

Assessment of Stress, Distress and Quality of Life in Children with Epilepsy aged 4-18 years: A Cross Sectional Study

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ABSTRACT

Introduction: Children with epilepsy often experience difficulties in cognitive, emotional, social, physical functioning, and experience hurdles in academics, sports, and other extracurricular activities. There is a scarcity of published data regarding assessment of stress, distress, and quality of life in children and adolescents for a better understanding of the psychological aspects to implicate the behavior management techniques in a dental environment. **Methodology:** A cross sectional questionnaire study was done for 40 children aged 4-18 years with epilepsy. Perceived stress scale was used for the assessment of stress, and Kessler's psychological distress scale was used for the assessment of distress in children (4-11 years) and adolescents (11-18 years). A 55 item Quality of Life in Childhood Epilepsy Questionnaire: QOLCE-55 Version 1.0 and 48 item questionnaire, Quality of Life in Adolescents: QOLCE-AD-48 Version 1.0 was used to understand the quality of life. Kruskal-Wallis test and Independent t-test were done for statistical analysis of collected data. **Results:** Adolescents (11-18 years, mean value=2.4222) showed more distress than children (4-11 years, mean value=2.059) (P value=0.00). Children showed better social functioning (mean value=3.3878) and worst cognitive functioning (mean value=2.7175). Females (mean value=3.5455) had better cognitive functioning than males (mean value=2.7175) (P value=0.00). Adolescents could better adjust with the effects of antiepileptic medication (mean value=3.4352) than the general health (mean value=2.5489) (P value=0.00). **Conclusion:** Children have increased distress and impaired quality of life due to repeated seizures and limited social, emotional, cognitive, and physical functioning. Children (4-11 years) have better social functioning, and Adolescents (11-18 years) could adjust better with the side effects of anti-epilepsy medications.

KEYWORDS: Epilepsy, Stress, Distress, Quality Of Life

INTRODUCTION

The leading neurological condition which is seen in children with special health care needs is epilepsy, which compromises their quality of life.^{1,2} Children with epilepsy, since their preschool age, often experiences difficulties in cognitive, emotional, social, physical functioning, and experience hurdles in academics, sports, and other extracurricular activities.^{3,4} They have difficulty in life due to depression, low self-confidence, lack of energy, concentration due to frequent seizure attacks, the side effect of antiepileptic medications.⁵⁻⁸ It is extremely important to assess the quality of life of children and adolescence seeking dental treatment. It is extremely important to treat the children cautiously in the dental office and for the selection of the behavior management techniques without causing additional emotional stress.

Stress is the interpretation of threat, anxiety, discomfort,

emotional tension, and difficulty in adjustment to the environment.⁹ Stress is developed in children and adolescents due to repeated epileptic attacks, side effects of medications, inferiority complex while comparing themselves with other children of the same age. It often leads to negative dental behavior and stress-induced seizure attacks on the dental chair. In distress, a person cannot completely adapt to stressors, and the state is represented by maladaptive behaviors.¹⁰ The distress often leads to intellectual impairment in such children, which leads to difficulty in behavior management.

There is a scarcity of supporting literature regarding the effect of stress, distress and quality of life in children and adolescents suffering from epilepsy. So, a unique cross sectional questionnaire study was done for assessment of stress, distress, and quality of life in children and adolescents for better understanding of the emotional,

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social, cognitive, and physical functioning of children and the psychological aspects to implicate behavior management techniques in a dental environment.

MATERIALS AND METHODS

A cross sectional questionnaire study was done for 40 children aged 4-18 years diagnosed with epilepsy who visited the department of Special Health Care Needs seeking dental treatment. Test samples were divided into 2 groups, group A=children between 4-11 years, group B= adolescents between 11-18 years. After taking consent from the parents, the children were assessed for stress, distress, and quality of life. Caregivers were allowed to answer the questions on behalf of the children with tender age, with intellectual impairment and delayed milestones. Perceived stress scale, a 10 item questionnaire was used for assessment of stress in children and adolescents.^[11] 10-item questionnaire scale, Kessler's psychological distress scale was used to know the distress experienced by the children with epilepsy.^[12] The percentage distribution of each question was done and compared, and the stress and distress between group A and group B were compared.

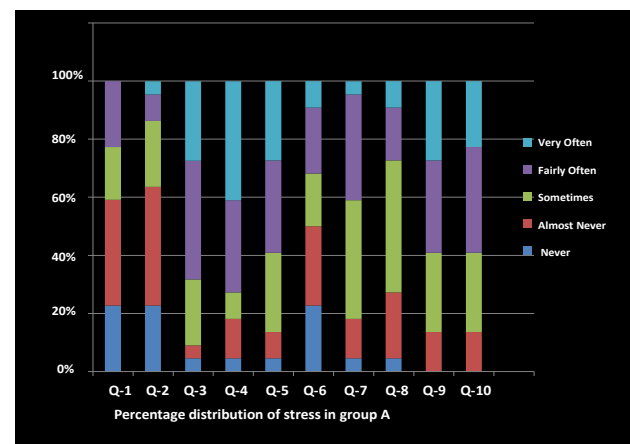
A 55 item questionnaire, named Quality of Life in Childhood Epilepsy Questionnaire: QOLCE-55 Version 1.0,^[13] was used to understand the quality of life in children with epilepsy aged between 4-11 years. QOLCE-55 has four components-a)Cognitive functioning (22 items), 2.Emotional functioning (17 items) 3.Social functioning (7 items) and 4.Physical functioning (9 items). The mean value of each question was assessed, and the functioning of each group was compared to each other using independent t- test and non-parametric test named, Kruskal –Wallis test.

A 48 item questionnaire, Quality of Life in Adolescents: QOLCE-AD-48 Version 1.0 (English).The questionnaire comprised mainly two sections-25 questions for checking general health (regular daily activities, feelings in the last 4 weeks, mental and language problems, family and friends support).Another section consisted of 12 questions on the effects of anti-epilepsy medications. The mean score of the two groups was compared to each other in 18 adolescents between ages 11-18 years. Questions 38-48 were comprised of the children's perception of epilepsy, feeling about themselves, and attitude towards their condition. The percentage distribution of the questions was done to assess the response based on each option. If $P \leq 0.05$, the differences were statistically significant.

RESULTS

Percentage distribution of each question for stress and distress assessment was assessed in group A, and group B. Stress assessment showed a total of 37.5% children responding that they were almost never upset because something unexpected happened in their life. 36.4% of children from group A and 38.9% of children from group B responded that they were almost never upset. A total of

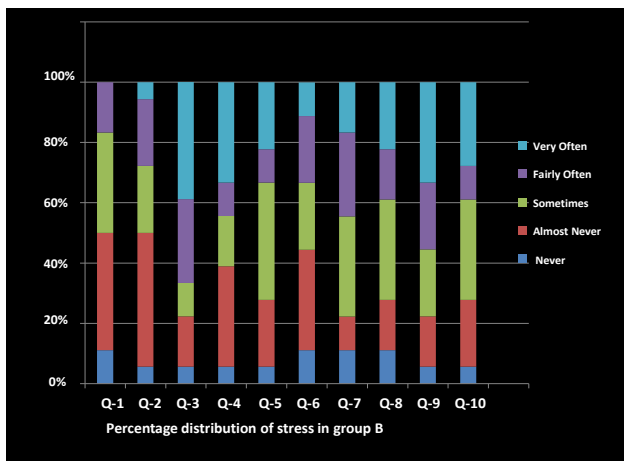
42.5% children responded that almost never they were unable to control important things in life. 40.9% of children from group A and 44.4% of children from group B felt the same. A total of 32.5% children in last month felt nervous and stressed very often. 27.3% of children from group A and 38.9% of children from group B felt nervous, stressed most of the time. 37.5% children felt confident about their ability to handle personal situations. 32.5% children thought that sometimes things were going their way. 31.8% children from group A thought fairly often, things were going their way, and 38.9% of adolescents confused sometimes things were under their control. 30.0% of children almost never felt that they could not cope with all the things they had to do. A total 37.5% of children could sometimes control irritations in their life 40.9% of children from group A 33.3% of children from group B could sometimes control their irritations in life. A total of 40.0% children could sometimes feel that they were on top of things. 45.5% of children from group A 33.3% of children from group B felt that they were on top of things sometimes. Total 30.0% were very often angered because things were out of their control. 27.3% of children from group A and 33.3% of children from group B were very often angered. 25.0% children very often felt that difficulties were piling up so high that they could not overcome them. 36.4% of children from group A fairly often felt, and 33.3% of children from group B sometimes felt that difficulties were piling up beyond their control (Graph 1).



Graph 1: Percentage distribution of stress in group A

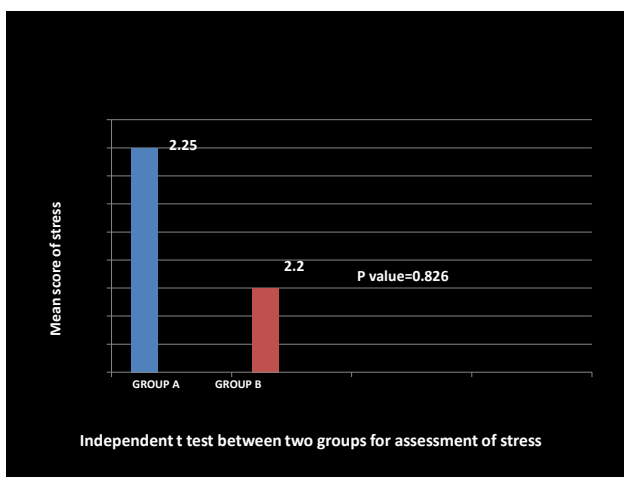
Assessment of distress showed total 40% of children responded that they were tired out of no reason none of the time and 10% of children answered that they were tired most of the time. 45.5% children from group A told that they were never tired, and 38.9% children from group B replied that they were tired a little of the time. A Total of 32.5% of children responded that they were nervous sometimes in the last 30 days. 36.4% of children from group A told that they were nervous some of the time and 27.8% of children from group B replied that they were nervous most of the time. 32.5% of children told that they were so nervous in the last 30 days that nothing could cheer them up. 36.4% children from group A told that they were never so nervous that they could not be calmed

down, and 44.4% of children from group B replied that sometimes they felt uncontrollable nervousness. A Total 35.0% of children responded that felt hopeless sometimes in the last 30 days. 31.8% of children from group A and 38.9% of children from group B replied that they felt hopeless some of the time. A total 35% of children told that they were felt restless and fidgety a little of the time in the last 30 days. 45.5% of children from group A told that they never felt restless and 44.4% children from group B replied that a little of time they felt restless. 2.5% children told all of the time they felt severely restless that they could not sit still. 32.5% of children told felt depressed a little of time in the last 30 days. 36.4% of children from group A and 27.8% of children from group B felt depressed a little of time. 37.5% of children sometimes felt that everything was an effort in the last 30 days. 36.4% of children from group A and 38.9% of children from group B felt the same sometimes. 35.0% of children sometimes felt so sad that nothing could cheer them up. 40.9% of children from group A and 27.8% children from group B felt sad (Graph 2).



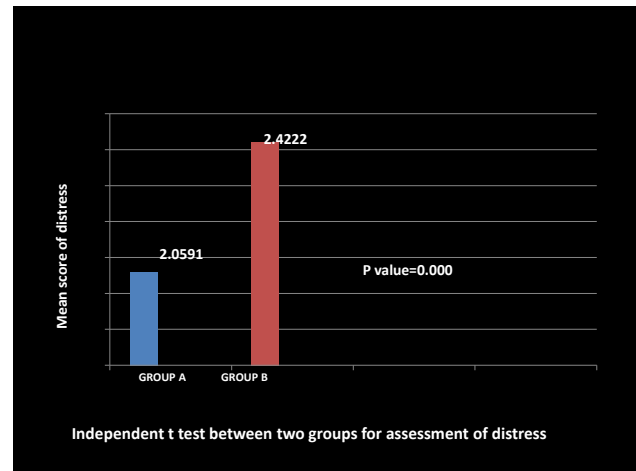
Graph 2: Percentage distribution of stress in group B

When the Independent t-test between the total mean score of two groups was done for assessment of stress group A showed a mean score of 2.25 and group B showed a mean score of 2.2, but the difference was not statistically significant (P value=0.826) (Graph 3).



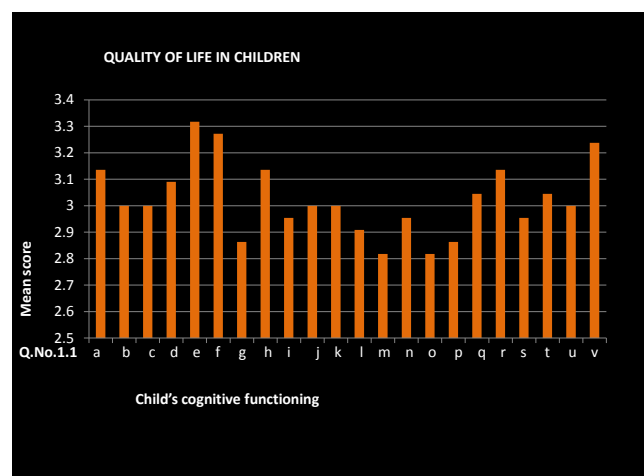
Graph 3: Independent t test between two groups for assessment of stress

Independent t-test between the total mean score of two groups was done for assessment of distress group A showed mean score of 2.0591, and group B showed a mean score of 2.4222, but the difference was statistically significant (P value=0.00) (Graph 4).



Graph 4: Independent t test between two groups for assessment of distress

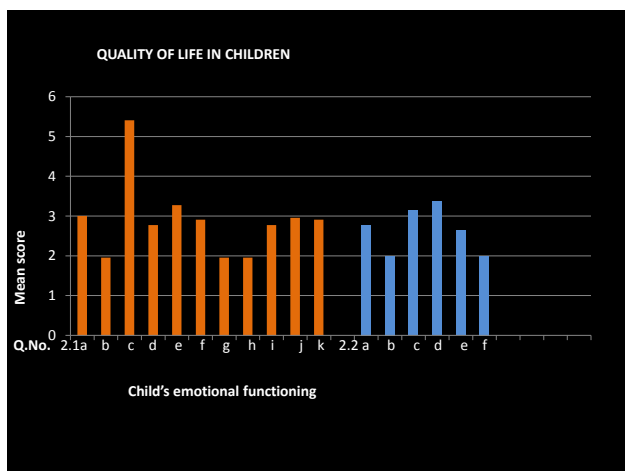
When the Quality of Life in Childhood Epilepsy Questionnaire: QOLCE-55 was analyzed, scores were given for 1, 2, 3, 4, 5, 6 for very often, fairly often, sometimes, almost never, never and not applicable. A higher value of the mean score for each question showed a better quality of life. When the cognitive functioning of children were analyzed compared to other children of their age it was concluded that children found it most difficult to do one thing at a time (mean value = 2.8636), remembering things he studied hours or days before (mean value = 2.818) and finding the correct words (mean value = 3.3182). Children found comparatively easier to concentrate on a task (mean value = 2.818) and to talk (mean value=3.2381) (Graph 5).



Graph 5: Child's cognitive functioning

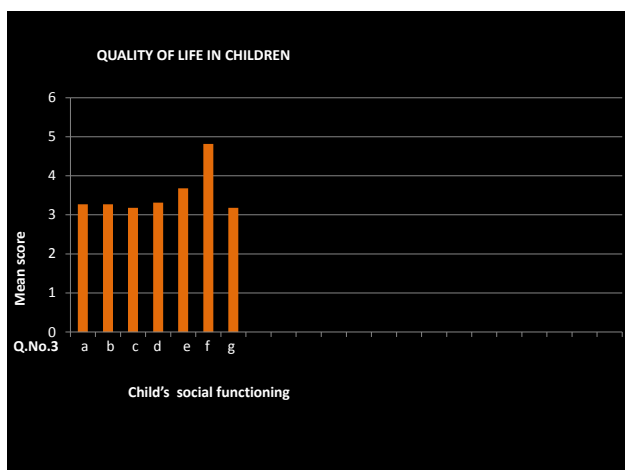
When children's emotional functioning was analyzed often, they felt happy (mean value=1.9545), excited in doing something new (mean value=1.9545), and felt pleased in achieving something (mean value=1.9545). Children could be easily angered (mean

value=2.0) and demanded lots of attention (mean value=2.0) (Graph 6).



Graph 6: Child's emotional functioning

When the social functioning was found, it was concluded that compared to other children, they limited their leisure activities (mean value=3.1818), but did not fright other people (mean value=4.8182) (Graph 7).

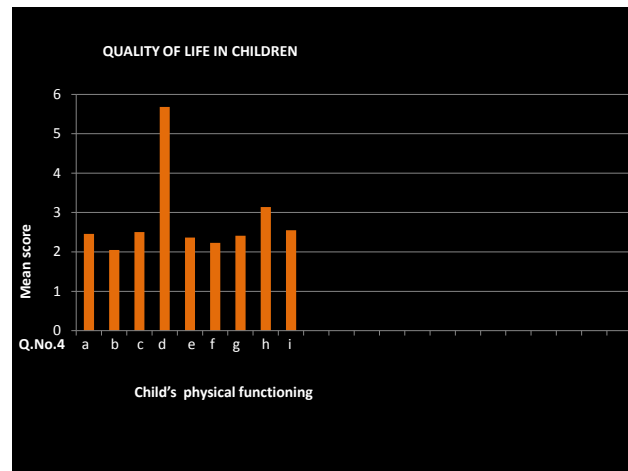


Graph 7: Child's social functioning

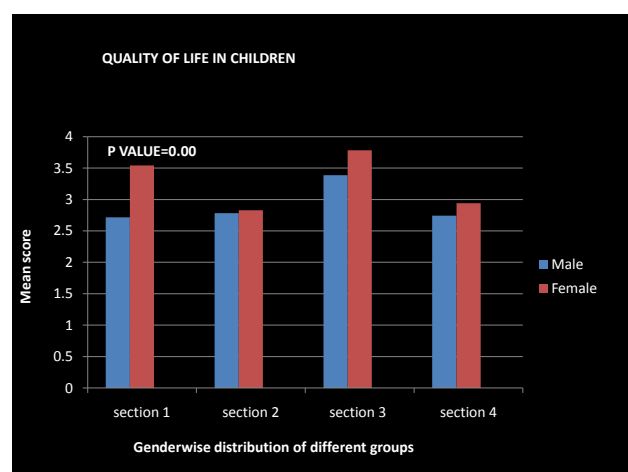
When the physical functioning was analyzed, children could play freely and easily like other children of their age (P value=2.0455), and they stayed out overnight with friends and family (P value=2.2273). No children could swim (P value=5.6818) and the children seldom went to parties without parent's supervision (P value=3.1364) (Graph 8)

When the cognitive, emotional, social, and physical functioning of children were compared using Kruskal – Wallis test, their social functioning (total mean value=3.3878) was better, and cognitive functioning was worst (mean value=2.7175). The difference between the four groups was statistically significant (Graph 9).

When cognitive functioning was compared between gender-wise, females (mean value=3.5455) had better functioning than males (mean value=2.7175) (P value=0.00). Males and females did not have a

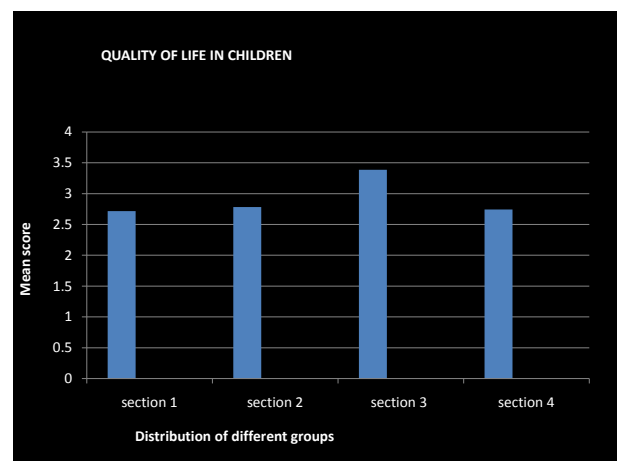


Graph 8: Child's physical functioning



Graph 9: Gender wise distribution of different groups

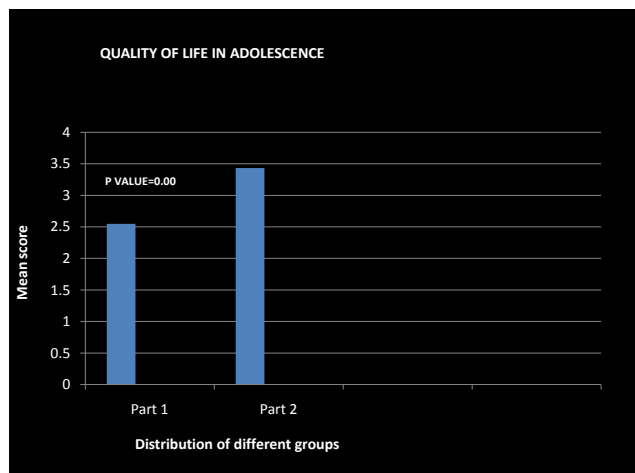
statistically significant difference when emotional, social, and physical functioning were analyzed (Graph 10).



Graph 10: Assessment of quality of life in children, distribution of different groups

When the quality of life for adolescents (QOLIE-AD-48) was assessed for 18 children between 11-18 years, it was found that children could better adjust with the effects of antiepileptic medication (mean value=3.4352) than the

general health (mean value= 2.5489).The difference between the two groups was statistically significant (P value=0.00) (Graph 11) .

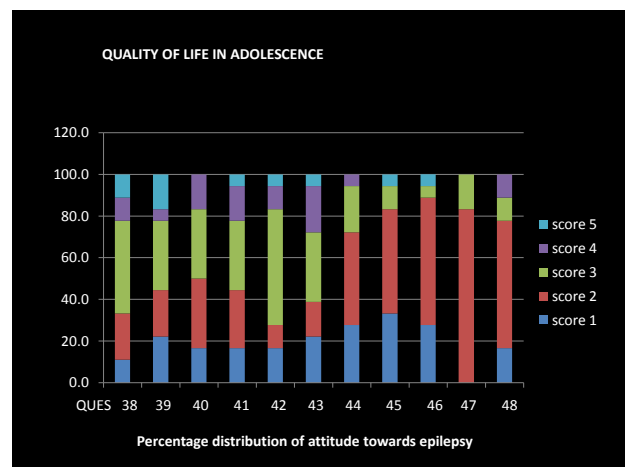


Graph 11: Assessment of quality of life in adolescents, distribution of different groups

When the percentage distribution was compared 61.1% children told that their health was fair and 50 % children told their health is somewhat worse now.44.4% children participated in heavy activities as running often ,22.2% in moderate activities such as walking to school very often but 38.9% of children never done the daily activities like going to school alone.44.4% children very often found difficulty in doing school activities, chores or sports and 44.4 % of children found difficulty with teachers in school.27.8% children had trouble concentrating on activity most of the time ,and 38.9% had a problem in concentrating on reading all of the time.38.9% found difficulty in thinking most of the time,55.6% of children found difficulty in figuring out and solving problems all of the time, 66.7% of children found difficulty in solving complicated problems and difficult homework. When questions were asked about the help and support from friends and family 33.3% children very often got help from friends, family when needed and 33.3% children very often got other people's help to sort things out.27.8% children very often got someone to accept their bad and good points.

When the effects of anti-epilepsy medications were assessed 38.9% of children never limited their social activities compared to other children of same age.38.9% children never felt isolated because of seizures,44.4% children never missed classes because of seizures or medications.44.4% children never felt embarrassed because of taking medications, 55.6% children never felt that seizure and medication limited their independence. 27.8% children very often felt that epilepsy medication limited their sports, physical activities.27.8% children felt very bad about their appearance and, 33.3% of children found very good about their appearance. 38.9% of children were not at all bothered by the limitations set by their parents/family due to medications. 44.4% children disagreed that they were less than perfect because of epilepsy,33.3% disagreed that they will not get a job

because of epilepsy.33.3% children disagreed that their epilepsy will make them mentally unstable.44.4% children felt a little bad that they had epilepsy; 61.1% of children often felt that epilepsy kept them from starting new things in life (Graph 12).



Graph 12: Percentage distribution of attitude towards epilepsy

DISCUSSION

Epilepsy is the most common neurological condition, which is seen in children with special health care needs which often limits their social life. Parents often deny the history of epilepsy and avoid discussing the social, emotional life of their children because of social stigma. As a pediatric dentist, it is our duty to understand the stress and distress of children's life, which prepares us for a holistic treatment and ensure a better quality of life. This study is unique because the answers depend upon the reports of the child as well as their caregivers with the questions covering the wide horizon related to the quality of life with limited literature regarding quality of life in children. Stress, distress, and quality of life of children were assessed based on a questionnaire. According to WHO, the domains of quality of life consist of physical functioning, including independence in daily activities; the psychological domain, involving emotional, cognitive, and behavioral functioning and social functioning.¹⁴

Epileptic children have more stress in their life because of repeated seizures, side effects of medications and compromised social life. In our study, the children with intellectual impairment showed poor social, physical, emotional, and cognitive functioning and severe stress and distress in their lives. The adolescents from group B felt more nervous, stressed, and could be angered more easily compared to the children between 4-11 years because of the pressure of study and emotional and intellectual development to understand the responsibilities. Children from group A could better control irritations in their lives and felt happy most of the time because of their carefree and tension-free attitude. But, when the overall stress was compared between group A and group B, the difference between the total mean score was not statistically significant (P value=0.824).

When the total mean score between group A and group B was analyzed, adolescents (11-18 years) showed more distress in their lives, and the difference was statistically significant (P value-0.00). The children from group B were more tired, more nervous, and hopeless about them and felt everything was an effort compared to the children of group A.

When the cognitive, emotional, social, and physical functioning of children were compared, their social functioning was better. They did not isolate themselves from the peer, could mix well with other children and epilepsy, and its effects did not affect their social interaction with friends and family. Cognitive functioning was affected in epileptic condition. Children could not solve problems easily, found difficulty in doing tasks, remembering things, and understanding directions.

The adolescents could better adjust to the effects of antiepileptic medications and their side effects because of adaptation to their lives. Some parents switched their children to ayurvedic therapy instead of antiepileptic medications in search of a better quality of life and to avoid the side effects of the medications.

A study done by Ovšonková et al. showed children finding difficulty in doing demanding activities, but they could do their homework, school assignments properly and did not miss classes due to epilepsy. In our study, girls had better cognitive functioning compared to boys similar to the result of the study done by Ovšonková et al.¹⁵

Several research studies support that children need social support from parents and family for a better quality of life.^[15] Thomas and Nair suggested that epilepsy is a normal disease until the person has a seizure in public.¹⁶ According to Sherman et al. epileptic people isolated themselves during their leisure time, family functions, or in professional life, which contradicted the results of our study.^[17] In a study done by Vágnerová et al. adolescents with chronic epilepsy found their limitations and values during finding a job similar to our study.¹⁵

In a study done by Adla et al. quality of life was compared with the type of seizure, frequency, type of antiepileptic medication, and education of caregiver. Cognitive functions were affected more severely, physical functions were better, children taking Sodium valproate, and Iminostilbene had a better quality of life than Phenytoin and Clobazam.¹⁸

Abbas et al. studied the quality of life of Sudanese children using a questionnaire by Petter Hoare in which the parental concern was evaluated, and it was concluded that epileptic children have the compromised quality of life.^[19] A study by Aggarwal et al. energy levels, language, and attention became better with the increase in age, and younger children had lower anxiety levels.²⁰ In another study, people with uncontrolled epilepsy had a higher level of psychological distress (100%) compared to controlled epilepsy.²¹

CONCLUSION

It is concluded analyzing this study, that children have increased stress and distress and impaired quality of life due to repeated seizures and limited social, emotional, cognitive, and physical functioning with different age groups. Girls have better cognitive functioning, and children (4-11 years) have better social functioning. Adolescents (11-18 years) could adjust better with the side effects of anti-epilepsy medications. This study can be a baseline for the health care professionals to further continue research with larger samples on stress, distress, and quality of life assessment in children suffering from epilepsy. Understanding these concerns definitely helps in accomplishing dental treatment in an empathetic and efficient way.

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