

Parental KAP and its Relation with the Quality of Life in Children with Epilepsy

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Abstract

Background: Epilepsy is a chronic disorder with recurrent unprovoked seizures which can affect children at any age. A child's quality of life (QOL) is significantly impacted by an epilepsy diagnosis throughout their formative years. Adjustment and QOL for the child and family are highly correlated with parental knowledge, attitudes, and practices (KAP) regarding epilepsy. **Objectives:** Determining the association between parental KAP and the QOL of children with epilepsy (CWE) and to study the association between them. **Materials and Methods:** Using convenience sampling procedure, 30 CWE between the ages of 6 and 14—of either sex—and their 30 parents made up the sample. The knowledge, attitude, and practice (KAP) tool, which was given to parents, and the Quality of Life in Childhood Epilepsy Questionnaire-55 (QOLCE-55), which was given to CWE, were used to gather the data. Frequency distribution, percentage, and correlation coefficient tests were used to assess the measures. **Results:** There were statistically significant relationships between the QOL and KAP domains and parental education, domicile, and socioeconomic position. The cognitive, emotional, and social domains of QOL were adversely connected with the knowledge domain in KAP, but the physical domain was positively correlated. Parents' behavior and physical QOL were found to be negatively correlated. **Conclusion:** Although educated parents had sufficient information and a positive outlook, there was a discrepancy between recommended and actual practice, and KAP has an impact on the QOL of CWE. Parental education initiatives may significantly improve understanding and promote healthy behaviors.

Keywords: Children with epilepsy, parental knowledge attitude and practice, quality of life

INTRODUCTION

Epilepsy is a common chronic neurological disorder that affects people of all ages. In children, epilepsy is among the most prevalent neurological conditions in the developing years. The unpredictability of seizure recurrence characterized by its episodic nature causes disruption in the child's normal routine activities. The associated psychological, social, behavioral, and academic difficulties and cultural factors create a significant impact on the lives of patients and their families.^[1]

Parents play a pivotal role in interpreting the diagnosis of epilepsy which lay the groundwork for the child's understanding of the illness and its significance.^[2] However, it was evident from the reviews that the parents or caregivers reported a lack of understanding about their child's condition.^[3] Meanwhile, they validated that knowledge about epilepsy would help reduce the perceived negative reactions, social isolation, perceived stigma, and equip them to deal with the emotional impact of both seizures and treatment.^[4,5]

Adjustment and quality of life (QOL) of the child are highly correlated with parental views, KAP about epilepsy.^[6] Numerous studies have been conducted on the QOL of CWE, considering various risks and contributing biomedical factors, co-morbid conditions, and psychosocial factors.^[7] Epilepsy during a child's formative years carries a larger risk of significantly affecting the QOL, especially in low- and middle-income countries with subpar socioeconomic and living conditions.^[8]

Many studies have investigated public awareness and attitudes toward epilepsy in both developed and developing nations. However, not much research has been done on Indian parents' knowledge and perceptions of CWE and their relationship to the quality of their children's lives. Therefore, the aim of the current study was to understand this phenomenon.

SUBJECTS AND METHODS

Study design

The objectives of this study were (i) to assess the KAP of the parents of CWE, (ii) to assess the QOL in CWE, (iii) to explore the association of KAP on the QOL of CWE. This cross-sectional, descriptive investigation was conducted in a South Indian tertiary care facility. The study was undertaken

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with the assumption that parents' KAP would have a positive impact on their children's QOL.

We included (i) children aged 6–14 years, diagnosed as having epilepsy as per International League Against Epilepsy (ILAE) Classification^[9]; (ii) receiving treatment from an outpatient consultation service for ≥ 6 months from a single unit at the neurology department from a tertiary care center and (iii) between September 2019 and February 2020. We excluded children with (i) drug-refractory epilepsy; (ii) who had a co-morbid diagnosis of medical or psychiatric illnesses, intellectual developmental disorder (IDD), cerebral palsy, autism, and attention-deficit hyperactivity disorder, and (iii) structural, metabolic, infectious, and immune-mediated causes of epilepsy. Ethical approval for the study was obtained from Institutional Ethics Committee. An informed assent from the children and consent from the parents to participate in the study was duly taken while ensuring confidentiality and non-monetary involvement.

Sample size and data collection

For this study, a feasible sample of 30 parents, either mothers or fathers and 30 CWE was obtained. The study recruited 60 samples instead of the 73 that the sample size estimate suggested because the data gathering had a deadline. As a result, the study used a convenience sampling method. Those participants who met the eligibility criteria were recruited from a single unit under the direction of a pediatric neurologist, and the sample was taken from the daily list of patients visiting the outpatient services of this tertiary care facility. The socio-demographic datasheet collected baseline demographic details in two sets (i) demographic data of children and parents, such as age, gender, educational status, occupation, and economic status of parents (ii) clinical data of epilepsy, such as age at the onset, type of seizure, duration, and treatment. The KAP tool^[10] was used to assess parents' understanding of the condition, and the QOL of children was measured by Quality of Life in Childhood Epilepsy Questionnaire-55 (QOLCE-55).^[11] The interviews were performed by one researcher to control the quality of the interview.

Statistical analysis

The data was recorded in pen-and-paper format and entered into SPSS version 22.0. The data followed a normal distribution and descriptive statistical analysis for the continuous variables obtained from frequency and percentage, whereas categorical variables are expressed in proportions. The data from KAP and QOL was analyzed using Pearson and Spearman correlation coefficients, as appropriate, for assessing the association between study variables and socio-demographic variables.

RESULTS

The overview of the parents' socio-demographic characteristics is shown in Table 1. The parents' mean age was 39; most of them came from rural and semi-urban areas (70%) and belong to lower socio-economic group (66.7%), spending between Rs. 1,000 and Rs. 5,000

Table 1: Socio-demographic profile of parents (n=30)

Variables	Number (n)
Age (years)	
25-35	11 (36.6)
36-45	14 (46.6)
46-55	4 (13.3)
56-65	1 (3.3)
Sex	
Male	18 (60.0)
Female	12 (40.0)
Education	
Illiterate	2 (6.7)
Primary	13 (43.3)
High school and secondary	8 (26.7)
Higher education	7 (23.3)
Occupation	
Unemployed	1 (3.3)
Unskilled work	15 (50.0)
Semi-professional	10 (33.3)
Professional	4 (13.3)
Socio-economic status	
Lower SES	20 (66.7)
Middle SES	7 (23.3)
Upper SES	3 (10.0)

per month on their children's medicines, and incurring a loss of wages up to Rs. 1,000 while visiting tertiary care center. The sample of CWE was from the age group of 9–11 years (46%), studying in upper primary or high school (73.3%), and had the first onset between the age of 4.1 and 9 years (53.3%), with the duration of illness ranging from 6 to 13 years (56.7%), and mothers (93.3%) were the primary caregivers [Table 2]. A small percentage of children (13.4%) received other forms of treatment such as Ayurveda/Homeopathy, faith healing, and magico-religious practices, whereas the majority of children (86.6%) took allopathic treatment.

The responses received from parents on the KAP tool presented in Table 3 are mainly related to children. On the knowledge domain of the KAP tool, most of the parents agreed that epilepsy is a neurological disorder (56.3%), treatable (86.7%), and controllable after regular drug therapy (76.6%). The attitude domain of the KAP tool showed favorable responses towards informing teachers of their children's disease (100%), these children are as intelligent as others (70%), and it is a disease not to be ashamed of (96.7%), and 70% of the parents felt that they should lower the expectations from their children. In the practice domain, 93.3% of the parents believed in taking the children to the hospital right after a seizure, while a few others attempted opening the mouth to put something between their jaws (43.3%), hold them tight to stop the seizure (50%), shouting and moving them in an attempt to wake them up (53.4%).

The socio-demographic characteristics of the parents such as parental education, place of residence, and socioeconomic

Table 2: Socio-demographic profile and illness characteristics of children with epilepsy (n=30)

Variables	Number (n)
Age	
6-8 Years	7 (23.4)
9-11 Years	14 (46.4)
12-14 Years	9 (30.0)
Sex	
Male	14 (46.0)
Female	16 (53.4)
Education	
Lower primary	8 (26.7)
Upper primary	13 (43.3)
High school	9 (30.0)
Primary Caregiver	
Mother	28 (93.3)
Father	0 (0.0)
Grandparents	2 (6.7)
Diagnosis	
Generalized	8 (26.7)
Focal	14 (46.6)
Others	8 (26.7)
Age at the onset	
Birth – 4 years	6 (20.0)
4.1 – 9 years	16 (53.3)
9.1 – 14 years	8 (26.7)
Duration of illness	
6 months – 6 years	13 (43.3)
6.1 – 13 years	17 (56.7)
Medication	
One drug	2 (6.7)
Two drugs	21 (70.0)
More than two drugs	7 (23.3)
Modes of Treatment (before the treatment from tertiary care center)	
Allopathy	26 (86.6)
Ayurveda/Homeopathy	2 (6.7)
Magico-religious/Faith-healing	2 (6.7)

status were correlated with the QOL of CWE as shown in Table 4. Parental education was significantly correlated with social (.603, $P = .000$) and physical functioning (.467, $P = .008$) on QOL; similarly, the domicile (.389, $P = .029$) and socio-economic status of parents (.480, $P = .007$) were positively correlated with social functioning and overall QOL, respectively.

The association of KAP with the QOL of children was assessed [Table 5]. A negative correlation between parents' knowledge and cognitive (-.379, $P = .039$), emotional (-.512, $P = .004$), and social (-.411, $P = .024$) functioning of QOL was observed in the current study. However, a positive correlation between knowledge and physical functioning (.429, $P = .018$) in QOL was observed. A negative correlation between the practice of the parents and the physical functioning (-.426, $P = .019$) of CWE was observed. However, the parental attitude and the overall QOL of the CWE did not have statistical significance.

DISCUSSION

In our cross-sectional study, we tried to establish the relationship between parental KAP with the QOL of CWE which has not been published from South India to the best of our knowledge. Parents' understanding of epilepsy might have an influence on how the children perceive epilepsy and practice the same tradition when they grow up and also have a bearing on health-seeking behavior and compliance to anti-epileptic drugs.^[12]

The current study findings on socio-demographic variables of CWE and parents corroborate with prior studies from India and other developing countries.^[8,12,13] Socioeconomic factors largely influence epilepsy care in India. A large-scale study reported that the major components of the economic burden of epilepsy in India are related to the monthly cost of epilepsy, travel expenses, and loss of productivity due to long trips which put together accounted for 14% of the total annual cost.^[14] Our study estimated almost comparable cost variables in terms of medication, travel to the tertiary care center for treatment, and the loss of wages. As the social security measures for epilepsy care are inadequate and not accessible to a sizeable number of people, especially from the rural parts of India and health insurance schemes are far beyond their reach, the increase in the cost of epilepsy care may create an additional financial burden to many Indian families. Pertaining to mothers as primary caregivers for most of the cohort in our study is reiterated in other studies from developing and developed countries which consistently showed a high percentage of female caregivers in managing CWE.^[10,15,16]

Recent studies on KAP from developed countries have shown an emergence of a positive attitude toward epilepsy, whereas studies from developing countries have reported inadequate information and limited awareness among parents.^[13] Our study revealed that parental awareness towards identifying epilepsy as a neurological disorder, treatable disease, and controllable after drug therapy was satisfactory which can be attributed to parental education and regular association with the tertiary care center for treatment. However, some parents' perception that epilepsy is a contagious disease and children need a special diet is a reflection that the parents are still not able to discern from the misconception that exists in our society. Some of the assertions on the attitude of parents have received favorable responses. The parental efforts to provide a supportive environment for the child's upbringing and slowly emerging attitudinal changes are observed in our study. In terms of certain practices carried out while managing their child, the parents even now apply some of the procedures that are potentially harmful. Similar practices have been reported in published studies from India and Nigeria^[17,18] which reiterates the fact that many families are still connected to mythical or sociocultural belief systems.

In recent years, the goal of epilepsy treatment has been not only the control of epileptic seizures but also the

Table 3: Knowledge, attitude, and practice of parents of children with epilepsy (n=30)

Items (n=30)	Yes (%)	No (%)	Don't Know (%)
Knowledge			
Epilepsy is a neurological disorder	17 (56.3%)	2 (6.7%)	11 (36%)
Epilepsy is treatable	26 (86.7%)	0 (0%)	4 (13.3%)
Most seizures are controllable after regular drug therapy	23 (76.7%)	2 (6.6%)	5 (16.7%)
Some children with epilepsy may need to follow special diets to prevent seizures	7 (23.3%)	11 (36.7%)	12 (40%)
Once being seizure-free, the medications can be withdrawn immediately	11 (36.7%)	13 (43.3%)	6 (20%)
Epilepsy is contagious disease	13 (43.3%)	12 (40%)	5 (16.7%)
Attitude			
Parents should inform school teachers of their children's disease	30 (100%)	0 (0%)	0 (0%)
Children with epilepsy should be able to play with others	30 (100%)	0 (0%)	0 (0%)
Children with epilepsy are as intelligent as others	21 (70%)	4 (13.3%)	5 (16.7%)
The society discriminates against people with epilepsy	21 (70%)	4 (13.3%)	5 (16.7%)
Parents should lower the expectations of the children with epilepsy	21 (70%)	4 (13.3%)	5 (16.7%)
Epilepsy is a disease to be ashamed of	0 (0%)	29 (96.7%)	1 (3.3%)
Practice			
Taking them to the hospital right after seizure	28 (93.3%)	0 (0%)	2 (6.7%)
Loosening pieces of clothing around their neck	8 (26.7%)	1 (3.3%)	21 (70%)
Rolling them carefully on their side	9 (30%)	0 (0%)	21 (70%)
Attempting to open the mouth to put something between jaws	13 (43.3%)	10 (33.3%)	7 (23.4%)
Holding them tight to stop seizure	15 (50%)	5 (16.7%)	10 (33.3%)
Shouting and moving them in attempt to wake them up	16 (53.4%)	10 (33.3%)	4 (13.3%)

Table 4: Association between QOL domains and socio-demographic variables

QOL domains	Education (Parents)	Domicile	Socio-economic Status
Correlation Coefficient (P)			
Cognitive	-0.214 (.256)	-0.210 (.264)	
Emotional	-0.279 (.136)	0.010 (.960)	
Behavioral	0.108 (.571)	-0.139 (.465)	
Social	0.603 (.000)**	0.398 (.029)*	
Physical	0.476 (.008)*	0.036 (.852)	
QOL overall	0.153 (.420)	0.789 (.789)	0.480 (.007)**

**Correlation is significant at the 0.01 level. *Correlation is significant at the 0.05 level

improvement in QOL.^[19] Assessing the QOL in pediatric epilepsy is particularly imperative because childhood is a critical phase of development during which age-specific cognitive and social skills are being learned. The inability to develop these skills at developmentally appropriate periods may impair their QOL as children and later as adults.^[20,21]

Our study reported that parental education, domicile, and socioeconomic status as having statistically significant correlations with QOL and KAP domains. Educated parents having better knowledge about epilepsy and accepting the condition with a positive attitude showed a significant positive association in social and physical domains and overall QOL of CWE. The CWE belonging to lower socioeconomic status was reported to have overall poor QOL which is in accordance with previous studies from India.^[22,23] Fayed *et al.*,^[21] study reaffirmed that recurrent positive everyday experiences at home or in school are more important to satisfaction with life in children than major life stressors such as the diagnosis of epilepsy.

The knowledge of parents in the KAP tool and cognitive, emotional, and social domains of QOL in CWE was negatively correlated. A negative correlation between parental practices and physical QOL of CWE was also observed. Previous studies have noted that the unpredictability of seizure recurrence in CWE is a constant concern to the family members, and this often results in overprotection, feeling of isolation, and needless restrictions on physical activity.^[24]

The parents in our study are largely from rural and semi-urban areas where the likelihood of overprotection the unwell children or oblivious to managing them with sensitivity exists, which could have led the children to feel that their QOL in those areas is affected. Besides, parents may be more prone to express negative perceptions about their child's health perhaps reflecting their worries about the future, which also could have manifested in the children's responses on their QOL. Studies on parental expectations reveal that, compared with siblings, parents had significantly lower expectations for their child with epilepsy in the areas such as school performance or ability to make friends.^[25] Indeed, better knowledge and attitude about epilepsy among CWE and their parents have been found to be associated with less perceived stigmatization and social isolation.^[26]

We tried to examine the emerging evidence from younger CWE as certain perceptions of the children will be otherwise overlooked by parents or healthcare professionals. Some of the parental practices that were identified in the study could be owed to ethnicity and cultural practices that may influence the management of their child's illness which in turn affects the QOL. We would like to postulate that some of these findings might have got influenced by compounding variables such as gender, age, rural background, socio-cultural factors, and largely prevalent local belief systems in the community rather than epilepsy alone.

Table 5: Association between QOL domains and KAP

QOL domains	Knowledge	Attitude	Practice
	Correlation Coefficient (P)		
Cognitive	-0.379 (.039)*	-0.168 (.374)	-0.192 (.310)
Emotional	-0.512 (.004)**	-0.204 (.279)	-0.004 (.983)
Behavioral	0.218 (.248)	-0.158 (.405)	-0.226 (.230)
Social	-0.411 (.024)*	-0.306 (.100)	-0.229 (.223)
Physical	0.429 (.018)*	-0.273 (.144)	-0.426 (.019)*
QOL overall	0.113 (.551)	0.037 (.844)	0.279 (.135)

**Correlation is significant at the 0.01 level. *Correlation is significant at the 0.05 level

Limitations

Given the relatively small sample size in this study, it may be insufficient data to find an association between the QOL of CWE and parental KAP. The subject selection was from an urban tertiary hospital and comprised school-aged children without co-morbidities; hence, the study results cannot be generalized to the entire epilepsy population.

CONCLUSION

The present study has made an attempt to examine parental awareness and its association with QOL among CWE from a developing country's perspective. Parental KAP needs improvement to enhance the overall QOL in our population. Hence, the current study accentuates the need for interventions that aim at enhancing knowledge and healthy practices among parents and encouraging empathetic acceptance by the neighborhood and schools to accommodate CWE which will have a significant beneficial effect in ensuring optimal therapeutic outcomes and better QOL in CWE.

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Conflicts of interest

There are no conflicts of interest.

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