Original Article

The Association between Stigma and Quality of Life among School Age and Adolescents with Epilepsy: A Cross-Sectional Study

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Abstract

Background: Epilepsy is one of the most common neurological diseases in children and adults and has a significant burden on physical and mental health. It is a condition that is particularly prone to stigma due to the unpredictable and uncontrollable nature of seizures, which often triggered fear and anxiety in the people who witness them. **Materials and Methods:** A descriptive cross-sectional study design was conducted on children with epilepsy at the Neuroscience Center in Al-Diwaniyah Province. The study aimed to find the association between stigma and quality of life among school age and adolescent epilepsy. Purposive sample included 106 parents of children (school age and adolescents) with epilepsy. **Results:** A total of 106 participants completed the QoL scale and (stigma assessment) questionnaire. The study found that the highest percentage (48%) of children ages were 11–15 years, and more than half of the sample were males, and 64% of the sample was educational level in primary school, and the result of the study revealed 50.9% had a moderate level of quality of life, but 60.4% had a high level of stigma. **Conclusion:** This study found the overall assessment of the quality of life for children with epilepsy was at a moderate level and a high level of stigma was there among children with epilepsy, and there is a significant relationship ($P < 0.05$) between social stigma and quality of life for children with epilepsy.

Keywords: Adolescent, epilepsy, quality of life, school age, stigma

Introduction

Epilepsy is one of the most common neurological diseases, and it differs from all other neurological diseases in terms of signs and symptoms and has a significant burden on physical and mental health.[1]

Children with epilepsy are at a higher risk of developing behavioral problems and psychiatric disorders than their healthy peers. The stigma attached to epilepsy, which serves as one of the obstacles to leading a fulfilling life, is a significant issue that children (children in school age and adolescents) with epilepsy frequently confront.[2]

Epilepsy leads to many psychological problems, such as anxiety, depression, stigma, mood disorders, feelings of guilt and shame, social isolation, and suicide. The actions of other people have an impact on children who have epilepsy. When peers see CWE as "different," peer attitudes are particularly significant. As a result, there will be physical harassment, verbal abuse, insults, bullying, and social marginalization. Children with epilepsy are impacted by the behaviors of their close relatives.[3,4]

As a result, persons who have epilepsy continue to face prejudice or the fear of standing out because of their disease. People with epilepsy have been shown to have lower QoL when they experience internalized stigma. Internalized stigma has been linked to reduced self-esteem, a worse sense of oneself, and more melancholy and anxiety among children and teenagers with epilepsy.[5]

Children with epilepsy, and maybe the parents, are often stigmatized and discriminated against due to

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Submission: 07-May-2023 **Accepted:** 21-May-2023 **Published:** 23-Jan-2026

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How to cite this article: Al-Mehnh MKJ, Kassim NH. The association between stigma and quality of life among school age and adolescents with epilepsy: A cross-sectional study. Med J Babylon 2025;22:1076-80.

Access this article online

Quick Response Code:

Website: https://journals.lww.com/mjby

DOI: 10.4103/MJBL.MJBL_516_23

misconceptions and negative attitudes and burden and lack of knowledge about the disease. Some common misconceptions are that epilepsy is equated with "madness." Stigma leads to the violation of human rights and social exclusion. In some contexts, for example, children with epilepsy are not allowed to go to school, adults cannot find suitable work, or they cannot marry.[6-8]

Epilepsy is a chronic disorder, and people who experience it have been said to exhibit traits of learned helplessness. Epilepsy sufferers have also been linked to a lack of information about the condition, which has been linked to stigma and discrimination by society. In the last few decades, understanding of epilepsy as a neurological disorder and its psychosocial repercussions, such as anxiety and depression, has considerably increased in industrialized nations.[9,10]

According to the theory of social comparison, people are forced to evaluate themselves in a competitive manner in social situations. Unidirectional comparisons based on talents are made between the individual and the outside environment in this evaluation.[11]

This comparison may be made with those who are in good health than others or with those who are with poorer health than others, or it may be done both ways. Therefore, stigma is a distinguishing feature for children with epilepsy, especially when comparing themselves with their healthy peers. Through this study, it is possible to identify the level of social stigma and its impact on children with epilepsy.[12]

Although it is challenging to determine how much stigma epilepsy sufferers experience, studies seem to indicate that this perception is very widespread. Fifteen percent of epilepsy sufferers report feeling extremely stigmatized, while 50% of sufferers say that they feel stigmatized in some way. This high prevalence provides ample justification for its study. The study of epileptic stigma is getting more significant interest from studies all around the world.[13]

Materials and Methods

Research design

A descriptive design, cross-sectional study was carried out to attain the stated objective which is to find the association between stigma and quality of life among school age and adolescent epilepsy.

Study sample and setting

A total of 106 parents of children with epilepsy were selected through a "non-probability" (purposive) sample from total parents of children with epilepsy that follow up in the Center of Neuroscience in Al-Diwaniyah Province, Iraq, in the present study.

Instrument of the study

The instrument used in the study is composed of three aspects:

First: Demographic variables were age, gender, and level of education for children. Second: The QOLCE-It is the modified version of the quality of life derived from the original quality of life 55 items. It has been modified and developed. This provides an overall assessment of the quality of life from the perspective of the parents, which they reported during the questionnaire for children with epilepsy, whose ages ranged between 6 and 18 years through the four domains of quality of life assessment: cognitive function (17 items), emotional function (13 items), social function (7 items), and physical function (6 items). Third: The stigma scale for children with epilepsy from the parents' view, which consists of seven questions, was designed by Austin *et al.*[14] in 1998. It has been modified and developed by researcher and presented to experts. After that, the researcher conducted the reliability and validity to ensure the validity of the questionnaire for the research. A 3-point Likert scale was also used to rate items as follows: always = 3, sometimes = 2; never = 1.

Data collection

Every children and parents with his/her caregiver were seen individually in their follow-up consultation in the neurology consultation. During the completion of the questionnaire, the researcher was present and clarified the inquiries about the questions and made sure that the items of the questionnaire were understood correctly. The interview time for each person ranged from 10 to 15 min, which was achieved from July 26 to December 13, 2022.

Statistical approach

The data were converted into calculated data, that is, converted into numbers, and it was ensured that there were no missing data and were included in Microsoft Office Excel 2010 program, where they were arranged and transferred to the SHSS program, version No. 25, to analyze these results statistically, as final results presented for study accomplishment.

Ethical approval

The study protocol and the subject information and the consent form were reviewed and approved by a local ethics committee and that No. 2407, dated July 17, 2022 to get this approval.

Results

Table 1 shows the statistical distribution of children by their demographic data; it explains that the highest percentage of the children subgroup are those aged between 11 and 15 years (48.1%); more than half are male (52.8%), with most of them in primary school as a level education (64.2%). The Sequence of the child in the family, children with epilepsy among his siblings in was rank first (38.7%). Table 2 and Figure 1 show the overall assessment of social stigma for children with epilepsy. It is clear from the results

Table 1: Child characteristic (n = 106)

Childe characteristic	Rating and interval	Frequency	Percentage
Age (years)	6–10	47	44.3
Mean ± SD	11–15	51	48.1
11.27 ± 2.65	16 +	8	7.5
Gender	Male	56	52.8
	Female	50	47.2
Levels of education	Does not read and write	14	13.2
	Primary school	68	64.2
	Secondary school	24	22.6
Sequence of the child in the family	1st	41	38.7
	2nd	26	24.5
	3rd	21	19.8
	4th	12	11.3
	5th	4	3.8
	6th	2	1.9

Table 2: Descriptive statistics and assessment of the level of stigma for the children with epilepsy

Items	Responses			Statistical measurement	Assessment
	Never	Sometimes	Always	MS	
1. Freq.	7	40	59	2.49	High
%	6.60	37.74	55.66		
2. Freq.	2	43	61	2.56	High
%	1.89	40.57	57.55		
3. Freq.	17	39	50	2.31	Moderate
%	16	36.8	47.2		
4. Freq.	12	35	59	2.44	High
%	11.32	33.02	55.66		
5. Freq.	5	57	44	2.37	High
%	4.72	53.77	41.51		
6. Freq.	11	50	45	2.32	Moderate
%	10.4	47.1	42.5		
7. Freq.	23	37	46	2.22	Moderate
%	21.7	34.9	43.4		

MS: Mean of scores; low: MS = 1–1.66; moderate: MS = 1.67–2.32; high: MS ≥ 2.33

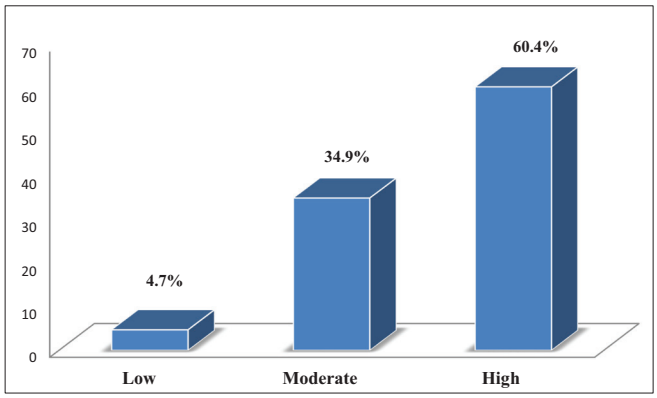

Figure 1: Overall assessment of stigma level for school-age children and adolescents with epilepsy

shown in the table that children with epilepsy have a high level of social stigma. Table 3 shows that the assessment of each part of the quality of life is displayed by calculating the mean; it is clear from the results that the highest mean was 2.38, which is for social functions, and means that the social functions of the child are good and has a high quality of life in this domain. As for the lowest mean, it was 2.26 for the emotional functions, and this means that the quality of life is moderate emotionally, as shown by the general assessment of the quality of life of children with epilepsy was moderate at an overall rate. As shown in Table 4, the study found that there is a statistically significant relationship between quality of life and stigma among children with epilepsy.

Discussion

Table 1 shows the statistical distribution of children by their demographic data, it explains that the highest percentage of the children subgroup are those aged between 11 and 15 years (48.1%); more than half are male (52.8%), this result agrees with Hameed and Jabur[15]

Table 3: Descriptive statistics of overall domains

Main domain		Responses			Statistical measurement	Assessment
		Low	Moderate	High	MS	
Cognitive domain	Freq.	3	43	60	2.31	Moderate
	%	2.8	40.6	56.6		
Emotional domain	Freq.	0	64	42	2.26	Moderate
	%	0	60.4	39.6		
Social domain	Freq.	0	39	67	2.38	High
	%	0	36.8	63.2		
Physical domain	Freq.	3	42	61	2.28	Moderate
	%	2.8	39.6	57.5		
Overall quality of life	Freq.	0	54	52	2.30	Moderate
	%	0	50.9	49.1		

Table 4: Association between Stigma and QoL of children with epilepsy

Model	Unstandardized coefficients		Standardized coefficients	*t*	Sig.
	B	Std. error	Beta		
Stigma	0.102	0.048	0.206	2.142	**0.035**

with most of them in primary school as a level education (64.2%). The Sequence of the child in the family, children with epilepsy among his siblings in was rank first (38.7%).

As mentioned in Table 2 and Figure 1, the results of this study show that there is a high level of stigma in general in all questions related to stigma during epilepsy, as well as the overall assessment of felt stigma, and more than half of the study sample (about 60.4%) showed an assessment high level of stigma among children with epilepsy, and about 34.9% had felt a moderate level of stigma. This result agrees with the results shown by the study by Aydemir *et al.*,[16] which showed that the assessment of stigmatization is about half or more. Also, the results of this study agree with the results shown by the study by Bielen *et al*.,[17] which showed that the percentage of males in this study ranged between (53%) who reported feeling stigma, with 136 (45%) feeling mild to moderate. The reason for the high level of stigma among children with epilepsy is due to the negative view of children with epilepsy and the community's fear of this disease. Therefore, the patient suffers from social prejudice and social misunderstanding, where epilepsy remains a societal burden on children with epilepsy in particular and a distinctive feature of their identity. It remains a major concern for many people and families as well as the child himself.

As for the overall quality of life assessment, it was found that the quality of life assessment was at moderate level for children with epilepsy. Also, this result agrees with the result of the study by Nikolić and Rogač.[18] Also, the results of this study agree with the results shown by the study by EL Nabawy and Abdelgawad[19] published in the year 2022, which showed that the quality of life of children with epilepsy from a parent's perspective that children with epilepsy have a moderate or less quality of life. The reason for this is the lack of control of seizures, in addition to the side complications associated with the disease and disability associated with it. In addition to many of the factors mentioned above, it leads to a low level in the quality of life for children with epilepsy. Table 4 shows that the quality of life among children with epilepsy and stigma are significant relationship. It is possible that the reason for this stigma of children with epilepsy can interfere with their social activities because children feel discriminated against the society and feel blamed, rejection, and exclusion. Thus, the stigma has a great relationship with the quality of life of the children. Also, the findings of this study agree with the results shown by the study by Anguzu *et al.*[20] in the year 2021. The study was conducted in the Uganda region on adolescents with epilepsy and one of its objectives was to assess the relationship between the quality of life of adolescents with social stigma during epilepsy.

Conclusion

The study concluded that the overall assessment of the quality of life for children with epilepsy was at a moderate level, and the study found that there is a high level of social stigma among children (school age and adolescents) with epilepsy. Also, there is a statistically significant relationship between quality of life and social stigma among children with epilepsy.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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