



AN EXPLORATORY STUDY ON PSYCHOSOCIAL BEHAVIOUR AND THEIR CONSEQUENCES IN SIBLINGS OF CHILDREN WITH EPILEPSY

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Abstract

Chronic illnesses like epilepsy in children have a significant impact on the entire family. Siblings of these children, typically within the same age range, may experience a range of psychological effects. There is limited data regarding the psychological state of siblings who share the same family environment as a child with epilepsy. To investigate the emotional effects and psychosocial aspects experienced by siblings of children with epilepsy. This study was qualitative in nature. The children with epilepsy were interviewed who has visited epilepsy clinic in last 5 years and with the help of a semi-structured questionnaire exploring the domains of their perceived severity of the sibling's epilepsy, their psychological reactions, their perception of parental behavior, family environment, and social life. The narratives were systematically transcribed into themes. The psychological responses of the children were examined for correlation with sociodemographic factors, characteristics of epilepsy, and themes derived from other domains. In summary, 55 %of children indicated experiencing anxiety;65 % reported feelings of parental negligence; and 42% described their family environment as disturbed. The psychological reaction of anxiety showed a significant correlation with the perceived severity of illness ($P = 0.007$). Children with siblings suffering from epilepsy have various psychological effects that are influenced by their perception of parental behaviour and family environment.

Keywords- Epilepsy, Psychological reactions, parental negligence, loneliness

Introduction

Epilepsy in children is frequently a chronic condition and is observed to affect not just the person but also the entire family as a support system. From a predominantly patient-centered approach to more family-oriented holistic treatment, contemporary medicine focuses on assisting the patients' families as well. The parents and direct caretakers are quickly identified as the unit to be cared for; however, the siblings frequently are the ignored targets of the same seeking help and care. Added to this poor impression of children and stigma associated with epilepsy gives little scope for open talk about the disease or expression of one's worries. The social shame, economic load, and feeling of sadness and frequently guilt erode the well-being of parents and carers of children with epilepsy. Their quality of life is determined by the degree of seizure management and the general well-being and productivity of their kid. However, siblings of such children are not left unscathed. They also feel the stress that

their parents and siblings undergo. The situation in our nation is further complicated owing to various reasons, including family structure, shortage of suitable treatment facilities, education and attitude of the parents, gender prejudice, societal stigma, and a lack of social support groups. Often, these siblings have unmet emotional needs and psychological concerns that can significantly influence their functioning and adjustment with family and society. Although there has been several studies to analyse the quality of life of parents of such children, there are relatively limited studies on the influence on the siblings of children with epilepsy. This study was designed to investigate the psychological and emotional implications in siblings of children with epilepsy.

Materials and methods

This study was exploratory and phenomenological in nature. The investigation was conducted in combined district hospital, Kushinagar UP at hospital's paediatric neurology outpatient department. During their interview, the parents were urged to pick up the child's siblings. Interviews about the psychological well-being of these siblings were conducted.

Participants in the study ranged in age from 4 to 14 years. The study excluded participants with any mental sub-normality or medical, surgical, or psychiatric disorders. Prior to the study's start, the institutional ethics committee gave its approval. Before data collection began, parents' informed consent and each participant's agreement were obtained after the participants were told about the purpose of the study. If the interview caused them discomfort or was having a detrimental effect on their emotional state, they were free to stop or withdraw.

The children with epilepsy were interviewed who has visited epilepsy clinic in last 5 years (from Jan 2019- June 2024) as per hospital record. 82 kids in all were questioned, and sample collection ceased when data saturation was reached and no new themes emerged. In a private, non-disturbing setting, the kid was made to feel at ease and only interviewed once. The purpose of the interview questions was to investigate the narratives in the following areas: (1) how the child perceived the sibling's illness; (2) how the child responded psychologically to the sibling's illness; (3) how the child perceived the behaviour of the parents; (4) how the child perceived the family environment; and (5) how the child perceived interpersonal and social relationships.

Statistical analysis

For all statistical analyses, SPSS software version 25.0 was used. Descriptive statistics were used to display findings for continuous variables. Results for qualitative variables were shown as percentages and frequencies. Associations between sociodemographic factors, child psychological responses, perceived parental conduct, family environment, and social life were examined using a chi-square or Fisher-exact test. Every result was displayed with 95% confidence. A value of $P < 0.05$ was deemed significant, and a 5% threshold of significance was applied overall.

Table 1 - Sociodemographic data of the children

1	Age	Less or equal to 12	55.1%
2	Gender	Male	48.3%
3	Birth order	Elder	24.1%
4	Duration of epilepsy	Less than 2 years	16.4%
5	Severity of epilepsy	Controlled	78.5%
6	Development delay	Yes/No	38.2%
7	Behavioral disorders	Yes/No	28.3%

Results

Interviews were conducted with 82 kids who had an epileptic sibling. The sociodemographic profile of children and the siblings' epilepsy features are shown in Table 1. The children questioned were 10.85 years old on average, with a standard deviation of 4.52. Children's answers to specific questions

were evaluated. When asked how they saw their sibling's epilepsy, 56.2% youngsters said they thought it was a serious condition; 24.2% even said they were afraid their sibling would die during a seizure. "I feel like my brother is really sick, so he needs to go to the hospital," a nine-year-old girl remarked. He might pass away at any time. 18% thought that their sibling's sickness was strange or strange. 44 youngsters were afraid when they saw a seizure episode and were worried about the health of their siblings. "I get really scared when I see my sister having a tantrum," said an 11-year-old brother. I'm anxious, and I question whether she will ever return to normal. 29 of the youngsters felt "shame" about telling their friends or acquaintances about their sibling's illness. "I have not told any of my friends about my sister's fits, because they will laugh at me," said a 17-year-old lad. Because their parents were too busy taking care of their siblings, 9 youngsters said they felt alone and unable to express their emotions to others. When the sibling had to be admitted to the hospital and was left alone at home with a carer, this emotion was very noticeable. 29 kids became too protective and gave the impacted sibling more attention. They avoided offending them and always tried to help. According to a 16-year-old older sister of a five-year-old with epilepsy, "I meet all of her needs." I worry that she will have a tantrum if I say "no" to anything and she starts crying or becomes upset. 11 of the kids were upset and irritated with their sibling or their friends and relatives.

The children's perceptions of their parents' actions were investigated. In all, 46 children thought that their parents had ignored them, despite the fact that they paid more attention to the brother who was impacted. Additionally, they stated that their parents neglected their regular pursuits, such as leisure and education. One youngster even desired to get ill to attract his parents' attention. 25 kids thought their parents were too protective of them. Even small health problems or even the smallest delay in going home cause their parents to worry. Infrequently, one child wished he had been born into a different family, and 8 kids said their parents were harsh or punishing towards them, even for little infractions. In all, 48 children stated that their parents hold them to high standards for completing domestic chores or performing well in school. 38 of the youngsters who were asked about their household environment said that it was unsettled. Children reported an overall sense of tension in the home, disagreements among family members, or a lack of communication. 21 believed that family recreation—such as vacations, family trips, or enjoyable activities done together—was lacking. 56 youngsters felt that their relationships with their neighbours or classmates were affected and that they were unable to communicate comfortably with them.

Table 2 - Sociodemographic data of the children with expression and correlation in terms of psychological reactions

			%age	With Anxiety	Pvalue	With Overprotection	Pvalue	With loneliness	Pvalue	With anger	Pvalue
1	Age	Less or equal to 12	55.1%	36	0.97	12	0.91	05	0.64	02	0.51
2	Gender	Male	48.3%	27	0.48	11	0.65	04	0.62	01	0.29
3	Birth order	Elder	24.1%	26	0.47	13	0.86	06	0.97	02	0.59
4	Duration of epilepsy	Less than 2 years	16.4%	08	0.35	04	0.68	01	0.51	01	0.91
5	Severity of epilepsy	Controlled	78.5%	25	0.75	19	0.61	09	0.12	03	0.95
6	Development delay	Yes/No	38.2%	15	0.18	16	0.63	04	0.65	03	0.51
7	Behavioral disorders	Yes/No	28.3%	12	0.19	06	0.68	02	0.61	03	0.16

Children's psychological responses were consistent for all genders and all age groups. The child's birth order in regard to the impacted sibling did not correlate with psychological responses. the clinical characteristics of the epileptic sibling, such as how long the condition has persisted. The children examined showed no discernible variations in their psychological responses to behaviour disorders or related developmental delays. Likewise, their psychological responses were not substantially influenced by the type of family . Age, gender, family type, and clinical features did not significantly correlate with social life, the family environment, or perceived parental behavior. It was discovered that kids who thought their sickness was serious had a lot of worry. The youngsters, who believed that their parents were harsh or punishing, felt lonely and ashamed of their sibling's

sickness. Children who reported a troubled family environment and a loss of recreational opportunities also reported feeling a substantial sense of loneliness. \

Table 3 - Sociodemographic data of the children with expression and correlation in terms of perceived parental behavior & family environment & social life

			Pvalue			Pvalue			Pvalue	
			With expectations from parental behavior		With harsh from perceived family		With disturbed from perceived family		With disturbed social life from social life	
1	Age	Less or equal to 12	08	0.91	01	0.98	04	0.61	06	0.65
2	Gender	Male	06	0.42	02	0.43	02	0.54	08	0.32
3	Birth order	Elder	08	0.49	03	0.76	07	0.87	07	0.43
4	Duration of epilepsy	Less than 2 years	05	0.38	04	0.45	02	0.45	02	0.76
5	Severity of epilepsy	Controlled	07	0.66	02	0.41	08	0.25	07	0.76
6	Development delay	Yes/No	05	0.22	02	0.56	03	0.56	04	0.45
7	Behavioral disorders	Yes/No	02	0.23	01	0.61	03	0.43	03	0.19

Discussion

Families are the foundation of each person's support network and the smallest social unit in a community. Parents, siblings, and other family members are significantly impacted psychologically by chronic conditions like epilepsy. The necessity of any kind of intervention for siblings is undervalued.

The majority of kids 70 experienced tension and anxiety due to their sibling's sickness. Another study by Hames and Appleton found that siblings of children with epilepsy were afraid and anxious about what would happen if they had a seizure or were alone in the house. Houtzager et al. found that siblings of children with chronic diseases had greater cognitive and particularly more emotional issues than their peers.

In general, 35 of kids were embarrassed to talk about their sibling's sickness. This demonstrates the social stigma associated with epilepsy and the perspective that parents pass on to their kids. Tsuchie et al. further underlined the serious impact on these children's lives and the poor impression of epilepsy.

Sixty-nine percent of the youngsters in our survey reported experiencing parental neglect. Due to their overwhelming sense of duty to the afflicted kid, parents who are active in the care of a child with a chronic disease frequently neglect the needs of their so-called "normal" children. According to Freeman et al., parental neglect of healthy children is frequent and can make it harder for the youngster to adjust. It can also make the sibling rivalry more intense. Thirty-seven percent of youngsters reported experiencing family environment disturbances. A family is at risk for poor integration, cohesion, and communication when a member has a chronic condition with unexpected symptoms, like epilepsy. In the end, a healthy child may become disappointed due to a damaged connection with the parents and restricted involvement in family or social activities. According to our research, it also caused kids to feel isolated and overly protective of their siblings. Siblings of children with various chronic illnesses have also been reported to experience loneliness, primarily as a result of a lack of understanding and support.

According to our research, the children's psychological responses were unaffected by sociodemographic factors like age, gender, or birth order. However, according to Alferder et al., female youngsters are more likely to feel upset about their sibling's illness. The likelihood of older children being protective of their siblings was higher, but this difference was not statistically significant. Furthermore, the psychological responses of the healthy kid were not statistically significantly impacted by the clinical features of the epileptic child, such as behaviour problems, developmental delays, or seizure management. Although it was not statistically significant, more kids who had epilepsy for more than two years reported a disrupted household environment. However, the children's psychological responses were impacted by how they perceived their parents' treatment of

them, as well as how they saw their familial and social surroundings. The importance of parental attitudes and behaviours on a child's psychological health has also been emphasised in other research. It is well recognised that chronic diseases alter family dynamics, which undoubtedly affects a healthy child's mental health. An intact family setting with sufficient parental guidance is crucial for promoting emotional health and reducing suffering. A well-adjusted family of a chronically ill child is possible with a supportive social network, appropriate balancing of needs and demands of all family members, and active coping and encouragement of growth within the family. Better care and situational acceptability will result from parents and kids communicating well. Anxiety and loneliness can lead to multiple major psychological sequelae in children that need to be addressed on time. It needs to be explored whether family-orientated psychosocial interventions lead to an improvement in the mental health parameters of the siblings of children suffering from epilepsy

Conclusion

Children who have sibling with epilepsy may have a variety of psychological effects that are mostly determined by how they perceive their parents' conduct and the home environment, rather than their sociodemographic profile or the sibling's epileptic characteristics.

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