BMC Public Health

RESEARCH Open Access

The relationship between stigma and psychological distress among Chinese youth with epilepsy: the mediating role of physical activity

Jing Zhao[1], Shuangzi Li[2*], Ni Zhang[3*], Junqi Zeng[1], Yuan Xie[1], Ting Wang[2] and Qing Xia[2]

Abstract

Background Youth with epilepsy suffer from stigma, which is closely associated with increased levels of psychological distress, particularly anxiety and depression. Studies have found that the stigma associated with epilepsy is strongly linked to reduced levels of physical activity (PA). However, the combined contribution of stigma and PA to psychological distress remains unclear.

Aim This study aims to investigate the mediating role of PA to determine whether PA mediates the relationship between stigma and psychological distress among youth with epilepsy.

Methods We conducted a multicentre cross-sectional survey involving youth with epilepsy in nine tertiary hospitals across China from October 2023 to March 2024. The study enrolled 226 youth with epilepsy between the ages of 8 and 18. The dependent variable was psychological distress, assessed using the Depression Anxiety and Stress Scale (DASS-21). Data collection involved the administration of a comprehensive questionnaire that included the DASS-21, the Kilifi Stigma Scale for Epilepsy (KSSE) to assess stigma, and the Physical Activity Rating Scale (PARS-3) to assess PA.

Results Psychological distress increased significantly with increasing levels of stigma, whereas a decrease was observed with increasing levels of PA ($p < 0.01$). The results showed PA mainly plays partial mediating roles in the relationship between stigma and depression (ab = 0.042, 95% CI: 0.016 to 0.068), anxiety (ab = 0.077, 95% CI: 0.054 to 0.099) and stress (ab = 0.092, 95% CI: 0.061 to 0.122) dimensions of psychological distress. Additionally, intensity and frequency respectively only intermediated the relationship between stigma and anxiety and stress; duration all mediated between stigma and the psychological distress dimensions.

Conclusions Stigma could increase psychological distress by indirectly influencing PA and its components. Interventions to improve physical activity may prevent or reduce psychological distress among youth with epilepsy.

Keywords Epilepsy, Stigma, Youth, Physical activity, Psychological distress

*Correspondence:
Shuangzi Li
1208123518@qq.com
Ni Zhang
1134699270@qq.com
[1]Department of Nursing, National Clinical Research Center for Child Health and Disorders, Ministry of Education Key Laboratory of Child Development and Disorders, Chongqing Key Laboratory of Pediatrics, Children's Hospital of Chongqing Medical University, Chongqing, China
[2]Department of Neurology, Children's Hospital of Chongqing Medical University, Chongqing, China
[3]Department of Traditional, Chinese Medicine Children's Hospital of Chongqing Medical University, Chongqing, China

Introduction

Epilepsy is a common chronic neurological disorder that affects about 70 million people globally, nearly 80% of these people living in low- and middle-income countries [1]. It is estimated that approximately 75% of epilepsy begins during childhood [2]. Epilepsy is characterized by chronic or recurrent seizures disorder. Seizures can lead to a range of involuntary physical responses, including vocalizations, loss of consciousness, salivation, incontinence, and involuntary defecation or urination [3]. These manifestations can be frightening for those experiencing or witnessing them [4]. Youth with epilepsy often experience a range of psychosocial difficulties [5], including social isolation, stigma, or disability [6]. Stigma, as defined by Goffman, is an attribute that is profoundly discrediting and arises from the perception of individuals as socially distinct [7]. Although seizures and their control are the main focus of clinical care, stigmatization is a major contributor to the overall burden associated with the condition [8].

Epilepsy is commonly seen as a mental disorder rather than a neurological condition in China [9]. Studies in China during the 1980s has estimated that up to 90% of people with epilepsy and 75% of their family members experience stigma [10]. An ethnographic study in rural and urban China found that most informants had negative attitudes towards epilepsy and people with epilepsy [11]. In a community-based survey, a third of people with epilepsy of all ages identified stigma as the most difficult part of living with epilepsy [12]. It is also worth noting that stigma has a major impact on both the physical and mental health of people with epilepsy. Many evidence has shown that stigma can be an important risk factor for psychological distress [13, 14]. The presence of stigma among youth with epilepsy is associated with low self-esteem, retardation in neurocognitive development, psychological distress [14, 15], poor academic progress [16, 17], and increased mortality (mainly suicide) [18]. The negative consequences of stigma worsen health conditions, leading to a vicious cycle of social marginalization and deteriorating health [19].

Psychological distress is a state of emotional suffering that is often characterized by symptoms of depression and anxiety, yet encompassing a wider range of conditions [20]. Psychological distress is common among youth with epilepsy and is associated with unfavourable outcomes and poor quality of life [21]. A meta-analysis revealed that the overall prevalence of anxiety and depressive symptoms among youth with epilepsy (under 18 years) was 18.9% and 13.5%, respectively [5], with rates three to five times higher than in the general youth population [22]. The social aspects of stigma are significant determinants to the development of anxiety and depression in epilepsy. Suurmeijer et al. [23] in Netherlands have confirmed that the main factor influencing anxiety and depression was social aspects of stigma. In addition, previous systematic reviews have reported a positive association between stigma and depression, anxiety, low self-efficacy, and substance abuse [24]. Enhancing our understanding of these associations can guide future research and interventions designed to address psychological distress among youth with epilepsy.

Physical activity (PA) may be an effective method of preventing or alleviating psychological distress and improving mental health of youth [25]. However, youth with epilepsy tend to lead more sedentary lifestyles and engage in lower level of PA than the general population [26]. Tedrus et al. [27] suggest that lower levels of PA are associated with higher levels of stigma and lower quality of life in adults with epilepsy. The experience of stigma has a negative impact on motivation to engage in physical exercise. Youth who report being teased because of epilepsy exhibit reduced confidence in being physically active and lower levels of physical fitness compared with their peers [28]. With the development of activity psychology [29], the positive effects of PA and exercise on the physical and mental health of children and young people have long been recognized [30]. Exercise could be encouraged as part of non-pharmacological treatment for young people [31]. Physical inactivity is a significant public health concern, but few studies have focused on the physical activity patterns of youth with epilepsy [30]. There is an imperative need to advocate for the creation and maintenance of an exercise routine in youth with epilepsy.

To date, most of the research on stigma in epilepsy has focused on adults or mixed youth/adult samples. There is a lack of research on youth with epilepsy. However, recent findings suggest a high level of stigma among Chinese young people with epilepsy [32]. Meanwhile, stigma may impose dual physical and psychological distress on individuals. Lack of PA have been shown to be a major risk factor for poor mental health. Therefore, PA may play a role in the relationship between stigma and psychological distress. To our knowledge, no studies have been conducted to investigate the relationship between the three. To remedy this gap, this study aims to investigate the relationships among stigma, PA, and psychological distress in Chinese youth with epilepsy. Additionally, the study will determine whether the association between stigma and psychological distress is mediated by PA, including activity intensity, duration, and frequency. A better understanding of the underlying mediating processes of PA may help to mitigate the adverse effects of stigma in youth with epilepsy and enable the development of more effective mental health interventions. Therefore, this study proposed the following hypotheses: (H1) High levels of stigma are associated with higher

levels of psychological distress in youth with epilepsy in China. (H2) There is a correlation between stigma and poor physical activity in youth with epilepsy. (H3) Physical activity, including intensity, duration, and frequency, partially mediates the relationship between stigma and psychological distress dimensions.

Materials and methods

Study design and participants

A multicenter cross-sectional study was conducted from October 2023 to March 2024 in China. The questionnaire was sent to nine tertiary children's and comprehensive hospitals in different regions of China by sharing the link to the questionnaire online. These regions included eastern, central and western China [33]. Participants were recruited using convenience sampling. The inclusion criteria comprised of: (1) Youth aged 8–18 years and diagnosed with epilepsy by neurologists according the 2014 International League Against Epilepsy criteria [34]; (2) The duration of epilepsy was at least 2 months, which is a period supported by clinical practice and aligns with the pathogenesis of epilepsy [35]; (3) Caregivers older than 18 years who provided care for youth with epilepsy, only one of the caregivers who was present with the child during the period of data collection was included in the study; (4) Both youth and caregiver were able to read and understand the questionnaire independently or with the help of the researcher; (5) Willing to participate the survey. The exclusion criteria were: (1) Youth with intellectual impairment, an intelligence quotient score lower than 80 on the Wechsler Intelligence Scale [36]; (2) Caregivers were diagnosed with severe medical conditions, cognitive impairment, or mental illness.

The questionnaire was distributed to the outpatient clinics and wards of the participating hospitals. Before conducting the survey, the researcher obtained the consent and active cooperation of the head of the hospital department where the survey unit was located. The questionnaires were distributed by the attending doctors and nurses. The doctors and nurses were trained in advance and gave the participants unified instructions on how to complete the questionnaire. Informed consent was obtained before completing the questionnaire in face-to-face interviews. For youth, consent was obtained from the caregiver. Typically, caregivers were responsible for collecting sociodemographic, disease-related characteristics and physical activity information, whereas youth focused on collecting data related to stigma and psychological distress. If any part of the questionnaire was left incomplete, participants was asked to complete the missing items immediately. 239 youth with epilepsy and caregivers was selected. A total of 13 patients declined to participate due to lack of interest (five patients), time (four patients), or other unspecified reasons (four patients). In the end, 226 (94.6%) participants were recruited and completed the survey (flow chart see Fig. 1). There were no statistically significant differences in the distribution of age, gender, or seizure type between respondents and non-respondents.

Instrument

Sociodemographic characteristics

The self-designed questionnaire was used to collect basic sociodemographic characteristics of youth and their families. The data included age, gender, region of residence, whether it is a one-child family, average monthly household income, height and weight. The data came mainly from the caregivers.

Disease-related characteristics

Disease-related characteristics involved age of seizure onset in years, disease duration, seizure type, whether it is drug-resistant epilepsy, frequency of seizures in recent 3 months, and comorbidities. The data were mainly collected from medical records and caregiver self-reports.

Stigma

The Kilifi Stigma Scale for Epilepsy (KSSE) is a 3-point Likert scale across 15 items, scored as follows: 0 for "not at all," 1 for "sometimes," and 2 for "always" [37]. The total score ranges from 0 to 30, with higher scores indicating greater stigma. The Chinese version of KSSE were translated and validated by Song et al. [38]. The translated version exhibits good reliability and validity (Cronbach's $\alpha = 0.93$). This scale is the only validated scale of stigma for epilepsy patients in China. A score above the 66th percentile of the total score indicates perceived stigma, while a score below the 66th percentile shows the absence of stigma.

Psychological distress

The Depression Anxiety and Stress Scale (DASS-21) is a shortened version of the full 42-item DASS developed by Lovibond et al. [39], which is a common instrument for screening psychological distress. In our study, we used the Chinese version of DASS-21 [40], which has been widely used in China and has shown high reliability and validity (Cronbach's $\alpha = 0.91$) [41, 42]. This scale comprises 21 items grouped into three subscales: depression, anxiety, and stress. Each item is rated on a 4-point Likert scale from 0 (not true) to 3 (very true). Subscale scores range from 0 to 21, and are calculated by summing the individual item scores. Higher scores reflect greater psychological distress.

Physical activity (PA)

The Physical Activity Rating Scale-3 (PARS-3), a three-question scale, was used to measure the level of physical

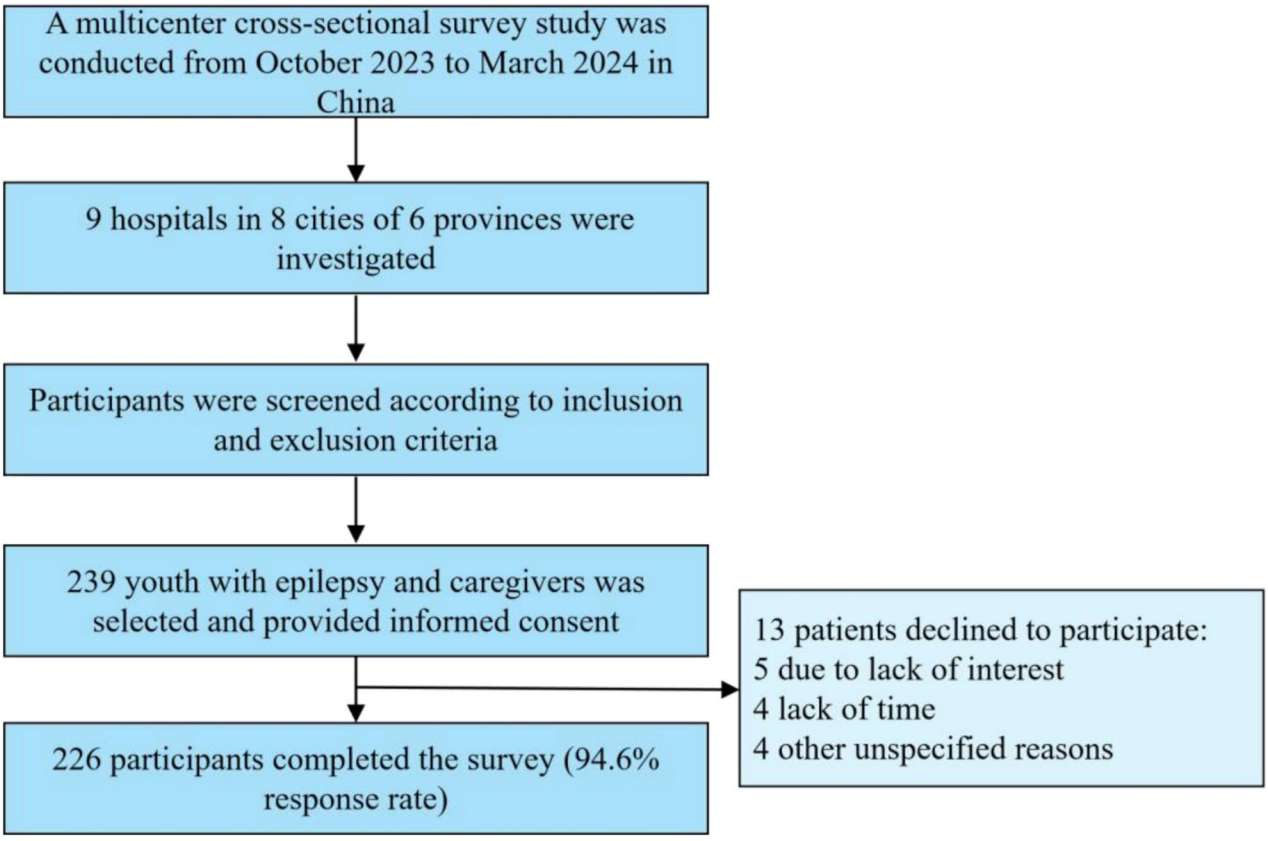

Fig. 1 Flow chart of participants selection figure

activity of participants in terms of intensity, duration and frequency of physical activity [43]. Rating of each item on a scale of 1 to 5 and the total score for physical activity were computed using the following equation: intensity×(duration-1) ×frequency, with a range of 0-100, and was further classified into three levels according to the score: high (>42), moderate (20–42), and low (0–19) physical activity. The scale demonstrated strong reliability and validity in Chinese individuals (Cronbach's $\alpha = 0.86$) [29], with an excellent test-retest reliability ($r = 0.82$) [44].

Ethical statement

Participation in this study was completely voluntary and anonymous. Researchers obtained participants and their caregivers informed consent before completing the questionnaire. This study was approved by the Medical Ethical Committee of Children's Hospital of Chongqing Medical University (No.2023 – 370).

Statistical analysis

The SPSS version 26 was used to analyze all data. Normally distributed measurement data were described by mean and standard deviation (SD), whereas non-normally distributed measurement data were described by median and quartile. The categorical variables were stated as the frequency and percentage. One-way ANOVA and the S-N-K test were used to assess continuous data, while the Chi-square test was used to assess categorical variables.

All analyses were adjusted for age, gender, one-child family, place of residence, average monthly household income, and seizure type. We used multivariate linear regression to determine the relationship among stigma, PA, and psychological distress. Andrew F Hayes' PROCESS macro v.3.5 was used to develop the mediation model. Psychological distress (depression, anxiety, and stress) was the dependent variable (Y), PA (intensity, duration, and frequency) was separately the mediating variable (M), and stigma was the independent variable (X).

The combination of the direct and indirect effects of stigma on psychological distress was the total impact (path c). After adjusting for PA, the direct effect (path c') was the effect of stigma on psychological distress. The indirect effect (path ab) mediated the relationship between stigma and psychological distress. In addition, the PA components were investigated independently as mediating variables. We used the PROCESS macro's bootstrap approach. The bootstrap method produces 95% bias-corrected CI for these effects from 5000 re-sample

of the data. CI that do not contain zero indicate a significant effect [45].

Results

Sociodemographic and disease-related characteristics of study participants

A total of 226 youth with epilepsy were included in the study. The sociodemographic and disease-related characteristics of all participants are shown in Table 1. The 66th percentile of the KSSE was 10. Thus, 83 participants (36.7%) reached the cutoff, which indicated the presence of stigma. In addition, 147 (65.0%) youth stated that they would kept epilepsy secret from others. Among the participants, 160 (70.8%) had PARS-3 scores ≤ 19, 57 (25.2%) scored 20–42, and 9 (4.0%) scored ≥ 43.

Association between stigma, physical activity and psychological distress

As shown in Fig. 2, scores in all dimensions of psychological distress increased significantly ($P < 0.01$) with increasing levels of stigma, while psychological distress decreased significantly ($P < 0.01$) with increasing levels of PA. Table 2 shows the multivariate linear regression analysis of the associations of the continuous variables. Stigma was significantly associated with all dimensions of psychological distress after controlling for variables. PA was negatively associated with psychological distress on all dimensions. In addition, intensity and duration were negatively associated with the depression, anxiety, and stress dimensions, and frequency was negatively associated with the anxiety and stress dimensions.

Mediating effect of physical activity

According to the hypothesis 3 proposed in this study, we use SPSS PROCESS (3.4) to establish a simple mediating model. The mediating effect of PA on the relationship between stigma and different psychological distress is further depicted in Table 3; Fig. 3. PA mediates between stigma and three dimensions of psychological distress (ab = 0.042, 95%CI: 0.016 to 0.068; ab = 0.077, 95%CI: 0.054 to 0.099; ab = 0.092, 95%CI: 0.061 to 0.122).

Mediating effects of physical activity components

A more detailed analysis of the mediating effects of the PA components is presented in Table 4; Fig. 4. Results showed the mediating effects of intensity, duration, and frequency on stigma and psychological distress dimensions. Intensity (ab = 0.027, 95%CI: 0.007 to 0.048) mediated the relationship between stigma and anxiety dimension. Duration (ab = 0.023, 95%CI: 0.002 to 0.044; ab = 0.034, 95%CI: 0.015 to 0.055;ab = 0.037, 95%CI: 0.012 to 0.061) mediated between stigma and all psychological distress dimensions. Moreover, frequency (ab = 0.028, 95%CI:0.010 to 0.049) only mediated the relationship between stigma and stress dimension.

Discussion

The objective of this study was to analyse the mediating effect of physical activity (PA) between epilepsy-related stigma and psychological distress dimensions in youth with epilepsy. The results indicated that stigma had a positive relationship with all dimensions of psychological distress, and that PA had a mediating effect after controlling for variables (depression 95%CI: 0.016 to 0.068; anxiety 95%CI: 0.054 to 0.099; stress 95%CI: 0.061 to 0.122). In addition, each of the PA components partially mediated the association between stigma and psychological distress. To the best of our knowledge, this was the first study to examine the effect of PA on the mediation of the relationship between stigma and psychological distress in Chinese youth with epilepsy.

This study found that the prevalence of stigma in children and adolescents with epilepsy was 36.7%, which is

Table 1 Sociodemographic and disease-related characteristics of study participants

Variables	Classification	Number (%)
Age (years)	8–11	102 (45.1%)
	12–14	82 (36.3%)
	15–18	42 (18.6%)
Gender	Male	118 (52.2%)
	Female	108 (47.8%)
One-child family	Yes	55 (24.3%)
	No	171 (75.7%)
Place of residence	City	75 (33.2%)
	Town	76 (33.6%)
	Rural	75 (33.2%)
Average monthly household income (yuan)	< 3, 000	58 (25.7%)
	3, 000–5, 000	82 (36.3%)
	5, 001–10, 000	49 (21.7%)
	> 10, 000	27 (16.4%)
BMI (kg/m2)	< 18.5	73 (32.4%)
	18.5–23.9	138 (61.3%)
	≥ 24	14 (6.2%)
Epilepsy duration (year)	< 1 years	45 (20.0%)
	1–5 years	112 (49.8%)
	> 5 years	68 (30.2%)
Seizure type	Focal onset	115 (50.9%)
	Generalized onset	68 (30.1%)
	Mixed	19 (8.4%)
	Unknown or unclassified	24 (10.6%)
Seizure frequency in recent 3 months	0	83 (36.7%)
	1–3	100 (44.2%)
	4–12	28 (12.4%)
	> 12	15 (6.6%)
Drug-resistant epilepsy	Yes	38 (16.8%)
	No	188 (83.2%)
Comorbidity	Yes	122 (54.0%)
	No	104 (46.0%)

Note: BMI: body mass index [46]

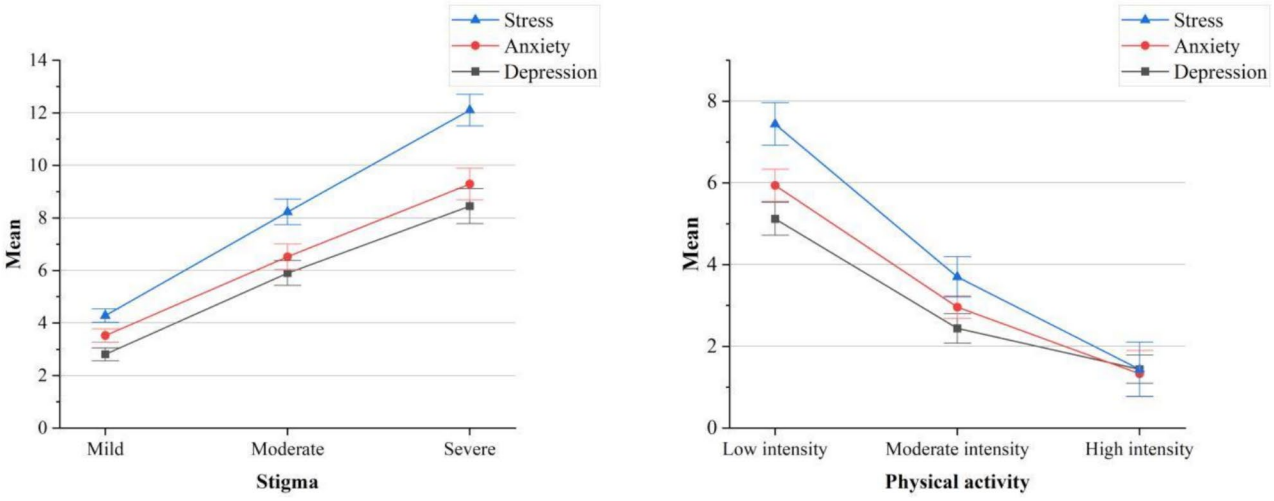

Fig. 2 The relationship between stigma, physical activity, and psychological distress in youth with epilepsy

Table 2 Multivariate linear regression analysis of associations between stigma, PA, and psychological distress

Variables	Mean (SD)	Depression		Anxiety		Stress	
		β (95%CI)	*p*	β (95%CI)	*p*	β (95%CI)	*p*
Stigma	9.761 ± 6.916	0.316 (0.287 to 0.346)	**< 0.001**	0.326 (0.298 to 0.355)	**< 0.001**	0.452 (0.416 to 0.487)	**< 0.001**
Physical activity	16.058 ± 11.648	-0.146 (-0.169 to -0.124)	**< 0.001**	-0.164 (-0.184 to -0.144)	**< 0.001**	-0.221 (-0.249 to -0.194)	**< 0.001**
Activity intensity	2.283 ± 0.961	-0.415 (-0.678 to -0.151)	**0.002**	-0.601 (-0.842 to -0.361)	**< 0.001**	-0.457 (-0.760 to -0.154)	**0.003**
Activity duration	2.289 ± 1.001	-0.418 (-0.671 to -0.164)	**< 0.001**	-0.626 (-0.857 to -0.395)	**< 0.001**	-0.692 (0.983 to -0.400)	**< 0.001**
Activity frequency	2.956 ± 1.078	-0.190(-0.408 to 0.028)	0.087	-0.283 (-0.482 to -0.085)	**0.005**	-0.603 (-0.854 to -0.353)	**< 0.001**

Note: Covariates: age, gender, one-child family, place of residence, average monthly household, income, and seizure type. Significant effects are shown in bold

Table 3 The general mediating effect of PA on the relationship between stigma and psychological distress

Independent variable	Mediating variable	Dependent variable	Coefficient (bias – correctedbootstrap95% CI)		
Stigma	PA	Psychological distress	Indirect effect (ab)	Total effect (c)	Direct effect (c')
		[1]Depression	**0.042(0.016, 0.068)**	**0.316(0.282, 0.346)**	**0.274(0.263, 0.316)**
		[2]Anxiety	**0.077(0.054, 0.099)**	**0.324(0.298,0.355)**	**0.250(0.212, 0.288)**
		[3]Stress	**0.092(0.061, 0.122)**	**0.452(0.416, 0.487)**	**0.360(0.312, 0.408)**

Note: covariates: age, gender, one-child family, place of residence, average monthly household income, and seizure type. Significant effects are shown in bold. The superscript number is the mediation model number

slightly higher than previous studies using the same scale in south-western Uganda (34%) [47], patients aged over 16 in China (34. 29%) [48], and 189 patients between the ages of 18–74 (32.27%) [49]. Moreover, Our study found that 65% of youth with epilepsy did not tell others about their disease (which could be a symbol of stigma), which were also slightly higher than for other age groups [50]. The high prevalence of stigma might indicate the huge influence of epilepsy on social life in China. Further more studies are needed to determine the status of children's stigma in China. In addition, the low level of physical activity exhibited by 70.8% of participants in the current study is a cause for concern. Youth with epilepsy are not meeting the recommended levels of physical activity, indicating a need for increased engagement in physical activity [51]. This finding is in line with previous meta-analysis that found people with epilepsy are less active than their peers for a variety of reasons including prejudice, stigma, fear, shame, lack of knowledge or medical advice [52]. Youth with epilepsy often suffer from stigma and psychological distress. Our findings confirmed that the relationship between stigma and psychological distress, that is, youth who experienced more stigma were at greater risk of psychological distress, including depression, anxiety, and stress, with hypothesis H1 being valid. Previous research has highlighted the deleterious effects of stigma on psychosocial and behavioral health of adults with epilepsy [53]. A study of adults with epilepsy in

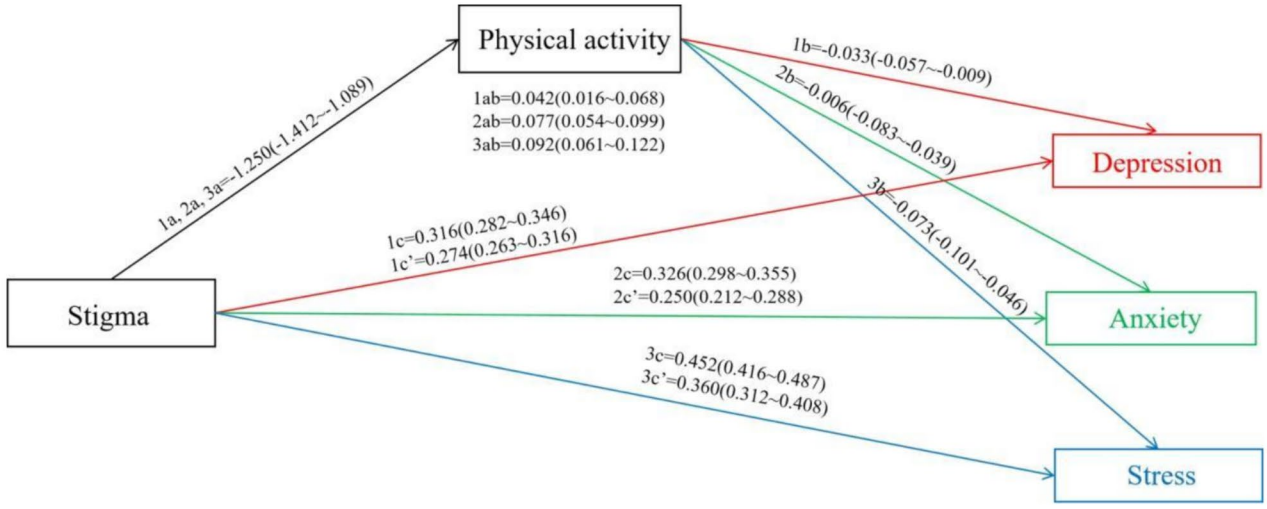

Fig. 3 Mediation model for the relationship between stigma and psychological distress (depression, anxiety, stress), mediated by PA. Covariates: age, gender, one-child family, place of residence, average monthly household income, and seizure type. The figure shows only data with a significant effect

Table 4 Summary of mediation analysis for stigma, PA components, and psychological distress

Independent variable	Mediating variable	Dependent variable	Coefficient (bias – correctedbootstrap95% CI)		
Stigma	**PA**	**Psychological distress**	**Indirect effect (ab)**	**Total effect (c)**	**Direct effect (c')**
	Intensity				
		[1]Depression	0.019(0.000, 0.040)	0.316(0.229, 0.346)	0.298(0.262, 0.333)
		[2]Anxiety	**0.027(0.007, 0.048)**	**0.324(0.298, 0.355)**	**0.300(0.266, 0.333)**
		[3]Stress	0.005(-0.017, 0.031)	0.452(0.416, 0.487)	0.446(0.404, 0.489)
	Duration				
		[4]Depression	**0.023(0.002, 0.044)**	**0.316(0.787, 0.346)**	**0.294(0.258, 0.330)**
		[5]Anxiety	**0.034(0.015, 0.055)**	**0.326(0.298, 0.355)**	**0.292(0.259, 0.326)**
		[6]Stress	**0.037(0.012, 0.061)**	**0.452(0.416, 0.487)**	**0.415(0.373, 0.457)**
	Frequency				
		[7]Depression	0.002(-0.013, 0.017)	0.316(0.287, 0.346)	0.315(0.281, 0.348)
		[8]Anxiety	0.002(-0.011, 0.016)	0.326(0.298, 0.355)	0.324(0.292, 0.356)
		[9]Stress	**0.028(0.010, 0.049)**	**0.452(0.416, 0.487)**	**0.423(0.385, 0.463)**

Note: covariates: age, gender, one-child family, place of residence, average monthly household income, and seizure type. Significant effects are shown in bold. The superscript number is the mediation model number

India found that overall perceived stigma strongly contributes 32.9% to the variance on stress, anxiety, and depression [54]. Similarly, Mar et al. [55] and Zhao et al. [56] have demonstrated that perceived stigma is strongly associated with increased depression severity, which in turn increases the suicide risk in people with epilepsy. Together, these findings reveal a complex stigma-mental disorder mechanism. Future studies are needed to measure and analyze the relationship between variables in longitudinal analysis.

While the benefits of regular participation in physical activity for youth are clear, youth with epilepsy are often excluded from physical exercise [57, 58]. Data analysis revealed that stigma was negatively correlated with physical activity. Youth with epilepsy may be reluctant to go outside due to concerns about the possibility of an involuntary loss of control in public places [4]. Moreover, Chinese culture and folk traditions may have diminished the status of people with epilepsy, considered by many a terrible and incurable disease [9]. The internalization of negative images about epilepsy may also dampen engagement in physical activities [31]. The mediation effect analysis revealed that the PA total score plays a partial mediating role between stigma and psychological distress dimensions. The analysis suggests that PA may act as a stress reliever, as it is known to produce endorphins and facilitate social connection [59]. Experimental studies have indicated that PA may provide mechanisms of neuronal protection, including the release of β-endorphins and steroids [60]. Epileptic discharges may decrease or disappear during exercise [61]. A Brazilian study documented that physical inactivity is a risk factor for the

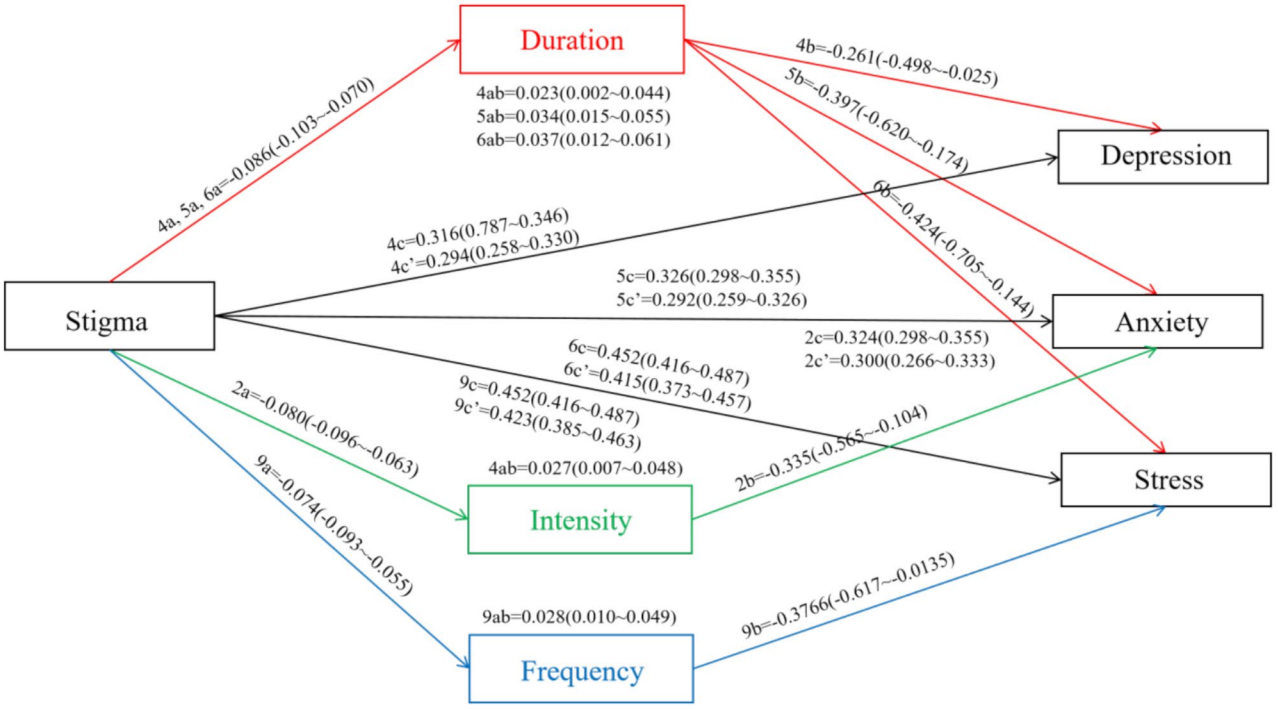

Fig. 4 Mediation model for the relationship between stigma and psychological distress (depression, anxiety, stress), mediated by physical activity components (intensity, duration, and frequency). Covariates: age, gender, one-child family, place of residence, average monthly household income, and seizure type. The figure shows only data with a significant effect

development of depression and anxiety in people with epilepsy [62]. Therefore, it is important for PA to reduce the adverse effect of stigma on psychological distress. Several studies have demonstrated that PA can help reduce stigma and improve psychological distress in children and adults with epilepsy [63, 64], which is also in line with our results.

To gain a more comprehensive understanding of the moderating effect of physical activity, this study extended the concept to include activity intensity, duration, and frequency. Different PA components are mediated in different psychological distress dimensions. The duration of PA was found to exert a moderating effect on depression, anxiety, and stress; intensity and frequency only had moderating effects in the anxiety and stress dimensions, with hypothesis H2 and H3 being valid. Youth with epilepsy should prioritize increasing the duration of PA. In fact, the mechanisms underlying the effects of PA on psychological distress remain unclear. Likewise, studies of the relationship between intensity, duration, and frequency of physical activity and psychological distress are inconsistent [65]. Further research could consider the inclusion of activity frequency, intensity and duration variables to assess the specific needed of youth with epilepsy.

In general, appropriate education and advice about particular types of physical activity is fundamental to avoid perceived risk of adverse events. Of note and interest, current evidence suggests that few restrictions are needed for youth with epilepsy, beyond water-related precautions and avoiding very risky activities [66, 67]. Thus, Schools should ensure that children and young people with epilepsy are included and supported to participate in physical activity and exercise without undue restriction. Meanwhile, clinicians should incorporate an assessment of physical activity into routine obtain medical history and provide physical activity recommendations and plans for families of children with epilepsy, further emphasizing the need to train health professionals to provide advice on physical activity [68]. Importantly, an individual medical advice is also needed to consider safety in specific sports and in those where seizures have not been well controlled. However, there remains a lack of evidence on the specific details of exercise prescription in epilepsy and future more work is needed [66].

Our results offer new insights into this research field. First, this study reaffirms the importance of interventions that enhance the physical activity of youth with epilepsy. School-based programs may provide children and adolescents with epilepsy for social and physical activities. Second, previous studies have mostly focused on the influencing factors of stigma and psychological distress [27, 54], and seldom delve deeper into the internal

relationships between variables, whereas the mediation effect allows to analyse direct and indirect effects between variables in a clear way. Our research provide theoretical basis and empirical support for reducing or delaying the occurrence of psychological distress. Physical exercise and psychoeducation can reduce the burden of epilepsy and improve the overall quality of life by reducing perceived stigma [59, 64]. Policymakers and practitioners can launch a range of public awareness campaigns to reduce stigma and stereotypes about epilepsy and raise awareness of mental health issues in epilepsy.

While this study has provided new insight into the potential mediating role of physical activity between stigma and psychological distress in youth with epilepsy, there are still limitations that need to be addressed in future studies. Firstly, the cross-sectional study could not analyze the causal relationship between variables, merely indicating correlations. In the future, longitudinal designs can be used to confirm the mediational models proposed in this study. Secondly, with 45.1% of the youth with epilepsy under 12 years old, caution is advised when interpreting the study's findings. Future research should use larger samples and more detailed age distribution analyses to validate our findings. Thirdly, self-report measures of PA measures are prone to inaccuracies. PA as measured by wearable technology should be more reliable. Furthermore, more detailed information about physical activity is needed, including types of physical activity (e.g., aerobic, resistance, and flexibility), metabolic equivalents (METS), and other personal factors that may influence participation. Fourthly, while this study controlled for seizure type, the influence of disease conditions on the mental and physical well-being of youth with epilepsy should not be overlooked. Future studies should further investigate the impact of disease factors on study outcomes, with a focus on subgroup analyses of seizure type, antiseizure medication (ASMs), and comorbidities.

Conclusions

This study demonstrates the possible influencing mechanism of stigma on the psychological distress of youth with epilepsy. The stigmatization of epilepsy in youth is a significant factor contributing to psychological distress, exerting both direct and indirect effects through physical activity as a mediator. Furthermore, duration exerts a more profound moderating influence than intensity and frequency. The findings indicate that promoting higher levels of physical activity, including increasing the duration of exercise, may be an effective intervention for improving the mental health of youth with epilepsy.

Abbreviations

ANOVA	One-way Analysis of Variance
ASMs	Anti-Seizure Medications
DASS-21	The Depression Anxiety and Stress Scale 21
KSSE	The Kilifi Stigma Scale for Epilepsy
METS	Metabolic Equivalents
PA	Physical Activity
PARS-3	The Physical Activity Rating Scale 3
SNK	Student-Newman-Keuls

Acknowledgements

The authors are particularly grateful to the Pediatric Neurology Care Professional Committee of the Chinese Pediatric Nursing Union and all nursing managers for their support of this study. The authors thank all participants for their valuable contributions.

Author contributions

JZh and SL conceived of and designed the study. JZh contributed to data collection, performed data analysis, and wrote the original draft to and final version of the paper. SL contributed to subject recruitment, funding acquisition, oversight, and revision of the manuscript. NZ contributed to the final version of the paper. JZe and YX mainly responsible for the data validation. TW and QX contributed to data collection. All authors reviewed the manuscript.

Funding

This work was supported by the Hospital of Chongqing Medical University Nursing hospital-level key project (CHCQMU2023.02), and the China Association Against Epilepsy (CAAE) Epilepsy Care - Kang Zhe Foundation (CK-2024-053).

Data availability

No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate

The study was approved by the Medical Ethical Committee of Children's Hospital of Chongqing Medical University (Approval ID: No. 2023 – 370). All of the participants provided oral consent and expressed their willingness to complete the study. Additionally, participants' legal guardians/next of kin were provided their written informed consent to participate in this study.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

Received: 28 July 2024 / Accepted: 25 April 2025
Published online: 14 May 2025

References

1. Beghi E. The epidemiology of epilepsy. Neuroepidemiology. 2019;54(2):185–91.
2. Stafstrom CE, Carmant L. Seizures and epilepsy: an overview for neuroscientists. Cold Spring Harb Perspect Med. 2015;5(6).
3. Demirci S, Dönmez CM, Gündoğar D, Baydar CL. Public awareness of, attitudes toward, and understanding of epilepsy in Isparta, Turkey. Epilepsy Behav. 2007;11(3):427–33.
4. Stangl AL, Earnshaw VA, Logie CH, et al. The health stigma and discrimination framework: a global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas. BMC Med. 2019;17(1):31.
5. Scott AJ, Sharpe L, Loomes M, Gandy M. Systematic review and meta-analysis of anxiety and depression in youth with epilepsy. J Pediatr Psychol. 2020;45(2):133–44.
6. Kanner AM. Management of psychiatric and neurological comorbidities in epilepsy. Nat Rev Neurol. 2016;12(2):106–16.
7. Austin JK, Birbeck G, Parko K, et al. Epilepsy-related stigma and attitudes: systematic review of screening instruments and interventions - report by the international league against epilepsy task force on stigma in epilepsy. Epilepsia. 2022;63(3):598–628.

8. Jacoby A, Snape D, Baker GA. Epilepsy and social identity: the stigma of a chronic neurological disorder. Lancet Neurol. 2005;4(3):171–8.
9. Ding D, Zhou D, Sander JW, Wang W, Li S, Hong Z. Epilepsy in China: major progress in the past two decades. Lancet Neurol. 2021;20(4):316–26.
10. Kleinman A, Wang WZ, Li SC, et al. The social course of epilepsy: chronic illness as social experience in interior China. Soc Sci Med. 1995;40(10):1319–30.
11. Yang RR, Wang WZ, Snape D, et al. Stigma of people with epilepsy in China: views of health professionals, teachers, employers, and community leaders. Epilepsy Behav. 2011;21(3):261–6.
12. Fisher RS. Epilepsy from the patient's perspective: review of results of a community-based survey. Epilepsy Behav. 2000;1(4):S9–14.
13. Kwon CS, Jacoby A, Ali A, et al. Systematic review of frequency of felt and enacted stigma in epilepsy and determining factors and attitudes toward persons living with epilepsy-report from the international league against epilepsy task force on stigma in epilepsy. Epilepsia. 2022;63(3):573–97.
14. Cobham VE, Hickling A, Kimball H, Thomas HJ, Scott JG, Middeldorp CM. Systematic review: anxiety in children and adolescents with chronic medical conditions. J Am Acad Child Adolesc Psychiatry. 2020;59(5):595–618.
15. LaGrant B, Marquis BO, Berg AT, Grinspan ZM. Depression and anxiety in children with epilepsy and other chronic health conditions: national estimates of prevalence and risk factors. Epilepsy Behav. 2020;103:106828. Pt A).
16. Mula M, Sander JW. Psychosocial aspects of epilepsy: a wider approach. BJPsych Open. 2016;2(4):270–4.
17. Baca CB, Vickrey BG, Hays RD, Vassar SD, Berg AT. Differences in child versus parent reports of the child's health-related quality of life in children with epilepsy and healthy siblings. Value Health. 2010;13(6):778–86.
18. Price P, Kobau R, Buelow J, Austin J, Lowenberg K. Improving understanding, promoting social inclusion, and fostering empowerment related to epilepsy: epilepsy foundation public awareness campaigns–2001 through 2013. Epilepsy Behav. 2015;44:239–44.
19. Gavan L, Hartog K, Koppenol-Gonzalez GV, et al. Assessing stigma in low- and middle-income countries: a systematic review of scales used with children and adolescents. Soc Sci Med. 2022;307:115121.
20. Arvidsdotter T, Marklund B, Kylén S, Taft C, Ekman I. Understanding persons with psychological distress in primary health care. Scand J Caring Sci. 2016;30(4):687–94.
21. Khalid A, Aslam N. Psychological distress among patients with epilepsy. Indian J Psychol Med. 2011;33(1):45–8.
22. Polanczyk GV, Salum GA, Sugaya LS, Caye A, Rohde LA. Annual research review: a meta-analysis of the worldwide prevalence of mental disorders in children and adolescents. J Child Psychol Psychiatry. 2015;56(3):345–65.
23. Suurmeijer TP, Reuvekamp MF, Aldenkamp BP. Social functioning, psychological functioning, and quality of life in epilepsy. Epilepsia. 2001;42(9):1160–8.
24. Temple J, Fisher P, Davies C, Millar C, Gemma Cherry M. Psychosocial factors associated with anxiety and depression in adolescents with epilepsy: a systematic review. Epilepsy Behav. 2023;149:109522.
25. Rodriguez-Ayllon M, Cadenas-Sánchez C, Estévez-López F, et al. Role of physical activity and sedentary behavior in the mental health of preschoolers, children and adolescents: a systematic review and meta-analysis. Sports Med. 2019;49(9):1383–410.
26. Capovilla G, Kaufman KR, Perucca E, Moshé SL, Arida RM. Epilepsy, seizures, physical exercise, and sports: a report from the ILAE task force on sports and epilepsy. Epilepsia. 2016;57(1):6–12.
27. Tedrus GMAS, Sterca GS, Pereira RB. Physical activity, stigma, and quality of life in patients with epilepsy. Epilepsy Behav. 2017;77:96–8.
28. Wilfred AM, Humphreys C, Patterson S, et al. Being physically active with epilepsy: insights from young people and their parents. Epilepsy Res. 2022;188:107035.
29. Wang K, Yang Y, Zhang T, Ouyang Y, Liu B, Luo J. The relationship between physical activity and emotional intelligence in college students: the mediating role of self-efficacy. Front Psychol. 2020;11:967.
30. Duñabeitia I, Bidaurrazaga-Letona I, Diz JC, Colon-Leira S, García-Fresneda A, Ayán C. Effects of physical exercise in people with epilepsy: a systematic review and meta-analysis. Epilepsy Behav. 2022;137:108959. Pt A).
31. Dimitri P, Joshi K, Jones N. Moving more: physical activity and its positive effects on long term conditions in children and young people. Arch Dis Child. 2020;105(11):1035–40.
32. Zhao J, Li S, Zhang N, et al. Felt stigma and associated factors in children and adolescents with epilepsy: a multicenter cross-sectional study in China. Front Neurol. 2024;15:1459392.
33. Lin Y, Hu S, Hao X, et al. Epilepsy centers in China: current status and ways forward. Epilepsia. 2021;62(11):2640–50.
34. Fisher RS, Acevedo C, Arzimanoglou A, et al. ILAE official report: a practical clinical definition of epilepsy. Epilepsia. 2014;55(4):475–82.
35. Hohmann L, Berger J, Kastell SU, Holtkamp M. Perceived epilepsy-related stigma is linked to the socioeconomic status of the residence. Front Public Health. 2022;10:952585.
36. Songjiang L, Tijiang Z, Heng L, et al. Impact of brain functional network properties on intelligence in children and adolescents with focal epilepsy: a resting-state MRI study. Acad Radiol. 2021;28(2):225–32.
37. Mbuba CK, Ngugi AK, Fegan G, et al. Risk factors associated with the epilepsy treatment gap in Kilifi, Kenya: a cross-sectional study. Lancet Neurol. 2012;11(8):688–96.
38. Song J, Li Z, Li H, Sheng Y. The level and influence factors of stigma in people living epilepsy. Chin J Nurs. 2016;51(01):40–4.
39. Lovibond PF, Lovibond SH. The structure of negative emotional states: comparison of the depression anxiety stress scales (DASS) with the Beck depression and anxiety inventories. Behav Res Ther. 1995;33(3):335–43.
40. Zhang Z, Lin R, Qiu A, et al. Application of DASS-21 in Chinese students: invariance testing and network analysis. BMC Public Health. 2024;24(1):2934.
41. Li Y, Sun Q, Sun M, Sun P, Sun Q, Xia X. Physical exercise and psychological distress: the mediating roles of problematic mobile phone use and learning burnout among adolescents. Int J Environ Res Public Health. 2021;18(17).
42. Zanon C, Brenner RE, Baptista MN, et al. Examining the dimensionality, reliability, and invariance of the depression, anxiety, and stress scale-21 (DASS-21) across eight countries. Assessment. 2021;28(6):1531–44.
43. Yang G, Li Y, Liu S, Liu C, Jia C, Wang S. Physical activity influences the mobile phone addiction among Chinese undergraduates: the moderating effect of exercise type. J Behav Addict. 2021;10(3):799–810.
44. Yang G, Tan GX, Li YX, Liu HY, Wang ST. Physical exercise decreases the mobile phone dependence of university students in China: the mediating role of self-control. Int J Environ Res Public Health. 2019;16(21).
45. Liu XY, Peng SZ, Pei MY, Zhang P. The effects of physical activity on depression and quality of life in Chinese perimenopausal women. J Affect Disord. 2023;328:153–62.
46. Appropriate body-mass. Index for Asian populations and its implications for policy and intervention strategies. Lancet. 2004;363(9403):157–63.
47. Kirabira J, Nakawuki M, Fallen R, Zari Rukundo G. Perceived stigma and associated factors among children and adolescents with epilepsy in South Western Uganda: a cross sectional study. Seizure. 2018;57:50–5.
48. Wei Z, Ren L, Liu C, Cao M, Yang Q, Deng Y. The concept map of felt stigma in patient with epilepsy. Seizure. 2020;80:138–42.
49. Wei Z, Ren L, Yang L, et al. The relationship between social anxiety and felt stigma in patients with epilepsy: a network analysis. Seizure. 2021;92:76–81.
50. Li S, Wu J, Wang W, Jacoby A, de Boer H, Sander JW. Stigma and epilepsy: the Chinese perspective. Epilepsy Behav. 2010;17(2):242–5.
51. He L, Li Y, Chen Z. The effect of subjective exercise experience on exercise behavior and amount of exercise in children and adolescents: the mediating effect of exercise commitment. Int J Environ Res Public Health. 2022;19(17).
52. Vancampfort D, Ward PB, Stubbs B. Physical activity and sedentary levels among people living with epilepsy: a systematic review and meta-analysis. Epilepsy Behav. 2019;99:106390.
53. Ranjan LK, Gupta PR, Srivastava M. Perceived stigma and its association with stress, anxiety, and depression among patients with epilepsy. J Nerv Ment Dis. 2022;210(3):219–22.
54. Ranjan LK, Gupta PR, Srivastava M. Perceived stigma and its association with stress, anxiety, and depression among patients with epilepsy. J Nerv Ment Dis. 2022;210(3).
55. Mar Htwe Z, Lae Phyu W, Zar Nyein Z, Aye Kyi A. Correlation between depression and perceived stigma among people living with epilepsy. Epilepsy Behav. 2023;146:109372.
56. Zhao Y, Liu X, Xiao Z. Effects of perceived stigma, unemployment and depression on suicidal risk in people with epilepsy. Seizure. 2021;91:34–9.
57. van den Bogard F, Hamer HM, Sassen R, Reinsberger C. Sport and physical activity in epilepsy. Dtsch Arztebl Int. 2020;117(1–2):1–6.
58. Odintsova G, Alexandrov M, Kravtsova S, Loviagina A, Koloteva A. Epilepsy, physical activity, sports, seizures. J Neurol Sci. 2019;405.
59. Philippot A, Dubois V, Lambrechts K, et al. Impact of physical exercise on depression and anxiety in adolescent inpatients: a randomized controlled trial. J Affect Disord. 2022;301:145–53.
60. Allendorfer JB, Arida RM. Role of physical activity and exercise in alleviating cognitive impairment in people with epilepsy. Clin Ther. 2018;40(1):26–34.

61. Carrizosa-Moog J, Ladino LD, Benjumea-Cuartas V, et al. Epilepsy, physical activity and sports: a narrative review. Can J Neurol Sci / J Canadien Des Sci Neurologiques. 2018;45(6):624–32.
62. de Lima. Cd CA, Arida RM, et al. Association between leisure time, physical activity, and mood disorder levels in individuals with epilepsy. Epilepsy Behav. 2013;28(1):47–51.
63. Eom S, Lee MK, Park J-H, et al. The impact of a 35-week long-term exercise therapy on psychosocial health of children with benign epilepsy. J Child Neurol. 2016;31(8):985–90.
64. Kaur K, Sharma G, Dwivedi R, et al. Effectiveness of yoga intervention in reducing felt stigma in adults with epilepsy: a randomized controlled trial. Neurology. 2023;101(23):e2388–400.
65. Currier D, Lindner R, Spittal MJ, Cvetkovski S, Pirkis J, English DR. Physical activity and depression in men: increased activity duration and intensity associated with lower likelihood of current depression. J Affect Disord. 2020;260:426–31.
66. Carrizosa-Moog J, Ladino LD, Benjumea-Cuartas V, et al. Epilepsy, physical activity and sports: a narrative review. Can J Neurol Sci. 2018;45(6):624–32.
67. Motl RW, Sandroff BM, Pilutti LA, Klaren RE, Baynard T, Fernhall B. Physical activity, sedentary behavior, and aerobic capacity in persons with multiple sclerosis. J Neurol Sci. 2017;372:342–6.
68. Arida RM, Sales E, Teixeira-Machado L, Prado GFD, Gutierre RC, Carrizosa J. Neurologists' knowledge of and attitudes toward physical exercise for people with epilepsy in Latin America. Epilepsy Behav. 2022;131(Pt A):108705.

Publisher's note