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LIVED EXPERIENCES OF PARENTS OF CHILDREN SUFFERING FROM EPILEPSY: A PHENOMENOLOGICAL STUDY

Nursing

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ABSTRACT

Epilepsy is one of the common neurological conditions characterized by recurrent episodes of epileptic fits. Parents of children suffering from Epilepsy face many social and psychological problems. The aim of the study was to explore the lived experiences of parents of children suffering from Epilepsy. Purposive sampling technique was used and twenty four parents of children suffering from Epilepsy were interviewed. Data was collected by taking in-depth interviews of parents of children suffering from Epilepsy. Recording of interviews was done by audio recorder. Verbatim were prepared, from which sixteen themes and forty seven subthemes were identified and described. The result highlighted that parents of children suffering from Epilepsy had various types of experiences they use various measures to treat Epilepsy including ayurvedic medicines, homeopathic treatment and also go to various witch quacks and temples. Parents of children suffering from Epilepsy passes through the stages from where they have to face many types of problems like psychological problems, social problems, family problems, financial problems and occupational problems. There is a need to create awareness about Epilepsy on a nation-wide basis to dispel the misconceptions and stigma through effective and robust programs with the aim to lessen the disease burden.

KEYWORDS

Children suffering from Epilepsy, lived experiences.

1. INTRODUCTION

Epilepsy is the second most common and frequently encountered neurological condition that imposes serious burden on individuals, families, and also on healthcare systems.[1] Epilepsy is considered present when two or more unprovoked seizures occurs more than 24 hours apart.[2] Five percent of children are estimated to experience one or more seizures in childhood, less than 1% have Epilepsy. The incidence is highest in the pre-schooler children. Intra-familial recurrence of convulsions, especially simple febrile convulsions, is very common.[3]

There are more than 12 million persons with Epilepsy in India, which contributes about one-sixth of the global burden.[1] It has been estimated that 10% of the burden of brain and mental disorders in the world is caused by Epilepsy which is calculated by disability-adjusted life year (DALYs) and which is verysignificant. This calculation includes loss of healthy life due to disability and premature deaths. However, it does not include the effects of stigma and social exclusion or their repercussions on the family.[4]

The impact of Epilepsy on an individual is a combination of physical consequences of the seizures, the effect on the social position, and psychological outcome of both of these. In addition to that not only the person with Epilepsy but also the family and indirectly the community also get affected due to this. Most of the parents were extremely distressed when their child is diagnosed with Epilepsy, mainly because of the stigma related to the condition. Typical parental responses were devastation, shock, anger, frustration, sorrow and ultimately depression.

Witnessing a tonic-clonic seizure in one's young child, can be one of the most anxiety-provoking experiences for parents. It usually leads to feelings of helplessness, fear and often results in overprotection or overindulgence of the child. Parents fear divulging their child's Epilepsy to their friends and relatives because they experience a sense of shame, self-blame and rejection. So, they consequently withdraw from their relatives and social circle.

It has been seen that these parents face many problems. These problems should be explored to assess the experiences associated with Epilepsy. So the need was felt to explore the experiences of parents that how they feel about their child Epilepsy and how this disease condition affects their family process and what type of difficulties the parents and their children have due to this disease condition.

2. Objective-

Present study aimed at exploring the lived experiences of parents of children suffering from Epilepsy in APC, PGIMER, Chandigarh.

3. Methods

3.1. Setting

Qualitative research approach was employed in the study. Phenomenological research design was selected to describe the lived experiences of parents of children suffering from epilepsy. Study was conducted in APC, PGIMER, Chandigarh. Ethical clearance was taken from Institute Ethics Committee PGIMER, Chandigarh. Permission from Head, Department of Paediatrics PGIMER, Chandigarh was taken. Informed consent was sought from each participant. Using purposive sampling technique 24 parents of children suffering from Epilepsy were included in the study.

3.2. Tools

The tools used for data collection were socio- demographic data of parents of children suffering from Epilepsy, Socio-demographic data of children, clinical profile of children suffering from Epilepsy, in depth interview guide and audio recorder. Tools were prepared after extensive review of literature and validated by experts in the field of Nursing and neurology. Semi structured interview guide was used which consisted of various questions in every important aspects of parents caring for a child suffering from Epilepsy.

3.3.Data collection

Data was collected from July- September 2018. Parents were made comfortable to sit in one room. Written consent was taken from each participant. Researcher had developed rapport with the patents of children suffering from Epilepsy. In depth interview of 24 parents were conducted with an average time spent on each interview was 25 minutes. Interviews were recorded with the help of audio tape recorder and transcribed into verbatim.

3.4. Data Analysis

The data was analyzed into two parts. In the first part, descriptive statistics was used to describe the socio demographic data of the parents of children suffering from Epilepsy, socio demographic profile of children suffering from epilepsy and clinical profile of children suffering from Epilepsy. In the second part, recorded interviews were transcribed into verbatim and analyzed by using colaizzi's steps of data analysis. It includes reading and re-reading of participant's description,

developing significant statements, formulating meaning of statements, grouping into cluster of themes, interpreting themes into exhaustive description of phenomenon, validating with clients and final description of the essence of the phenomenon.

3.5. Clinical profile of children suffering from Epilepsy

Table 1. depicts clinical profile of children suffering from Epilepsy. 87.5% children have generalized seizures. Out of 20 children 90% had history of previous hospitalization due to epileptic fits. Out of 15 children 40% children had co-morbidities i.e. developmental delay. 45.8% children have weekly epileptic episodes and duration of epileptic fits ranging from 2-10 minutes. 12.5% children have family history of Epilepsy.

Table 1. Clinical profile of children suffering from Epilepsy. N=24

S. No.	Variables	n(%)
1	Mode of delivery	
	NVD	16(66.7)
	LSCS	8(33.3)
2	Types of seizures	
	Generalized	21(87.5)
	Simple/Partial	3(12.5)
3	Co-morbidities (n=15)	
	Developmental delay	6(40.0)
	Drooling of saliva	3(20.0)
	Intellectual disability	3(20.0)
	Microcephaly	1(6.7)
	Vision problems	1(6.7)
	Hearing defect	1(6.7)
4	Family history of Epilepsy	
	Yes	3(12.5)
	No	21(87.5)
5	Previous history of hospitalization (n=20)	
	Due to epileptic fits	18(90.0)
	Due to accidental fall	1 (5.0)
	At the time of birth due to bradypnea	1 (5.0)
6	Frequency of fits	
	Daily	7 (29.2)
	Weekly	11(45.8)
	Monthly	5(20.8)
	Yearly	1(4.2)
7	Duration of epileptic fits	
	Up-to 30 seconds	7(29.2)
	30 seconds to 2 minutes	6(25.0)
	2 minutes to 10 minutes	11(45.8)

3.5. Thematic analysis

Colaizzi's method was used to analyze the data. Firstly in depth interviews of twenty four parents of children suffering from Epilepsy were taken by using audio tape recorder. A total of 265 responses were evolved from the transcript audio taped interviews. Out of them 342 responses were grouped under sixteen themes and forty seven sub-themes formulated from these responses.

Table 2. Cluster of parents themes with frequency and percentage of formulated responses N=342

Theme Emerged	Subthemes	n(%)
Reasons of child's Epilepsy (n=21)	Health issues	12 (57)
	Family issues	6 (28)
	Myths	3 (14)
Changes done in activities of daily living of child after Epilepsy (n=21)	Continuous observation of child	21 (100)
Side effects of antiepileptic drugs (n=15)	Physical	9(60)
	Myths related to medicines side effects	6 (40)
Measures taken to treat Epilepsy (n=11)	Witch quacks	6 (54)
	Others	5 (45)
Problems faced by the child in the school (n=25)	Problems in studying	14 (56)
	Bullying by classmates	5 (20)
	Over protective teachers	2 (8)
	School dropout	4 (16)
Before epileptic episodes (n=9)	Abnormal Physical sensation	8 (89)
	High grade fever	1 (11)
During epileptic episodes (n=39)	Abnormal body movements	24 (61)
	Frothing from mouth	10 (26)
	Altered level of consciousness	2 (5)
	Loss of bladder control	3 (8)
Types of injuries (n=4)	Minor injuries.	4 (100)

Table 2.(b) Cluster of parents themes with frequency and percentage of formulated responses N=342

Theme Emerged	Subthemes	n(%)
Measures taken during epileptic episodes (n=26)	Existing practices	16 (61)
	Malpractices	8 (31)
	Properly following all safety measures.	2 (8)
After epileptic episodes (n=23)	Exhausted	5 (22)
	Feeling Sleepy	11 (48)
	Irritated	2 (9)
	Loss of interest in food and play	2 (9)
	Forget everything	3 (13)
Psychological concerns of parents (n=41)	Related to study and job of child	10 (24)
	Related to health and treatment of child	21 (51)
	Related to female child	6 (15)
	Related to care of siblings	4 (10)
Effect on the care of other siblings (n=21)	Other siblings are neglected	9 (43)
	More focus on sick child	9 (43)
	Studies of other siblings get affected	3 (14)
Siblings reactions towards child's Epilepsy (n=21)	Taking care of sick sibling.	12 (57)
	Give medications	5 (24)
	Belittling and making fun	2 (9)
	Sibling Jealousy	2 (9)
Social burden/ Stigma (n=29)	Negative response from society	9 (31)
	Social isolation	11 (38)
	Loss of interest in social life	3 (10)
	Social Isolation	6 (21)
Financial problems (n=18)	Treatment is very costly	7 (39)
	Borrow money from others	11 (61)
Occupational problems (n=18)	Extra leaves from workplace	6 (33)
	Cancel important appointments	2 (11)
	Not able to do work properly	10 (55)

4. RESULTS

4.1 Reasons of child's Epilepsy

Parents give various reasons for their child's epilepsy the three subthemes included were health issues, family issues and have various myths regarding their child epilepsy.

4.1.1. Health issues

When this child was born his sugar level was very low, almost zero sugar level was there due to which he might be getting fits. Secondly, it may be that these fits appeared due to the surgery (LSCS).(Father of a child).

4.2 Changes done in activities of daily living of child after Epilepsy

4.2.1. Continuous observation of child

Parents replied that from the day when epileptic fits started in their child they had done various changes in the child daily activities. *Daily routine is that we never let him alone. All the time someone is a must to be with him, even we feed him on our own. We never let him go out on the road alone. Whenever we go out together we always hold his hand firmly. We never let him go nearby fire or water*

4.3. Measures taken to treat Epilepsy

Apart from medical management whatever the parents heard from anyone they tried it for their child. The parents tried witch quacks, and various other methods to treat their child. *There was a temple where a little pious witchcraft was done and a little donation was also done through her hands. We went to the temple 7 times. The witchdoctor called us 7 times and we went 7 times. No money was given to him as he said that he would take money when the girl would be fine.*

4.4. Problems faced by the child in the school- Most of the parents reported that their children were upset because of their disease condition as the children were bitten and bullyed by their other classmates in the school. One of the parent said that, "*He looks oldest in the class, so children used to make fun of him. He used to tell us that children used to make fun of him as he looked oldest in the class".*

4.5. Before epileptic episodes

4.5.1. Most of the parents verbalize that Epileptic fits are only due to fever. If they noticed high grade fever in their child there is more

chances of fits in their child that day.

If it's a mild fever then there is no attack and if there is a severe fever then there is an attack. And the fever starts from the head and goes out by the feet.

4.5.2. There were various practices followed by parents when their child got epileptic fits. Some of them do malpractices while their child was undergoing fits.

When the child get fits he is held tightly, his teeth are found jammed then his mouth is opened with the help of a spoon as lever. And then his hands and feet are held. Then he breathes after that he is laid down on the bed and we clean the froth coming out of his mouth.

4.5.3. After epileptic fits most of the children feel tired, exhausted and sleep after some time. Sometime there were minor injuries seen in children after epileptic episodes.

He feels like tired suddenly. It seems like his body has become exhausted and he has no strength. After fits he remains absolutely calm and then he falls asleep soon.

4.6. Psychological concerns of parents

She is a grown up of 6-7 years old now. After a few days how will she walk, wander, how will she study, how will she eat, how will she see the world, all this worries me. Who will marry her if she gets paralysed? This is all the tension along with the tension of her studies. If she doesn't study what will she do staying at home?

4.7. Effect on the care of other siblings-

Every parent verbalize that the care of other siblings get affected due to the illness of the child as they were busy with the sick child.

Earlier when she came from school I used to give her food and help her in homework but when the problem started to increase I was not able to help her in her homework. Now she is doing by herself only.

Siblings of sick child showed various reactions on the sickness of child some of the siblings take care of child, others make fun fun of the child.

They don't beat him and also they don't ask much questions from him as they know our brother has got problem. She keeps him good and feeds him. If we are not at home then her sister gives medicine to her on time.

4.8. Social burden/ Stigma-

Community people say that there is a ghost or spirit in our house, and don't wish to visit us and don't let their children to play with ours. If our children go to them then they scold them. We think that we become totally seclude from society due to this disease condition.

4.9. Financial problems-

Yes, it is expensive but what can be done? The child is very important to us so we spend upon him without any second thought. My mother-in-law also gets pension but that also is spent. Sometimes it becomes very hard to run the house expenses.

4.10. Occupational problems

My husband was also being asked by his boss that where is all of your attention these days? He is also much tensed. One the child is not well and the second is his father is also not well. Moreover, the load of office work. He remains puzzled most of the time.

5. DISCUSSION

Epilepsy is a group of neurological disorders characterized by epileptic fits, and these can vary from brief and nearly undetectable to long periods of vigorous shaking.

In this study according to the understanding of parents, they have given a variety of reasons for their child's Epilepsy. Most of the parents said that due to certain health issues like fever, fall, hypoglycaemia etc are the reasons behind their child's Epilepsy. Similar results were shown in funded project of ICMR in 1989 in which a multi-centric study on epidemiology of Epilepsy was carried out. Results revealed that sizable number of people in India believed in divine and supernatural causes of Epilepsy. Out of them, 22.8% of the urban and 32.3% of the rural patients thought that it is because of supernatural causes.[5]

As the people of India more believe on Jhad funk, God and miracles so in present study 54% of the parents of children suffering from Epilepsy also tried for witch- quacks treatment and religious temples visit for their children to be cured from Epilepsy. A similar study was conducted in Dehradun 2011 in this study (75.8%) believed that Ayurveda is a better option than allopathic (61.1%) for treatment. A small proportion (17%) believed that holy treatment with worship is effective in treatment of Epilepsy.[6]

There were various problems and frequent epileptic episodes, due to this 16% of children in this study had school dropout. Similar study was conducted in 1989 in Nigeria 100 children with Epilepsy participated in the study. Result revealed that only 49% of children were attending normal schools, 40% had attended schools but left due to repeated frequencies of seizures.[7]

Most of the parents have certain existing practices like holding the child during epileptic fit, put the child in lying down position and take the child in lap to prevent injuries in their children. A few parents put something in child mouth to force the teeth to open the mouth during epileptic fits.

In the present study according to parents of children suffering from Epilepsy their siblings also showed more concerns for the sick child. They taking care of child and give medications to the child at proper time but sometimes they belittling and making fun of the child. Some cases reported in the study who showed jealousy for their diseased brother/sister. A survey completed by SOS-KIDS study at American Epilepsy society 70th annual meeting The results showed that there were a very few disappointing feelings among siblings towards their brothers and sisters with Epilepsy. 64% of parents said that the siblings feel protective of the child with Epilepsy. 15% parents said that siblings complaints the child with Epilepsy got more attention.[8]

After a child has diagnosed with Epilepsy parents often experience feeling of fear or worry, which is normal and understandable. The parents of children suffering from Epilepsy have various psychological problems which should not be neglected. In the present study when the parents had asked about their tension and worries it has been seen that parents have worries regarding the study and job of child, health and treatment of child, sex of child (female child) and care of other siblings of child. A study was conducted in Sri Lanka in (2016) showed that most of the parents were concerned about Epilepsy affecting their child's chances of continuing education, securing a good job and marriage point of view. Parents indicated Epilepsy related stigma for their child's upcoming future also.[9]

The result showed that parents of children suffering from Epilepsy have social stigma in the form of social isolation, negative response from society and loss of interest in social life. Social acceptance of the child and coping with Epilepsy remain as a concern for parents as the family try to hide Epilepsy because of discrimination in social issue like taking job and getting marriage. A study was conducted in Ireland in 2016 showed that children with Epilepsy and their parents felt and enacted stigma via social exclusion, activity restriction, teasing/ bullying, various negative feelings to Epilepsy and camouflage of Epilepsy.

In this study some of the parents said that it is very hard for the parents of children suffering from Epilepsy to get medications, all the diagnostic evaluations and lab tests done for their child regularly. A population based study was conducted in United State of America in (2018) revealed the Epilepsy had a very significant impact on family functioning including increased restrictions on family activities and increased financial burden on family members.[10]

In the present study most of the parents not able to do their work properly as they have very much stress of their child sickness. A qualitative study was conducted Tehran, Iran (2016) showed that Parents of children with Epilepsy have numerous problems like limitation in relationships, travel restrictions, drop out from school, leaving the job. Parents either mother or father had to quit their job due to child's disease condition.

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