society makes vulnerable in the parents self perception. Parents often feel both misunderstood by the society at large and ashamed of themselves and so sometimes they try to be away from public in order to avoid the humiliation of tag that they have a epileptic child.

Methodology

Objectives of the Research Study

1. To assess the knowledge of the parents regarding Epilepsy.
2. To study the psycho-social, economical problems faced by parents of children with epilepsy.
3. To suggest better way and means for the handling of epileptic children

Universe of the Study

The study includes parents of the epileptic children who are taking treatment in District Government Hospital chikkamagaluru.

Sample Size and Techniques

The study included 50 parents of epileptic children in Chikmagaluru district. Simple random method was selected by the researcher and samples were chosen through lottery method.

Method of Source of Data Collection

The data collection in the research was primary data. The researcher used interviews with interview schedules. Local languages were utilized to investigate and approximately an hour was utilized to interview samples.

Inclusive criteria: Respondent whose children are below 15 years is only taken in to consideration.

Exclusion criteria: Parents of children with co-morbiditory diseases are not considered.

Limitations of the Study

- Depth study with accuracy was constrained due to resources and time factor.
- Lack of rapport with respondents affected the quality of answers.
- Since the sample size is small the accurate conclusion could not be drawn.

Analysis & Interpretation

Assessment of parents regarding the knowledge on epilepsy: Parents of epileptic children commonly experience a gamut of emotions over the years. Most parents have aspirations for their child and their dreams get shattered when they realize that their child is special and they start examining their own conscience and start finding the reason for the condition of their child. Some parents struggle with the guilty conscience and they find no answer for their 'Why's in their mind.

The parents from rural area have different reason for the condition of their child and semi urban / urban has their own reasons and the answer for their queries. Among the children the cause is unknown but the parents attribute to various reasons because of which their children suffer.

Table 1.1 Parents perception about the various causes of epilepsy of their child.

Respondent	Evil eye	Mental Problem during pregnancy period	Hereditary	Birth injury	Stress during pregnancy	Any other
Rural	13(26%)	3(6 %)	1(2 %)	1(2 %)	5(10%)	0
Semi urban	3(9 %)	2(4 %)	1(2 %)	7(14 %)	4(8%)	0
Urban	1(2 %)	3(6 %)	5(10 %)	1(2 %)	0	0

The table displays that each individual will look differently at the causes of Epilepsy. With multiple answers given by the individual from rural area the researchers feel that thinking and reasoning differs from the individual belonging to semi urban and urban areas. The above table clearly shows that 13 (26%) respondents from rural area believe that it is the evil eye that has caused their child to develop this condition and 3(6%) feel that it is the condition which the child developed during the pregnancy of mother some of them feel since they are educated that this has resulted when the fetus did not develop properly during pregnancy and 1(2 %) feels that it is hereditary that is the genetic conditions sometimes it is caused by abnormal genes inherited from parents and 1 (2 %) rural people feel that is the injury during birth that is the cause for this condition. 5(10%) respondent reported that they had stress during their pregnancy. But the semi urban have their own way of attributing this condition. Education plays an important role in the thinking pattern of the parents who have epileptic child.

Table 1.2: Awareness of the parents regarding Epilepsy

Respondent	Below 5 Years	Between 6 to 10 year	11 year to 15 year	Later
Uneducated	1(2 %)	5(10 %)	1(2 %)	00
Below 9 th	6(12 %)	6(12 %)	2(4 %)	1(2 %)
PUC/SSLC/ITI	7(19.04%)	11(28.57%)	5(19.04%)	1(4.76%)
Graduate	4(100%)	00	00	00

Table 1.2 clearly shows that uneducated parents of epileptic children are not having any knowledge of retardation. They sometimes are not able to find the real condition of the child and are ignorant of the condition of the child and may not be able to take to the physician or a counselor for guidance. Parents who are graduates know that their child is not like any other normal child below 5 years. They are ready to take the guidance of the physicians and counselor in order to help their child and cope with the disabilities. 7(19.04%) parents who are qualified with High school, Pre University and other technical training know that their child is disabled at the time of below 5 years, 11 (28.57%) of the respondents come to know about the condition when the child is between 6 to 10 years, 5(19.40%) of the respondents know between the age of 11 to 15 years and 1 (4.76%) come to know the condition of the child after 15 years of age. Identification of the problem is another aspect the researcher studied. The respondents from rural area mentioned that their parents though illiterate were first to identify the condition of the child. When they realized that the child was not like any other normal child they took the child to physician or other relative who had some knowledge about the condition.

Table 1.3: The first identification of the problem by the respondent

Problem Identification	Parents	Clinician	Relative	Friends
Rural	11(22%)	2(4%)	1(2%)	3(6%)
Semi urban	10(20%)	8(16%)	1(2%)	2(4%)
Urban	6(12%)	5(10%)	00	1(2%)

The above table clearly shows that 27 respondents comprising of 54% said that their parents were the first to identify the problem and tried to find solution for their problem in spite of being illiterate. Only 15 respondents comprising of 30% said that the condition was noticed by the clinician and then the parents came to know about it and were really in shock when they came to know that their child was not able to be like any other normal child. 2 respondents comprising of 4% said that they came to know about the condition from their relatives who had visited them and 6(12%) of respondent they came to the problem from their friends.

Families with disabled children perceived greater financial stress, frequent disruption of family routine and leisure, poor social interaction, and ill effects on their physical and mental health as compared to families of normal children.

Table 1.4: Opinion on Social Status.

Respondent	Yes	No
Rural	14(28%)	3(9 %)
Semi urban	15(30 %)	3(6 %)
Urban	13(18%)	2(12 %)

The above table clearly depicts that the social status of the parents is affected in one way or the other. They perceive that there is a greater disruption of family routine life and the leisure that they want to enjoy. Many times they find it difficult to go for social gatherings or to have any social interaction with any outsider or friends as they feel that it is awkward or uncomfortable to have a child with disability.

In rural set up the 14(28%) respondents say that they feel bad in the company of epileptic child to go for social gatherings or get together. In a semi urban set up 15 (30%) respondents perceived that they found difficult to go out for social interaction or for family leisure outside having the retarded child and 13 respondents consisting of 18 % from urban set up felt that they feel going out with a epileptic child. They felt that their social status is affected much by taking the child out when compared with a normal child. But the other respondents from rural, urban and semi urban, comprising of 8(16 %) felt that their life is not affected at all with the presence of the epileptic child in the family. They are able to cope with any stress in the family.

Parents will feel that their child is a burden to them in spite of having so many disabilities. They will never abandon their child only because of the mental retardation. The study shows the feelings of the respondents about the special child and whether they take the child as a burden or not.

Table 1.5: Special child is felt a Burden to the parent based on the monthly income

Respondent	Never	We don't mind it	Some Times	Yes Definitely
Below Rs.10000	00	1(2%)	7(14 %)	14(28%)
Rs.11000 to Rs.19999	00	1(2%)	6(12%)	9(18 %)
Rs.20000 to Rs.35000	2(33.33%)	1(2%)	5(10%)	00
Above Rs.35000	2(42.29%)	2(4%)	00	00

The table 1.5 shows that 19(38%) parents from all income groups feel that sometimes epileptic child becomes burden. 23(46%) of the respondent facing burden due to child illness. With individual interviews the researcher comes to know that due to social stigma, growing price rate of every commodity and medical expenses of the child, emotional stress and job stress, all these make them feel that the special child sometimes is a burden to the family. 5 (10%) respondents don't mind about burden due to child illness. 4(8%) respondents of different income groups feel that they are never a burden to them and they are able to cope with any psychological, emotional, financial stress that they undergo. One respondent was quite sure that the child is obviously burden to the family.

Suggestion & Conclusion

Suggestions:

- Parents should be made aware of problem related to epilepsy and their causes. Educating the parents with regard to welfare, care and treatment is very essential.
- They should gain suggestions from clinician in time to time and also should inform behavioral changes of child to physician.
- Parents should create a good environment which may help the children to develop their mentality.
- Positive thinking about the problem and having optimistic attitude by the parents will help the children to grow in a positive way
- Parents should try to spend more time with their children.
- Always try to follow suggestions of clinician and psychiatrist.

Conclusion:

Our society has developed at a faster rate. But the general attitude towards the some children disabilities or illness needs to be changed. They are not to be sympathized; protected, ridiculed rather they need to be helped in growing and developing within their strengths and limitations. Their education or training should begin at home, thereafter special schools and institutions may be involved for their education and training. The society and the state, then should take responsibility for their treatment.

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