

# Quality of life in paediatrics with intractable epilepsy in a large paediatric university hospital in Riyadh, Saudi Arabia

Waleed A. Altwajiri<sup>1</sup>, Buthaina J. Yahya<sup>2</sup>, Lama B. Alasmari<sup>2</sup>, Rofan N. Alsultan<sup>2</sup>, Shoq M. Alsuhaibani<sup>2</sup>, Rawan M. Alsemih<sup>2</sup>, Afaf K. Moukaddem<sup>3</sup>

<sup>1</sup>Department of Pediatric Neurology, King Abdullah International Medical Research Center (KAIMRC), Riyadh, <sup>2</sup>Departments of College of Medicine and <sup>3</sup>Medical Education, King Saud bin Abdulaziz University for Health Sciences, Riyadh, Saudi Arabia

## ABSTRACT

**Context:** Epilepsy is said to be intractable when two or more trials of anticonvulsants fail to control the seizures. Literature suggests that intractable epilepsy carries a higher morbidity than controlled epilepsy in children and their caregivers. **Aims:** The aim of this study is to assess the quality of life (QOL) in children with intractable epilepsy (IE) in KASCH, a tertiary care hospital in Riyadh, Saudi Arabia. **Settings and Design:** This is a cross-sectional study utilizing a self-administered questionnaire filled by caregivers of epileptic patients visiting the outpatient neurology clinics. **Methods and Materials:** The quality of life in childhood epilepsy (QOLCE-55) scale examined four domains of life: cognitive, emotional, social, and physical. The sample consisted of 59 parents whose children aged 4-14 of either sex. **Statistical Analysis Used:** The collected data were analyzed by Statistical Package for the Social Sciences (SPSS) version 22. **Results:** The mean age of children was 8.9 (SD = 2.9). The mean QOL was 52.8 (SD = 12.9), which reflected a poor QOL. Age was not related to the QOL. Gender was significantly associated with the total and social scores, ( $P = 0.04$ ) ( $P = 0.001$ ), respectively. Out of all comorbidities, global developmental delay (GDD) and encephalopathy were significantly associated with the QOL ( $P < 0.05$ ). **Conclusions:** Intractable epilepsy impacted all functioning domains of life rendering a poor QOL. Males have reported better QOL and social functioning compared to females. Children with GDD and encephalopathy showed lower well-being.

**Keywords:** Epilepsy, intractable, pediatric, quality of life

## Introduction

Epilepsy is a neurological disease characterized by two or more unprovoked seizures. It is an abnormal electrical firing of neurons.<sup>[1]</sup> Depending on which part of the cortex the excessive electrical discharge affects, seizures are divided into two types. One type is focal seizures, which affect only one cerebral hemisphere. Focal seizures can be further classified depending

on the presence of aura, motor features, and awareness or responsiveness.<sup>[1]</sup> Generalized seizures, on the other hand, affect both cerebral hemispheres, and are always accompanied by loss of consciousness.<sup>[1]</sup> Some seizures originate in one hemisphere then gradually spread to the whole cortex; in this case they are called secondary generalized seizures.<sup>[1]</sup> It is important to highlight that a single seizure is not necessarily indicative of epilepsy.<sup>[2]</sup> Seizures could be provoked by other factors such as sleep deprivation, alcohol withdrawal, medications, and infections. Ten percent of the world's population will have at least one seizure, and one-third of whom will develop epilepsy.<sup>[3]</sup> The incidence of epilepsy is age-dependent. It most commonly starts at childhood

**Address for correspondence:** Dr. Waleed A. Altwajiri, P.O box 11593 Riyadh - 53983, Saudi Arabia. E-mail: TuwajiriW@ngha.med.sa

Received: 15-06-2020

Revised: 05-09-2020

Accepted: 15-09-2020

Published: 30-11-2020

### Access this article online

#### Quick Response Code:



**Website:**  
www.jfmipc.com

**DOI:**  
10.4103/jfmipc.jfmipc\_1172\_20

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**How to cite this article:** Altwajiri WA, Yahya BJ, Alasmari LB, Alsultan RN, Alsuhaibani SM, Alsemih RM, *et al.* Quality of life in paediatrics with intractable epilepsy in a large paediatric university hospital in Riyadh, Saudi Arabia. *J Family Med Prim Care* 2020;9:5523-36.

or after the age of 60, while middle-aged people are less likely to develop epilepsy.<sup>[1,4,5]</sup> Epilepsy is a common neurological disorder where every year 50 – 70 cases in 100,000 population are reported.<sup>[4,5]</sup> In around 70% of cases, epileptic seizures are controlled on antiepileptic drugs (AEDs). Intractable epilepsy is defined as the failure of two or more AEDs trials, provided that optimal doses and the right choice of AED are achieved.<sup>[6]</sup> Depending on the way of development into intractable epilepsy, drug resistance can be categorized into *de novo*, progressive, and waxing and waning.<sup>[6]</sup> *De novo* is when the drug resistance occurs before any AEDs were given. Progressive drug resistance is when epilepsy used to be but no longer controlled by AEDs. The waxing and waning is the state of interchanging between drug responsiveness and resistance.<sup>[6]</sup>

After the failure of one appropriate trial, only 11% of patients become seizure-free, while 3% become seizure-free after the failure of the second appropriate trial.<sup>[7]</sup> Studies have shown that the quality of life (QOL) in patients with intractable epilepsy is less optimistic than in those with controlled epilepsy.<sup>[8]</sup> In countries where sufficient diagnosis and treatment are obtainable, 30-40% of patients with epilepsy have seizures that cannot be controlled with medications.<sup>[9]</sup> A study conducted in Canada to assess the QOL in pediatrics with intractable epilepsy showed the negative impact on physical, emotional, cognitive, and social aspects of life.<sup>[10]</sup> Physically, the major complaint was persistent fatigue and need for sleep. Emotionally, anger and frustration scored higher (67%) than fear (49%) and depression (45%). Cognitively, 70% reported memory and learning problems, and social isolation was highly reported.<sup>[10]</sup> Another study conducted in Sudan in 2011 also measured the QOL in pediatrics and their caregivers.<sup>[11]</sup> Results showed a significant low QOL in both the pediatrics and their caregivers. The study reflected the caregivers' commonest concerns. Socially, it was the increased supervision that their children needed compared to other children. Physically, it was self-harm and psychologically, it was the moodiness.<sup>[11]</sup> Locally, a study was conducted in three hospitals in Jeddah to assess the impact of epilepsy on children.<sup>[12]</sup> The cause of seizure, monthly income, and child's nationality were significantly associated with QOL. Hypoxic-ischemic encephalopathy (HIE) and cerebral palsy (CP) were strongly linked with lower QOL. More than 94% of families earning <5000 SAR a month reported lower QOL. Furthermore, non-Saudi children compared to Saudis had lower QOL.<sup>[12]</sup>

Epilepsy has a significant impact on the everyday life of affected individuals.<sup>[13]</sup> This mandates a multidisciplinary team utilizing all levels of care. Primary care physicians can help improve the QOL by offering continuous counseling to the patients and their parents, find out their expectations and concerns, assess treatment adherence and side effects, and refer to a specialist if indicated. The morbid fear of having an unpredictable seizure not only affects the patients' physical function, but also emotional well-being, cognitive function, and social function. This study assessed QOL in pediatrics with intractable epilepsy at King

Abdullah Specialist Children Hospital, Riyadh, Saudi Arabi using The Quality of Life in Childhood Epilepsy (QOLCE-55) scale.<sup>[14]</sup>

## Subjects and Methods

### Study design and settings

This is a cross-sectional study utilizing a self-administered questionnaire filled by caregivers of epileptic patients visiting the outpatient neurology clinics between August 2018 and January 2019 at King Abdullah Specialist Children Hospital (KASCH) in Riyadh, the first specialized children hospital in Saudi Arabia (Institutional Review Board approval was obtained on 16-5-2018).

### Identification of study participants

This study included a total of 59 caregivers of both genders of Saudi pediatrics aged 4-14 years with intractable epilepsy in KASCH, Riyadh. Non-probability convenience sampling was used in the selection of the subjects. Caregivers of children with intractable epilepsy who agreed to participate in the study were included.

### Study instrument and data collection process

Data were collected by the co-investigators using a self-administered questionnaire. This Questionnaire is composed of a demographic section with characteristics of the epileptic patients like age (in years), gender, and presence of comorbidities. As for QOL, QOLCE-55 was used. QOLCE-55 is a validated questionnaire recommended by The National Institute of Neurological Disorders and Stroke Common Data Elements to assess the QOL of patients with epilepsy. Parents must answer 55 questions regarding how often do their children experience certain problems compared to other children of their age during the past 4 weeks. The QOLCE-55 sections' included the following domains: cognitive, emotional, social, and physical functioning. Each item is on a 6-point Likert scale and includes anchors that are subjectively rated based on perceived QOL (e.g., 1 = very often, 2 = fairly often, 3 = sometimes, 4 = almost never, 5 = never, 6 = non-applicable). Scores are linearly transformed to a 0- to 100-point scale (1 = 0, 2 = 25, 3 = 50, 4 = 75, 5 = 100). Scores are composed of averages for each of the four domains, and an overall QOL score is derived by summing all the individual scores. Higher scores reflect a better QOL. Patients who scores  $\geq 75$  are considered to have a good QOL. High internal consistency has been found for the QOLCE. Cronbach's  $\alpha$  values ranging from 0.72 to 0.93 across subscales have been reported, with the overall health-related quality of life (HRQOL) score demonstrating internal consistency reliability of 0.93. QOLCE-55 was translated into Arabic by native Arabic speakers and pilot tested prior to data collection. English and Arabic versions of QOLCE-55 are attached in Appendix 1.

Ethical approval was sought from King Abdullah International Medical Research Center (KAIMRC) and informed consent was taken from the study subjects. Patients' confidentiality and privacy were maintained throughout the research.

**Data analysis**

Data were entered and analyzed using the Statistical Package for the Social Sciences (SPSS) version 22. Categorical variables were presented as frequencies (percentages). Numerical data were described as mean ± standard deviation (S.D.). Independent samples T-test was used to test the association between the scores of the different domains with gender and comorbidities. For testing the association of the scores with age, linear regression was used. Any test was declared significant at a *P* value < 0.05.

**Results**

This study included 59 caregivers of both genders of Saudi epileptic children aged 4 – 14 years old. The mean age of children was 8.9 (SD = 2.9) with slightly higher percentage of males, 33 (55.9%). Age distribution is shown in Figure 1. Comorbidities were present in 47 (79.7%) children. Almost a third of the children (28.8%) had global developmental delay (GDD), 5 (8.5%) had attention deficit hyperactivity disorder (ADHD), and 4 (6.8%) had encephalopathy. Only 3 patients (5.1%) had spasticity, while 18 (30.5%) children had other comorbidities. Demographic data are summarized in Table 1.

Regarding the four domains of QOL, cognitive functioning had a mean score of 50.2 (SD = 29.1), emotional functioning a mean score of 49.4 (SD = 13.6), social functioning a mean of 58.7 (SD = 30.3), and physical functioning with a mean of 54.9 (SD = 23.0). The mean total score = 52.8 (SD = 12.9). All domains had low scores which reflects the negative impact of intractable epilepsy on the QOL. Mean scores for all domains of QOL are summarized in Table 2.

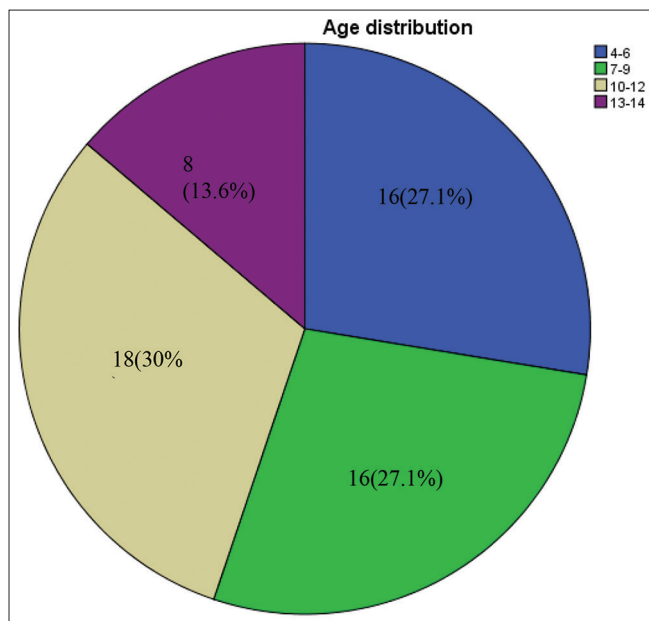
Associations of the scores with the predictors revealed that gender was significantly associated with the social domain (*P* = 0.001)

whereby males had a higher score (70.0, 26.2) compared to females (44.8, 29.7). Gender was also significantly associated with the total score (*P* = 0.04), and males were also having a better QOL. Although gender was not significantly associated with neither cognitive nor emotional scores (*P* > 0.05), males were doing better off. Physical score was also not significantly associated with gender (*P* = 0.17). However, females had a higher score in this domain (59.8, 24.2) compared to males (51.3, 21.7). These results conclude that males have a better QOL compared to females, especially in the social domain. As for age, it was not related to any domain nor the total score (*P* > 0.05).

Regarding comorbidities’ association with the various domains, GDD (0.3, 0.5) was significantly associated with the total score, cognitive, emotional, and social scores, (*P* < 0.05). Physical score, on the other hand, was not associated with GDD (*P* = 0.62). Spasticity (0.1, 0.2) was not found to be associated with the total score (*P* = 0.16), yet it was associated with the cognitive score (*P* = 0.007). Furthermore, encephalopathy (0.1, 0.3) was only associated with the total score (*P* = 0.007) and ADHD (0.1, 0.3) was not associated with any domain nor with the total score. Other comorbidities (0.3, 0.5) were not associated with any score. For all comorbidities which were found to be significant with the quality of life domains, having the comorbidity was associated with lower well-being. In summary, GDD and encephalopathy had a negative association with the QOL, while ADHD had null association with the QOL. Association of scores with predictors is summarized in Table 3.

**Discussion**

Epilepsy is a well-known neurological disorder that affects a large scale of the population worldwide. The diagnosis is usually



**Figure 1:** Age distribution

**Table 1: Characteristics of epileptic pediatric patients (n=59)**

| Variable       | Frequency | Percentage |
|----------------|-----------|------------|
| Age (mean±SD)  | 8.9±2.9   |            |
| Gender         |           |            |
| Male           | 33        | 55.9       |
| Female         | 26        | 44.1       |
| Comorbidities  |           |            |
| GDD            | 17        | 28.8       |
| ADHD           | 5         | 8.4        |
| Encephalopathy | 4         | 6.7        |
| Spasticity     | 3         | 5.1        |
| Others         | 18        | 30.5       |

**Table 2: Mean scores for cognitive, emotional, social and physical functioning domains and total QOL score (n=59)**

|                             | Mean | SD*  |
|-----------------------------|------|------|
| Cognitive functioning score | 50.2 | 29.1 |
| Emotional functioning score | 49.4 | 13.6 |
| Social functioning score    | 58.7 | 30.3 |
| Physical functioning score  | 54.9 | 23.0 |
| Total quality of life score | 52.8 | 12.9 |

\*Standard deviation

made in childhood or early adolescence.<sup>[15]</sup> Studies indicate that epileptic children showed poorer QOL compared to patients with other chronic conditions and healthy individuals.<sup>[16,17]</sup> Patients with intractable epilepsy showed lower scores in both physical and psychological domains than those with other conditions.<sup>[16,18]</sup> Patients who have intractable epilepsy are at risk of depression and suicide, especially patients who have severe and frequent seizures.<sup>[19,20]</sup> The predicted prevalence of depression in patients with intractable seizures treated at epilepsy centers is as high as 50%.<sup>[19,21,22]</sup> The present cross-sectional study investigated the association of certain demographics with cognitive, emotional, social, and physical functioning and the total QOL score in patients with intractable epilepsy.

The current study found that age was not significantly related to any domain nor the total score, these results mismatched with Shetty *et al.* and Ohaeri *et al.* who reported a negative association between increasing age and QOL scores of physical pain, emotional well-being, and memory and language domains.<sup>[23,24]</sup> Taylor *et al.* found that age was only related to self-esteem, where adolescents had lower scores compared to young children.<sup>[25]</sup> Nagarathnam *et al.* results supported the nil association between age group and QOL.<sup>[26]</sup>

In almost all of the chronic diseases, gender variation plays a major role in the patients' QOL.<sup>[27]</sup> Some of the published literature revealed that females are found to have poorer QOL than males.<sup>[23,28]</sup> In the current study, associations of the QOL domain scores with the predictors revealed that gender was significantly associated with the social domain, and the total score of QOL where males were significantly associated with a better QOL. In a study that showed the correlation between epilepsy and school attendance, females had a higher percentage of absenteeism.<sup>[29]</sup> On the contrary, Nabukenya *et al.* results found that being a female is significantly associated with better HRQOL.<sup>[30]</sup> Other studies reported no significant associations between QOL and gender.<sup>[25,26]</sup> This wide variation in results might be due to differences in living conditions and needs further evaluation.

In relation to cognitive function, Oyegbile *et al.* demonstrated that chronicity of seizures correlates with worsening mental status, especially in patients with low cerebral reserve.<sup>[31]</sup> Gotman

reported that verbal memory deficits are related to the impact of refractory epilepsy in patient's lives.<sup>[32]</sup> These difficulties brought an impact on the daily life once interfering in learning, professional, and social processes.

The current study was in harmony with Mantoan *et al.* in which clinical characteristics, seizure frequency as well as seizure types had a strong correlation with QOLIE-31 domains of emotional well-being and social function.<sup>[33]</sup> These characteristics have been considered the most significant predictors of QOL in some studies since patients with more severe seizures reported significantly poorer QOL.<sup>[34]</sup>

For all comorbidities which were found to be significant with the quality of life domains, having the comorbidity was associated with lower well-being. The current study results were similar to Miller V *et al.*'s study who reported that co-morbid impairment was the best predictor for poor QOL.<sup>[35]</sup> Haider S's study also reported similar results.<sup>[28]</sup>

One of the limitations in the present study is the convenience sampling technique, which can lead to sampling bias.<sup>[36]</sup> The study was conducted in one hospital, therefore, lacks clear generalizability.<sup>[36,37]</sup> Unfortunately, reliability and the psychiatric condition of the caregivers were not assessed. Another limitation is the response bias due to the survey-based nature of the study.<sup>[38]</sup>

## Conclusion

Intractable epilepsy impacted all functioning domains of life, rendering a poor QOL. Males reported better QOL and social functioning compared to females. For all comorbidities which were found to be significant with the quality of life domains, having the comorbidity was associated with lower well-being. Specifically, GDD and encephalopathy showed lower well-being. A multi-center study is suggested to increase the sample size in different societies, which may provide a valid and accurate results. Also, a cohort study would be more informative and could provide valuable data.

## Acknowledgements

We would like to acknowledge the respondents for participating in the study.

**Table 3: Association of quality of life scores with predictors in epileptic patients (n=59)**

| Predictor         | Cognitive score<br>Mean, SD | Emotional score<br>mean, SD | Social score<br>Mean, SD | Physical score<br>Mean, sd | Total score<br>mean, sd |
|-------------------|-----------------------------|-----------------------------|--------------------------|----------------------------|-------------------------|
| Gender            |                             |                             |                          |                            |                         |
| Male              | 54.1, 29.0                  | 50.5, 14.1                  | 70.0, 26.2               | 51.3, 21.7                 | 55.9, 12.2              |
| Female            | 45.1, 28.9                  | 48.2, 13.2                  | 44.8, 29.7               | 59.8, 24.2                 | 48.9, 12.9              |
| P                 | 0.25                        | 0.52                        | 0.001*                   | 0.17                       | 0.04*                   |
| Age, P            | 0.94                        | 0.12                        | 0.13                     | 0.68                       | 0.06                    |
| GDD, P            | <0.001*                     | 0.003*                      | 0.002*                   | 0.62                       | 0.02*                   |
| ADHD, P           | 0.90                        | 0.39                        | 0.86                     | 0.83                       | 0.82                    |
| Spasticity, P     | 0.007*                      | 0.57                        | 0.37                     | 0.13                       | 0.16                    |
| Encephalopathy, P | 0.11                        | 0.12                        | 0.27                     | 0.74                       | 0.007*                  |
| Others, P         | 0.44                        | 0.08                        | 0.43                     | 0.43                       | 0.45                    |

\*Statistically significant at P<0.05

## Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form the patient has given his/her consent for his/her no images were obtained clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

## Financial support and sponsorship

Nil.

## Conflicts of interest

There are no conflicts of interest.

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Appendix 1

**Quality of Life in Childhood Epilepsy Questionnaire: QOLCE-55  
Version 1.0 (English)**

Goodwin SW, Lambrinos AI, Ferro MA, Sabaz M, Speechley KN. Development and assessment of a shortened Quality of Life in Childhood Epilepsy Questionnaire (QOLCE-55). *Epilepsia* 2015;56(6):864-72.

**INSTRUCTIONS**

The following questions ask about your child’s health and well-being. Answer the questions by ticking the appropriate box. Certain questions may look alike but each one is different. Some questions may ask about problems your child does not have. Please try to answer each question as it is important for us to know when your child does not have these problems. There are no right or wrong answers. If you are unsure how to answer a question, please give the best answer you can.

**SECTION 1: YOUR CHILD’S COGNITIVE FUNCTIONING**

The following questions ask about some problems children have with concentrating, remembering, and speaking.

1.1 Compared to other children of his/her own age, how often during the past 4 weeks has your child:

|   | <b>Very Often</b>        | <b>Fairly Often</b>      | <b>Some-times</b>        | <b>Almost Never</b>      | <b>Never</b>             | <b>Not Applicable</b>    |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| a. had difficulty attending to an activity?                       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. had difficulty reasoning or solving problems?                  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. had difficulty making plans or decisions?                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. had difficulty keeping track of conversations?                 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. had trouble concentrating on a task?                           | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f. had difficulty concentrating on reading?                       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| g. had difficulty doing one thing at a time?                      | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| h. reacted slowly to things being said and done?                  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| i. found it hard remembering things?                              | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| j. had trouble remembering names of people?                       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| k. had trouble remembering where s/he put things?                 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| l. had trouble remembering things people told him/her?            | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| m. had trouble remembering things s/he read hours or days before? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| n. planned to do something then forgot?                           | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

|  | Very Often               | Fairly Often             | Some-times               | Almost Never             | Never                    | Not Applicable           |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| o. had trouble finding the correct words?                          | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| p. had trouble understanding or following what others were saying? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| q. had trouble understanding directions?                           | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| r. had difficulty following simple instructions?                   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| s. had difficulty following complex instructions?                  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| t. had trouble understanding what s/he read?                       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| u. had trouble writing?  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| v. had trouble talking?  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

**SECTION 2: YOUR CHILD'S EMOTIONAL FUNCTIONING**

Below is a list that describes how your child might feel in general.

2.1 During the past 4 weeks, how much of the time do you think your child:

|   | All of the time          | Most of the time         | Some of the time         | A little of the time     | None of the time         | Not Applicable           |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| a. felt down or depressed?                  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. felt happy?                              | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. wished s/he was dead?                    | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. felt frustrated?                         | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. worried a lot?                           | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f. felt confident?                          | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| g. felt excited or interested in something? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| h. felt pleased about achieving something?  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| i. felt nobody understood him/her?          | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| j. felt valued?                             | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| k. felt no one cared?                       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |



Below are statements that describe some children’s behaviour.

Please try to answer all questions as well as you can, even if some do not seem to apply to your child.

2.2 Compared to other children his/her own age, how often during the past 4 weeks do each of the following statements describe your child?

|  | <b>Very Often</b>        | <b>Fairly Often</b>      | <b>Some-times</b>        | <b>Almost Never</b>      | <b>Never</b>             | <b>Not Applicable</b>    |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| a. was socially inappropriate (said or did something out of place in a social situation) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. angered easily  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. hit or attacked people  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. swore in public   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. was obedient  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f. demanded a lot of attention   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

**SECTION 3: YOUR CHILD’S SOCIAL FUNCTIONING**

Below are statements that describe some children’s social interactions and activities.

Please try to answer all questions as well as you can, even if some do not seem to apply to your child.

3.1 During the past 4 weeks, how often has your child’s epilepsy:

|   | <b>Very Often</b>                              | <b>Fairly Often</b>                           | <b>Some-times</b>                                 | <b>Almost Never</b>                         | <b>Never</b>                                | <b>Not Applicable</b>    |
|---|--|---|---|---|---|--------------------------|
| a. limited his/her social activities (visiting friends, close relatives, or neighbours)?  | <input type="checkbox"/>                       | <input type="checkbox"/>                      | <input type="checkbox"/>                          | <input type="checkbox"/>                    | <input type="checkbox"/>                    | <input type="checkbox"/> |
| b. affected his/her social interactions at school or work?  | <input type="checkbox"/>                       | <input type="checkbox"/>                      | <input type="checkbox"/>                          | <input type="checkbox"/>                    | <input type="checkbox"/>                    | <input type="checkbox"/> |
| c. limited his/her leisure activities (hobbies or interests)?   | <input type="checkbox"/>                       | <input type="checkbox"/>                      | <input type="checkbox"/>                          | <input type="checkbox"/>                    | <input type="checkbox"/>                    | <input type="checkbox"/> |
| d. isolated him/her from others?  | <input type="checkbox"/>                       | <input type="checkbox"/>                      | <input type="checkbox"/>                          | <input type="checkbox"/>                    | <input type="checkbox"/>                    | <input type="checkbox"/> |
| e. made it difficult for him/her to keep friends?   | <input type="checkbox"/>                       | <input type="checkbox"/>                      | <input type="checkbox"/>                          | <input type="checkbox"/>                    | <input type="checkbox"/>                    | <input type="checkbox"/> |
| f. frightened other people?   | <input type="checkbox"/>                       | <input type="checkbox"/>                      | <input type="checkbox"/>                          | <input type="checkbox"/>                    | <input type="checkbox"/>                    | <input type="checkbox"/> |
| g. <u>During the past 4 weeks</u> , how limited are your child’s social activities compared with others his/her age because of his/her epilepsy or epilepsy-related problems? | <input type="checkbox"/><br>Yes, limited a lot | <input type="checkbox"/><br>Yes, limited some | <input type="checkbox"/><br>Yes, limited a little | <input type="checkbox"/><br>Yes, but rarely | <input type="checkbox"/><br>No, not limited |                          |

**SECTION 4: YOUR CHILD’S PHYSICAL FUNCTIONING**

The following questions ask about physical activities your child might do.

4.1. In his/her daily activities during the past 4 weeks, how often has your child:

|   | <b>Very<br/>Often</b>    | <b>Fairly<br/>Often</b>  | <b>Some-<br/>times</b>   | <b>Almost<br/>Never</b>  | <b>Never</b>             | <b>Not<br/>Applicable</b> |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|---------------------------|
| a. needed more supervision than other children his/her age?               | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>  |
| b. played freely in the house like other children his/her age?            | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>  |
| c. played freely outside the house like other children his/her age?       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>  |
| d. gone swimming (i.e., swam independently)?                              | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>  |
| e. participated in sports activities (other than swimming)?               | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>  |
| f. stayed out overnight (with friends or family)?                         | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>  |
| g. played with friends away from you or your home?                        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>  |
| h. gone to parties without you or without supervision?                    | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>  |
| i. been able to do the physical activities other children his/her age do? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>  |

استبانة عن جودة الحياة لدى الأطفال المصابين بالصرع QOLCE-55  
النسخة الأولى ( العربية )

الاستشهاد:

Goodwin SW, Lambrinos AI, Ferro MA, Sabaz M, Speechley KN. Development and assessment of a shortened Quality of Life in Childhood Epilepsy Questionnaire (QOLCE-55). *Epilepsia* 2015;56(6):864-72.

جوانب الاستبانة:

- 1 - الوظائف الإدراكية (٢٢ بنداً): القسم ١,١ الفقرات من أ إلى ك.
- 2 - الوظائف العاطفية (١٧ بنداً): القسم ٢,١ الفقرات من أ إلى ز و القسم ٢,٢ الفقرات من أ إلى ح.
- 3 - الوظائف الاجتماعية (٧ بنود): القسم ٣,١ الفقرات من أ إلى خ.
- 4 - الوظائف البدنية (٩ بنود): القسم ٤,١ الفقرات من أ إلى ذ.

نظام النقاط:

- 1 - إعادة إدراج البنود ذات النقاط العالية و التي تعني جودة الأعلى.
- 2 - تحويل جميع الرموز الرقمية للبنود إلى سلم نقاط ٠ إلى ١٠٠، حيث تشير النقاط العالية إلى مقياس أعلى في جودة الحياة. ستكون بذلك الأجوبة على شكل رموز ٠-٢٥-٥٠-٧٥-١٠٠.
- 3 - حساب القيمة المتوسطة للبنود تحت كل فقرة، ثم تعديل المقام ليتضمن البنود المجاب عليها.
- 4 - لحساب مجموع النقاط يتم القيام بجمع المتوسط للفقرات الفرعية الأربعة.

## التعليمات

بين أيديكم استبانة تعنى بدراسة جودة الحياة لدى الأطفال المصابين بالصرع وهي تهدف إلى تقييم صحة وسلامة طفلك. فضلاً التكرم بالإجابة وذلك بوضع إشارة داخل المربع المناسب، قد تبدو بعض الأسئلة متشابهة و لكن هناك فروق دقيقة بينها. علمًا بأن بعض الأسئلة قد تشير إلى مشاكل غير موجودة لدى طفلك، نرجو الإجابة عنها لأهميتها في النتائج. لا توجد إجابة صحيحة أو خاطئة. في حال عدم التأكد من إجابة سؤال ما، نرجو محاولة الإجابة قدر المستطاع.

## البند الأول: الوظائف الإدراكية لدى طفلك:

الأسئلة التالية تشير إلى بعض المشكلات لدى الأطفال من ناحية التركيز، الذاكرة، اللغة.

١،١ مقارنة بأقرانه في نفس الفئة العمرية، كم مرة خلال الأربع الأسابيع الماضية:

| غير متاح | أبدأ | نادراً | أحياناً | في أغلب الأحيان | غالبًا  |
|----------|------|--------|---------|-----------------|---|
|          |      |        |         |                 | أ- واجه صعوبة في القيام بعمل ما.                            |
|          |      |        |         |                 | ب- واجه صعوبة في حل مشكلة.                                  |
|          |      |        |         |                 | ت- واجه صعوبة في تخطيط أو اتخاذ قرار.                       |
|          |      |        |         |                 | ث- واجه صعوبة في الاسترسال في محادثة.                       |
|          |      |        |         |                 | ج- واجه صعوبة في التركيز على مهمة.                          |
|          |      |        |         |                 | ح- واجه صعوبة في التركيز عند القراءة.                       |
|          |      |        |         |                 | خ- واجه صعوبة في إنجاز كل عمل على حدة.                      |
|          |      |        |         |                 | د- ردود أفعال بطيئة لما يقال له أو يفعل أمامه.              |
|          |      |        |         |                 | ذ- وجد صعوبة في تذكر الأشياء.                               |
|          |      |        |         |                 | ر- وجد صعوبة في تذكر أسماء الأشخاص.                         |
|          |      |        |         |                 | ز- وجد صعوبة في تذكر أين وضع أشياءه.                        |
|          |      |        |         |                 | س- وجد صعوبة في تذكر ما قيل له.                             |
|          |      |        |         |                 | ش- وجد صعوبة في تذكر ما قرأ خلال الساعات أو الأيام الماضية. |
|          |      |        |         |                 | ص- خطط لعمل شيء ثم نسي.                                     |
|          |      |        |         |                 | ض- وجد صعوبة في إيجاد الكلمات الصحيحة.                      |
|          |      |        |         |                 | ط- وجد صعوبة في فهم ما يقال له.                             |
|          |      |        |         |                 | ظ- وجد صعوبة في فهم الاتجاهات.                              |
|          |      |        |         |                 | ع- وجد صعوبة في اتباع التعليمات البسيطة.                    |
|          |      |        |         |                 | غ- وجد صعوبة في اتباع التعليمات المعقدة.                    |
|          |      |        |         |                 | ف- وجد صعوبة في فهم ما قرأ.                                 |
|          |      |        |         |                 | ق- وجد صعوبة في الكتابة.                                    |
|          |      |        |         |                 | ك- وجد صعوبة في الكلام.                                     |

## البند الثاني: الوظائف العاطفية لدى طفلك:

الأسئلة التالية تصف أحاسيس طفلك بصفة عامة.

٢،١ خلال الأربع الأسابيع الماضية كم من الوقت تعتقد أن طفلك:

| كل الوقت | أغلب | أحياناً | بعض من | أبدأ | غير |
|----------|------|---------|--------|------|-----|
|----------|------|---------|--------|------|-----|

| متاح |  | الوقت |  | الوقت |                             |
|------|--|-------|--|-------|-----------------------------|
|      |  |       |  |       | أ- حزين أو مكتئب.           |
|      |  |       |  |       | ب- سعيد.                    |
|      |  |       |  |       | ت- تمنى الموت.              |
|      |  |       |  |       | ث- محبط.                    |
|      |  |       |  |       | ج- كثير الفلق.              |
|      |  |       |  |       | ح- واثق من نفسه.            |
|      |  |       |  |       | خ- متحمس أو مهتم لشيء ما.   |
|      |  |       |  |       | د- سعيد بإنجاز معين.        |
|      |  |       |  |       | ذ- يشعر بأن لا أحد يفهمه.   |
|      |  |       |  |       | ر- يشعر بقيمته.             |
|      |  |       |  |       | ز- يشعر أن لا أحد يكثرث به. |

الجملة التالية تصف تصرفات بعض الأطفال. نرجو منك المحاولة في إجابة جميع الأسئلة بقدر استطاعتك حتى لو لم تكن تنطبق على طفلك.  
٢,٢ مقارنة بأقرانه في نفس الفئة العمرية، كم مرة خلال الأربع الأسابيع الماضية تنطبق الحالات التالية على طفلك:

| غير متاح | أبداً | نادرًا | أحيانًا | في أغلب الأحيان | غالبًا   |
|----------|-------|--------|---------|-----------------|--|
|          |       |        |         |                 | أ- كان غير لائق اجتماعيًا ( قال أو فعل شيء غير ملائم). |
|          |       |        |         |                 | ب- غضب بسرعة.  |
|          |       |        |         |                 | ت- ضرب أو تعدى على أحد.                                |
|          |       |        |         |                 | ث- سب أو شتم في العلن.                                 |
|          |       |        |         |                 | ج- كان مطيعًا.   |
|          |       |        |         |                 | ح- كان متطلبًا للفت الانتباه.                          |

البند الثالث: الوظائف الاجتماعية لدى طفلك:

الجملة التالية تصف تصرفات بعض الأطفال من خلال تفاعلاته و أنشطته الاجتماعية. نرجو منك المحاولة في إجابة جميع الأسئلة بقدر استطاعتك حتى لو لم تكن تنطبق على طفلك.

١,٣ خلال الأربع الأسابيع الماضية ما مدى تأثير حالة الصرع على طفلك:

| غير متاح | أبداً | نادرًا | أحيانًا | في أغلب الأحيان | غالبًا   |
|----------|-------|--------|---------|-----------------|--|
|          |       |        |         |                 | أ- محصورة في الأنشطة الاجتماعية ( زيارة الأصدقاء، الأقارب، الجيران). |
|          |       |        |         |                 | ب- أثرت على تفاعله الاجتماعي في المدرسة أو العمل.                    |

|  |  |  |  |  |  |  |
|--|--|--|--|--|--|--|
|  |  |  |  |  |  | ت- حصرت أنشطته الترفيهية (الهوايات أو الاهتمامات). |
|  |  |  |  |  |  | ث- عزلته عن حوله.                                  |
|  |  |  |  |  |  | ج- صعبت عليه الحفاظ على صداقاته.                   |
|  |  |  |  |  |  | ح- أخافت من حوله.                                  |

| لا، غير محدودة | نعم، لكن نادرًا | محدود قليلاً | نعم، محدود بعض الشيء | نعم، محدود جدًا |   |
|----------------|-----------------|--------------|----------------------|-----------------|---|
|                |                 |              |                      |                 | خ- خلال الأربع الأسابيع الماضية ما مدى تأثير الصرع و مشاكله على أنشطة طفلك الاجتماعية مقارنة بأقرانه. |

البند الرابع: الوظائف البدنية لطفلك:

الأسئلة التالية تدور حول الأنشطة البدنية التي قد يمارسها طفلك.

١،٤ في الأربع الأسابيع الماضية و من خلال أنشطته اليومية إلى أي مدى:

| غالبًا | في أغلب الأحيان | أحيانًا | نادرًا | أبداً | غير متاح |  |
|--------|-----------------|---------|--------|-------|----------|--|
|        |                 |         |        |       |          | أ- احتاج إلى رقابة أعلى من أقرانه.                     |
|        |                 |         |        |       |          | ب- لعب بحرية في المنزل كأقرانه.                        |
|        |                 |         |        |       |          | ت- لعب بحرية خارج المنزل كأقرانه.                      |
|        |                 |         |        |       |          | ث- ذهب للسباحة ( سبح بمفرده).                          |
|        |                 |         |        |       |          | ج- اشترك في أنشطة رياضية ( غير السباحة).               |
|        |                 |         |        |       |          | ح- بات خارج المنزل ( مع الأصدقاء أو العائلة).          |
|        |                 |         |        |       |          | خ- لعب مع الأصدقاء بعيدًا عنك أو عن منزلك.             |
|        |                 |         |        |       |          | د- ذهب إلى حفلة بدونك أو بدون رقابة.                   |
|        |                 |         |        |       |          | ذ- استطاع أن يقوم بالأنشطة بدنية التي يقوم بها أقرانه. |