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Original Research Article

Assessment of the quality of life in parents of children suffering from epilepsy

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ABSTRACT

Background: In case of paediatric epilepsy, parents are responsible for providing medicines, round the clock care to the child, while also sustaining their own needs and expectations from life. Socioeconomic status, interaction with healthcare workers, and the level of monetary and emotional support from external agencies play an important role in modelling the quality of life of these parents. The authors' objective was to assess the quality of life of parents of children suffering from epilepsy and evaluate the influence of demographic and clinical variables.
Methods: We conducted a cross-sectional analytical study at the out-patient department of our hospital. We recruited parents of epileptic children and those of children not suffering from any chronic illness and elicited demographic data, clinical history of illness, and QOL using the Quality of Life in the Child's Chronic Disease Questionnaire of parents in both groups followed by analysis of the data by applying appropriate statistical tests. We used Student t- test to find the significance of data on continuous scale and Chi-square test for discrete variables. One-way ANOVA test was performed to find the influence of various variables on QOL of parents.
Results: Male child, female caregiver, Hindu religion, illiterate parent, low monthly family income, residence in rural areas, GTCS type of seizure, frequent seizures during the day, and multiple medications negatively affected the QOL of parents.
Conclusions: To provide holistic care to epileptic children, we need to integrate and provide social, occupational, emotional, and financial help to their parents in an acceptable, affordable, and sustainable way.

Keywords: Epilepsy, Epileptic children, Paediatrics, Parents, Quality of life

INTRODUCTION

Of the 70 million epilepsy patients worldwide, about 70 to 90% are found in developing countries.[1] Today, the management of epilepsy revolves primarily around keeping the child free of convulsions and minimising the neurological sequelae. Apart from providing medicines for the treatment of disease, parents are responsible for providing round the clock care to the child, taking time out for regular follow-up visits, meeting the increased expenses, providing emotional support to the child, while also sustaining their own needs and expectations from life. The life satisfaction of parents of children suffering from other chronic, debilitating diseases like asthma and diabetes is mainly affected by inability to alleviate their children's symptoms and having to tell others about their disease respectively.[2-4] WHO defines quality of life (QOL) as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns.[5] Understandably, the socioeconomic status, interaction with healthcare workers, and the level of monetary and emotional support from external agencies play an important role in modelling the quality of life of parents with epileptic kids. India, being a developing country, has a huge fraction of its population belonging to the lower socioeconomic strata. Therefore, it is important for us to know how the Indian parents cope up with their children's illness and what problems are commonly faced by them. This study was designed to throw some light on how paediatric epilepsy affects the quality of life of parents who come to our tertiary care government hospital. This way, we can make amends in the currently practiced paediatric epilepsy management and set up special 'parent-aide' units to give them information regarding the disease, side-effects of the medications, link them to NGOs for monetary support, and organise group therapies for emotional support.

METHODS

Study design, location and duration

This was a cross-sectional analytical study design to give us an insight into different variables affecting the QOL of parents of children with epilepsy. This was a hospital-based study conducted at the epilepsy clinic and out-patient department (OPD), department of paediatrics of SSG hospital and Baroda Medical College at Vadodara, Gujarat, India. We randomly selected parents of children with epilepsy coming to the paediatric epilepsy clinic for group 1 and group 2, we selected parents who came to the paediatric OPD for minor ailments of their child. The study was conducted over a period of three months from May 2019 to July, 2019.

Inclusion criteria

Inclusion criteria for current study were; Group 1: Parents (or guardian/primary caregiver) of children aged 5-15 years suffering from epilepsy for at least six months. The operational definition of epilepsy was taken as two or more unprovoked seizures. (ILAE, 2017). Group 2: Parents (or guardian/primary caregiver) of children aged 5-15 years not suffering from any chronic disease. The operational definition of chronic disease was taken as one lasting for 3 months or more.[7]

Exclusion criteria

Exclusion criteria for current study were; Parents of children with other neurodevelopmental problems like mental retardation, autism, attention deficit hyperactivity disorder (ADHD), cerebral palsy, developmental delay, etc. Parents of children with other chronic medical conditions like asthma, chronic renal disease, chronic lung disease, chronic liver disease, thalassemia, hypothyroidism, hypertension, etc. Adults who were not the primary caregivers of children with epilepsy.

Sample size and sampling methods

From a previously published study, "Quality of life in children with epilepsy" in the Annals of Indian Academy of Neurology, the sample size for this study was derived at 60 for each group, i.e. 60 parents of children with epilepsy and 60 parents of children not suffering from any chronic illness.[8] From previously published studies, the sample size for this study was derived at 60 for each group by measuring the difference between two means, i.e. 60 parents of children with epilepsy and 60 parents of children not suffering from any chronic illness. The power of study was 80% at type 1 error=0.05 and type 2 error=0.20.

Instruments used for data collection, source of data, and data variables

After eliciting the medical history of children from parents and previous medical records for ruling out the exclusion criteria, parents were subjected to three questionnaires as follows: Questionnaire 1 for demographic profile: age, gender, education of child and parents, occupation of parents, family economic status (according to modified Prasad classification). Depending on their literacy, we asked some capable parents to write this information themselves while for those who were unable to read or write, we collected this information in the form of a semi-structured interview. Questionnaire 2 for clinical data of epilepsy: age of onset, type of seizure, frequency of seizures, age at diagnosis, age at starting medication, current medication. We asked the parents to elicit this information and for questions that they were not able to answer, we referred to the children's case files to procure the missing information. Quality of life questionnaire: We assessed the quality of life of the parents using the QLCCDQ (quality of life in the child's chronic disease questionnaire) developed by Farnik et al. to measure the quality of life in parents of children suffering from chronic disease and to evaluate and validate the new instrument. The QLCCDQ is available at an open access, online journal – Health and Quality of Life Outcomes.[9] This questionnaire consists of 15 questions and covers three major functioning areas, i.e., emotions (four questions), patients'-perceived symptoms (three questions), and role limitations (eight questions). The last major functioning area is subdivided into social (three questions), occupational (three questions), and family roles (two questions). The QLCCDQ is based on a seven-point Likert scale ranging from one (most limited or bothered) to seven (not limited or bothered). The responses were based on the parents' outlook on their children's illness and how it affected their life over a previous two-week period. Scores were allocated to the combination of answers for all major functioning areas and their subdivisions. After calculating the mean score for each area as well as the combined score, we found the relationship between different demographic variables and disease characteristics with the quality of life of the parents. We also established if there was any significant difference between the quality of life of parents of children suffering from epilepsy and quality of life of parents of children not suffering from any chronic disease.

Quality control

The translated version of the original questionnaire was piloted in the form of semi-structured interviews with ten parents from each group, i.e., ten parents of children with epilepsy and ten parents of children not suffering from a chronic illness, as a part of pretest validity testing. Cronbach's alpha for the translated version of the questionnaire was 0.895 thus, internal consistency and test-retest reliability was ensured.

Data confidentiality and analysis

We have refrained from mentioning the name of the parents and their child. Confidentiality of other personal information of parents and children was also maintained. All the data was analysed using appropriate statistical tests. A p value of <0.05 was considered significant assuming normal distribution of dependent variables and randomization of independent variables. Qualitative data was expressed in percentage and quantitative data were expressed as mean standard deviation. We used Student t-test (two tailed, independent) to find the significance of data on continuous scale and Chi-square test for discrete variables. One way ANOVA test was performed to find the influence of demographic and clinical variables on QOL of parents. Data was entered with the help of Microsoft Word and Excel and analysed by MedCalc Software Version 12.5.0.

RESULTS

Distribution of children according to age, gender, and education

In both groups, the majority of children belonged to the age group of five to ten years. In group 1, majority children were male (76.7%) while in group 2, the ratio of male (50%) to female (50%) children were equal. In the first group, the maximum number of children were non-school going (35%) while in group 2, 48.3% of children belonged to first to third standard.

Demographic distribution of parents

In group 1, 11(18.3%) parents were male while the rest were female (81.7%) while all were female (100%) in group 2. Most parents from both groups were Hindu (83.3% in group 1 and 75% in group 2) and housewives (70% in group 1 and 81.7% in group 2) and all the parents were married. With an average family income in group 1 = Rs. 6316.7 (84.3 USD) and in group 2=Rs. 7983.3 (106.5 USD), all families belonged to class five of modified Prasad classification of socioeconomic status on taking the current consumer price index (CPI) for Gujarat = 935.[10] The monthly income in both groups was mainly between Rs. 5,000-10,000 earned by 73.3% caregivers in group 1 and 38.3% in group 2. In group 2, 31.7% parents earned>Rs. 10,000 per month while only 10% earned this amount in group 1. In group 1, 55% of parents came from rural areas while 60% of parents from group 2 resided in cities (Table 1).

Clinical data

The average age of onset of epilepsy symptoms, its diagnosis, and treatment commencement was 6.97 years with maximum cases of GTCS (70%). 83.3% patients suffered from one to five episodes of convulsions per day. Most patients (61.7%) had no appreciable nighttime convulsions while 23 (38.3%) patients had one to five episodes at night. In group 1, 46 (76.7%) patients were on monotherapy while 14 (23.3%) patients were given polytherapy with no children having adverse effects of the drugs. In group 2, 29 (48.3%) patients presented with respiratory complaints while 19 (31.7%) patients had gastrointestinal complaints and 12 (20%) had other complaints and these symptoms were present for an average duration of 4.6 days.

Quality of life questionnaire

Under patient perceived symptoms the difference between the scores was significant for anxiety (p value=0.01) and guilt (p value<0.01) and not for worrying symptoms (p value=0.35). There was a significant difference between the average scores in patient perceived symptoms between the two groups (G1=4.18 with SD=1.54, G2=4.79 with SD=1.77) with p value = 0.05. Under emotions, the average scores for anxiety due to chronic illness, depression, shame and worry for the child's future, the difference between the scores was significant for all with a p value less than 0.01 for all. Under social role limitations, the difference between the scores was significant for limitations in household work (p value <0.01) and hobbies (p value < 0.01) and not for meeting friends/ relatives (p value=0.24). There was a significant difference between the average scores in social role limitations between the two groups (G1=5.66 with SD=0.96, G2=6.57 with SD=0.09) with p value <0.01. Under occupational and family role limitations, the difference between the average scores was significant with p values less than 0.01 for all. There was a significant difference between the overall average scores between the two groups (G1=4.01 with SD=1.09, G2=6.00 with SD =0.79) with p value <0.01 (Table 2).

Influence of demographic factors

Gender of the child (p value=0.01), gender of parent (p value<0.01), religion (p value=0.01), education of parent (p value<0.01), monthly family income (p value=0.05), and residence (p value<0.01) significantly affected the QOL of parents while age of child (p value=0.47), education of child (p value=0.07), age of parent (p value=0.20), occupation of parents (p value=0.08), and type of family (p value=0.08) had no significant effect on QOL of parents (Table 3).

Table 1: Demographic distribution of parents.

Parameters		Number in group 1 (N)	%	Number in group 2 (N)	%
Age (years)	21-25	2	3.3	3	5
	26-30	21	35	28	46.7
	31-35	24	40	12	20
	36-40	7	11.7	7	11.7
	41-45	3	5	6	10
	46-50	3	5	4	6.7
Gender	Male	11	18.3	0	0
	Female	49	81.7	60	100
Religion	Hindu	50	83.3	45	75
	Muslim	10	16.7	15	25
	Others	0	0	0	0
Education	Illiterate	4	6.7	0	0
	1-6 standard	14	23.3	10	6
	7-12 standard	42	70	45	75
	Graduate	0	0	5	8.3
Occupation	Housewife	42	70	49	81.7
	Farmer	7	11.7	5	8.3
	Labourer	8	13.3	3	5
	Vendor	3	5	0	0
	Teacher	0	0	3	5
Marital status	Married	60	100	60	100
	Unmarried	0	0	0	0
Type of family	Nuclear	42	70%	21	35%
	Joint	18	30%	39	65%
Monthly family income (Rupees)	<5,000	10	16.7	18	30
	5,000-10,000	44	73.3	23	38.3
	>10,000	6	10	19	31.7
Modified Prasad Classification	Class 1	0	0	0	0
	Class 2	0	0	0	0
	Class 3	0	0	0	0
	Class 4	0	0	0	0
	Class 5	60	100	60	100
Residence	City	27	45	36	60
	Rural	33	55	24	40

Table 2: Quality of life questionnaire (QOLQ).

Major functioning areas		Average score (G1)	Standard deviation	Average score (G2)	Standard deviation	P value
Patient perceived symptoms	Does the child show worrying symptoms	3.12	1.56	3.38	1.44	0.35
	Do you experience anxiety due to your Childs symptoms	3.48	1.59	4.20	1.42	0.01
	Do you feel guilty for the Childs symptoms	5.95	1.18	6.78	0.41	< 0.01
	Total	4.18	1.54	4.79	1.77	0.05
Emotions	Do you have anxiety due to the Childs chronic illness	3.48	1.48	4.53	1.98	<0.01
	Are you depressed due to the Childs illness	3.63	1.33	6.75	0.44	< 0.01
	Are you ashamed of the Childs illness	6.21	0.80	6.95	0.22	< 0.01

Continued.

Major functioning areas		Average score (G1)	Standard deviation	Average score (G2)	Standard deviation	P value
	Are you worried for the Childs future	4.08	1.73	5.05	1.89	<0.01
	Total	4.35	1.27	5.82	0.69	< 0.01
Role limitations - social	Meeting friends/ relatives	6.41	0.77	6.57	0.70	0.24
	Household activities	4.58	1.37	6.48	0.93	< 0.01
	Hobbies and entertainment	5.98	0.72	6.67	0.60	< 0.01
	Total	5.66	0.96	6.57	0.09	< 0.01
Role limitations - occupational	Limitation in work related activities	3.9	1.50	6.08	1.14	< 0.01
	Savings	2.77	1.37	5.93	1.22	< 0.01
	Miscellaneous expenses	4.18	1.50	6.17	1.21	< 0.01
	Total	3.62	0.75	6.06	0.12	< 0.01
Role limitations - family roles	Time spent with other family members	6.03	0.82	6.8	0.40	< 0.01
	Attention to other family members	6.43	0.59	6.8	0.40	<0.01
Total		6.23	0.28	6.8	0	< 0.01
Grand total		4.01	1.09	6.00	0.79	< 0.01

Table 3: Influence of demographics on quality of life of parents of children suffering from epilepsy.

Demographic variable		N	Mean score±SD	P value
Age of child (years)	5-10	38	3.90±1.35	0.47
	11-15	22	4.16±1.26	
Gender of child	Male	46	3.50±1.89	0.01
	Female	14	4.86±1.23	
Education of child	Non school going	21	3.75±1.45	0.07
	1-3	14	4.08±1.21	
	4-6	18	4.66±1.36	
	6-8	7	5.01±0.56	
Age of parent	21-25	2	3.35±0.19	0.20
	26-30	21	3.19±1.72	
	31-35	24	4.12±1.55	
	36-40	7	4.65±1.01	
	41-45	3	4.39±0.24	
	46-50	3	4.22±0.29	
Gender of parent	Male	11	4.96±1.76	<0.01
	Female	49	3.22±1.35	
Religion	Hindu	50	4.45±1.43	0.01
	Muslim	10	3.19±1.15	
Education of parent	Illiterate	4	3.01±0.27	<0.01
	1-6	14	3.76±1.72	
	7-12	42	5.13±1.55	
Occupation	Housewife	42	3.12±1.78	0.08
	Farmer	7	4.01±1.21	
	Labourer	8	3.99±0.89	
	Vendor	3	5.2±0.42	
Type of family	Nuclear	42	4.53±1.62	0.08
	Joint	18	3.71±1.72	
Monthly family income	<5,000	10	3.60±1.05	0.05
	5,000-10,000	44	4.47±1.21	
	>10,000	6	4.98±0.89	
Residence	City	27	4.79±1.34	<0.01
	Rural	33	3.43±1.47	

Table 4: Influence of clinical factors on quality of life of parents of children suffering from epilepsy.

Parameters		Number of children/ Number of years/Number of days	%	Mean score±SD	P value
Average age of onset of symptoms		6.97 years of age			
Type of seizure	GTCS	42	70	2.97±1.89	<0.01
	Absent	4	6.67	6.04±0.59	
	Focal	7	11.67	5.89±0.43	
	Atonic	3	5	3.93±0.71	
	Tonic	4	6.67	4.18±1.20	
	Clonic	0	0	-	
Frequency of seizures during the day	1-5	50	83.33	5.10±1.83	0.02
	6-10	4	6.67	4.20±1.06	
	11-15	6	10	3.01±1.45	
Frequency of seizures at night	0	37	61.67	3.90±1.26	0.24
	1-5	23	38.33	4.27±1.01	
	6-10	0	0	-	
	11-15	0	0	-	
Average age at diagnosis		6.97 years of age			
Average age at starting medication		6.97 years of age			
Duration of illness (years)	0.5-1	31	51.67	4.77±0.83	0.3
	1.5-2	7	11.67	4.38±0.70	
	2.5-3	12	20	4.42±0.58	
	>3	10	16.67	4.94±0.95	
Current medication	Monotherapy	46	76.67	4.91±1.40	<0.01
	Polytherapy	14	23.33	3.59±0.97	
Adverse effects of drugs		0	0	-	-
Present illness (G2)	RTI	29	48.33	-	-
	GIT	19	31.67	-	
	Others	12	20	-	
Average duration of present illness (G2)	-	4.58 days	-	-	-

Influence of clinical factors

Type of seizure (p value<0.01), frequency of seizures during the day (p value=0.02), and current medication (p value <0.01) significantly affected the QOL of parents while frequency of seizures at night (p value=0.24) does not have any significant effect (Table 4).

DISCUSSION

Demographic and clinical data

In our study, 76.7% children with epilepsy were male with an average age of 8.6 years (with a range of 5 to 15 years) out of which 35% were non-school going. Im et al study found that the average age of parents was 41.1 years with 96.7% females and 83.9% belonging to nuclear families.[11] In our study, the average age of parents of children with epilepsy was 30 years with 81.7% females, 100% married, and 70% belonged to a nuclear family. Majority of parents in our study belonged to the age group 31-35 years (40%) followed by 26-30 years (35%) which is comparable to Mishra et al study which had 68.1% parents in 20-30 years age group followed by 26.5% in >30 years age group. In our study, all participants belonged to class 5 of Modified Prasad classification for socioeconomic status. Whereas Mishra et al study had majority of participants (57.3%) belonging to the upper lower socioeconomic class followed by lower middle class (30.8%).[12] Our study showed more Hindus (83.3%) in group 1 as compared to Muslims (16.7%) similar to Mishra et al study with 88.1% Hindus, 8% Muslims, and 3.9% christians.[12]

In our study, 70% caregivers were housewives while the rest worked as either farmers, labourers or vendors. Mishra et al study had 77.7% housewives/ unemployed and 22.3% employed caregivers.[12] In our study, 70% of parents in group 1 had studied till 7-12th standard, 23% till 1-6th standard, and the rest were illiterate.

Comparison of QOL of parents between group 1 and group 2

There was a significant difference between the two groups in scores given to anxiety due to child's symptoms, anxiety due to chronic illness, guilt, depression, worry for the child's future, limitations in household activities, hobbies/ entertainment, work related activities, savings, miscellaneous expenses, time with other family members, attention to other members, time for self, and not being able to leave the child alone. Steps taken to redeem these factors may have a positive impact on the QOL of caregivers. Since the majority of caregivers coming to the hospital were females and most of them were housewives, household chores were significantly affected in group 1. Limitations on occupation and financial savings were the most affected in group 1 as compared to the control group.

Influence of demographic and clinical data on QOL of parents

Parents of male child were more adversely affected in terms of quality of life as compared to parents of female child (p value=0.01) probably as a result of stereotypically giving more importance to the ailments of male child in certain sections of the populations. Similar to studies by Lai et al and Pinquart et al, we obtained significantly higher scores from male caregivers as compared to their female counterparts.[13,14] Upon further questioning, we concluded that since females usually are solely responsible for childcare, their QOL is more affected by the chronic illness of their child. There was a significant difference between the QOL of Muslim and Hindu caregivers with the former being more adversely affected (p value=0.01). Educated parents showed to have a significantly lesser burden of their child's illness as compared to the lesser educated and illiterate (p value<0.01). Similar trends are seen in Tanriverdi et al study (p value<0.01 on Parental Stress Scale).[15] This is because illiteracy hinders the ability of parents to understand the diagnosis of their child's illness and also affects their compliance to treatment and follow-up. Since all participants belonged to class 5 of modified Prasad classification, income show only a weak correlation with QOL (p=0.05) as compared to other significant findings. Household income did not significantly affect the QOL of caregivers in the study by Lai et al (p value=0.10) but personal income affected QOL with a p value of 0.02.[13] There is a significant discrepancy in the QOL of parents residing in urban and rural areas (p value<0.01) which can be attributed to lesser access to healthcare and lower socioeconomic status of those residing in rural areas. Parents of children with generalized tonic clonic seizures have very low scores on QLCCDQ (p value<0.01) mainly due to worrying and more dramatic symptoms and a greater adverse effect on brain functions.[16] Polytherapy has a direct correlation with a detrimental effect on the QOL of parents due to more severe disease affecting the child and also due to the high cost of medications. (p value<0.01) Similarly, as frequency of seizures during the day increases, the stress levels of parents go significantly up as well (p value=0.02).

CONCLUSION

From this study, we conclude that maintaining the quality of life of caregivers of sick children is an important hurdle in the management of paediatric epilepsy and needs to be studied in detail before appropriate actions can be taken. We can integrate patient management with district rehabilitation centres and provide a counsellor to the parents to help them cope up with their child's morbidity. We may also inform the parents about the ongoing government schemes and financial help programs best suited for them depending on their demographic profile. In addition to the medical aspects of epilepsy, parents need to be sensitized towards the consequences of long-term hospital stay on sick kids and also their siblings who tag along for visits. Further research is needed to understand this aspect of patient care better and also to look for ways how parents can prepare their children for repeated and lengthy hospitalizations.

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