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A Forty-year Bibliometric Analysis on the Stigma in Children with Epilepsy

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Abstract

Objective: Stigma in children with epilepsy is an important issue that negatively affects children with epilepsy and their immediate environment. However, examining the relevant literature revealed that systematic reviews on this subject were limited, and there was no bibliometric study. The aim of this study is to conduct a bibliometric analysis of the studies conducted over the past 40 years on stigma in children with epilepsy.

Methods: This study used the Web of Science Core Collection database. Articles in this widely used globally database were searched on August 14, 2024, using the following keywords: topic search (TS) = ("epilepsy" or "seizure" or "convulsion" or "epileptic" or "status epilepticus") and TS = ("stigma*" or "social stigma*" or "stereotyping" or "discriminat*" or "prejudice" or "social exclusion" or "social cohesion") and TS = ("child*" or "adolescent*" or "pediatric" or "preschool"). Original research articles published in English between 1980 and 2024 in the Social Sciences Citation Index, the Science Citation Index Expanded, and the Emerging Sources Citation Index were selected.

Results: In this study, a total of 883 articles in the Web of Science database were examined and analyzed. Studies on stigma in children with epilepsy have been increasing since the 1980s. Eight hundred eighty-three articles were published in 333 different journals, among which 47 included three or more related publications. The journals in which the relevant publications were published were Epilepsy and Behavior (n=221), Epilepsia (n=54), Seizure-European Journal of Epilepsy (n=41).

Conclusion: The number of published articles increased over the years, with more studies conducted in developed countries. In recent years, it has been observed that stigma in children with epilepsy has focused on topics such as quality of life and intervention. This study will guide researchers who will publish on stigma in children with epilepsy.

Keywords: Epilepsy, stigma, children, bibliometric study

INTRODUCTION

Epilepsy is a chronic neurological disorder, usually diagnosed during childhood and adolescence, that causes abnormal electrical activity in the brain and predisposes the individual to recurrent seizures.[1] The word epilepsy is derived from the Greek word epilepsia and can be divided into two separate words, epi (on) and lepsis (to hold or have a seizure).[2]

Epilepsy affects approximately 50 million people worldwide. Approximately 50% of epilepsy diagnoses are made during childhood and adolescence, affecting the lives of 10.5 million children under the age of 15.[3] The lifetime prevalence rate of epilepsy in children is 7.2 per 1,000 individuals. Approximately 5% of these individuals will have at least one epileptic seizure during their lifetime.[4] In recent studies, the prevalence of epilepsy has been reported as 139/100,000 in underdeveloped and developing countries and 49/100,000 in developed countries. Four out of five of individuals with epilepsy live in underdeveloped and developing countries.[3] Individuals with epilepsy in disadvantaged areas often do not receive treatment due to lack of access, which negatively affects both their physical and psychological health.[5]

Epilepsy and seizures are caused by genetic, structural, metabolic, infectious, immune, and unknown causes. These causes are not hierarchical and epilepsy can result from multiple causes.[6] Antiepileptic drugs are effective in epilepsy and can control the symptoms. The symptoms observed are effectively managed in 7/10 of individuals with epilepsy when using appropriate antiepileptic drugs.[3] Individuals with epilepsy and their families face difficulties. Discrimination and stigmatization are among the challenges faced by individuals with epilepsy.

Stigma is defined as a discrediting attitude towards those who deviate from the norms of society. It can be a source of social rejection, isolation and discrimination.[7] Stigmatization experienced by individuals with epilepsy is a global problem that negatively affects quality of life.[8,9] Stigma comes from ancient Greek and means "to carve, mark as a sign of shame, punishment or disgrace".[10] People with epilepsy may feel embarrassed and ashamed if they have seizures in public due to symptoms such as limb tremors, staring, chewing, and urinary or bowel incontinence.[11] Uncontrolled seizures in people with epilepsy can be very debilitating. People may even be afraid to go out of their homes unaccompanied. They may fear what people will think of them if they have a seizure in public. For these and similar reasons, epilepsy has been a culturally devalued condition throughout the world and throughout history.[12]

Stigma in epilepsy, is defined in two ways: felt by individuals and applied to them. Applied stigma refers to discriminatory behavior against individuals with epilepsy, which is also observable externally. Felt stigma, on the other hand, consists of the emotions that individuals associate with epilepsy. These emotions include shame, embarrassment and fear.[13] Stigma in epilepsy may lead to increased anxiety and depressive symptoms and decreased quality of life in individuals with epilepsy.[14]

In light of the above, this study aims to address the issue of stigma in children with epilepsy from a bibliometric perspective.

Bibliometric analysis is a systematic study of the scientific literature to identify patterns, trends and influences in a particular field. The major steps include collecting data from relevant databases, cleaning and refining the data, and subjecting the data to various bibliometric methods to produce meaningful knowledge. Bibliometric analysis is an increasingly popular and comprehensive technique for examining and evaluating large amounts of scientific data increasingly used in research.[15] It is reported that studies utilizing bibliometric analysis are more advantageous than traditional review studies. In addition to analyzing a large number of studies on the topic, it brings together the relevant literature in a systematic and comprehensive manner.[16] Traditional review studies can be based on the subjective understanding of the academics who conduct these reviews.[17]

There is no bibliometric study focusing on the concept of stigma in children with epilepsy in the relevant literature. This study aims to address the issue of stigma in children with epilepsy from a bibliometric perspective. Specifically, we focus on: (1) identifying the general trend of studies on stigma in children with epilepsy; (2) identifying studies on stigma in children with epilepsy by topics, articles, journals, countries, etc.; (3) identifying trending topics and gaps in studies on stigma in children with epilepsy. By examining the studies on stigma in children with epilepsy in the last 40 years, this study will pave the way for new research by guiding researchers on this topic.

MAIN POINTS

- Stigmatization experienced by individuals with epilepsy is a global problem that negatively affects quality of life.
- This study aims to address the issue of stigma in children with epilepsy from a bibliometric perspective.
- Specifically, we focus on: (1) identifying the general trend of studies on stigma in children with epilepsy (2) identifying studies on stigma in children with epilepsy by topics, articles, journals, and countries (3) identifying trending topics and gaps in studies on stigma in children with epilepsy.

METHODS

The aim of this study is to examine how the studies on stigma in children with epilepsy have developed since 1980 and to assess the current situation. For this purpose, the articles published on this subject, authors, institutions, country collaborations, number of citations, and trending topics are analyzed.

Data Collection

This study used the Web of Science (WOS) Core Collection database. Articles in this globally widely used database were searched on August 14, 2024, using the following keywords: topic search (TS) = ("epilepsy" or "seizure" or "convulsion" or "epileptic" or "status epilepticus") and TS = ("stigma*" or "social stigma*" or "streotyping" or "discriminat*" or "prejudice" or "social exclusion" or "social cohesion") and TS = ("child*" or "adolescent*" or "pediatric" or "preschool"). Original research articles published in English between 1980 and 2024 in the Social Sciences Citation Index (SSCI), the Science Citation Index Expanded (SCI-EXPANDED) and the Emerging Sources Citation Index (ESCI) were selected.

When keywords were entered into WOS, there were no restrictions on the type of literature, and 1,174 results were initially obtained. Two researchers independently assessed each publication and selected article as the document type, SSCI, SCI-EXPANDED and ESCI as the WOS index, and English as the language. Only articles were included in this study. Document types such as editorial material, meeting abstract, proceeding paper, and book chapter were not included. BibTeX and Tab Delimited File formats were downloaded from the WOS export section and analyses were performed on these files. In this study, a total of 883 articles were included in the analysis.

Statistical Analysis

We used the bibliometrix R open source package for quantitative research in bibliometrics to perform bibliometric analyses on the entire collection number.[18] As part of the bibliometric analysis in our study, we used biblioshiny to perform science mapping and performance analyses. Biblioshiny is a Web interface for bibliometrix that supports data import (www.bibliometrix.org/Biblioshiny.html), transformation into a data frame, data filtering, analysis and plots for sources, authors, and documents.[19,20]

VOSviewer, used in this study, is a software tool that allows creating maps based on network data and the visualization and analysis of these maps.[21]

Ethical Approval

The study was conducted as a bibliometric analysis. All data sources were available on the internet, and no animal or human subjects were involved. Ethics committee permission was not, therefore, required.

RESULTS

Main Information About Data

Our investigation into the stigma in children with epilepsy from 1980 revealed that 883 articles in English had been published in this domain cataloged within the SSCI, the SCI-EXPANDED, and the ESCI, with a total of 3,940 authors involved. The annual growth rate is 8.12% and the number of citations per study is 26.41 (Table 1).

Studies on stigma in children with epilepsy have been increasing since the 1980s, with fluctuations in some years. In general, there is a trend from the 1980s to the present day. While the number of publications was 2 in 1980, it increased to 10 in 2000, 28 in 2012, and 74 in 2021 (Figure 1). Although publications on stigma in children with epilepsy have increased over the years, the number remains insufficient relative to the total 883 articles published.

Table 1. Data information

Main information about data	
Timespan	1980:2024
Sources (journals, books, etc.)	333
Documents	883
Annual growth rate %	8.12
Document Average Age	9.3
Average citations per doc	26.41
References	24,299
Document contents	
Keywords Plus (ID)	1,848
Author's Keywords (DE)	2,084
Authors	
Authors	3,940
Authors of single-authored docs	48
Authors collaboration	
Single-authored docs	51
Co-authors per doc	5.41
International co-authorships %	27.63
Document types	
Article	763
Article; early access	8
Article; proceedings paper	14
Review	98

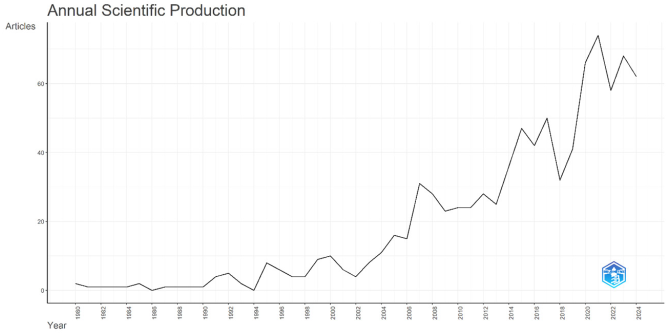

Figure 1. Annual scientific production

Bibliometric Analysis of Journals and Articles

In our study, we used Bradford's law to evaluate the journals in which publications on stigma in children with epilepsy were published. Bradford's law is a principle in bibliometrics. This law defines the distribution of scientific contributions in a field. It consists of the most cited first region, a less cited second region, and an even less cited third region. In essence, it identifies the key journals that contribute significantly to a particular field and allows researchers and information professionals to focus their attention on these key sources.[22] Epilepsy and Behavior, Epilepsia, and Seizure-European Journal of Epilepsy were found to be in zone 1 (Figure 2).

Epilepsy and Behavior is the leading journal for publications on epilepsy and seizures, focusing on clinical neurology, neurosurgery, neuropsychiatry, neuropsychology, neurophysiology, neuropharmacology, and neuroimaging. Epilepsia is a leading journal that publishes current clinical and research results on all aspects of epilepsy, focusing on clinical neurology, neurophysiology, molecular biology, neuroimaging, neurochemistry, and therapeutic trials. Seizure-European Journal of Epilepsy is a journal that publishes articles on all topics related to epilepsy and seizure disorders. The journal reflects on the social and psychological burden and impact of the condition on people with epilepsy, their families, and society at large, and methods and ideas that can help alleviate the disability and stigma that the condition can cause.

The most cited articles on stigma in children with epilepsy are "the global burden and stigma of epilepsy (de Boer et al.[12])," "epilepsy and social identity: stigmatization of a chronic neurological disorder (Jacoby et al.[23])", and "refractory epilepsy and treatment outcomes (Laxer et al.[24]) (Table 2).

Bibliometric Analysis of Authors, Institutions and Countries

The publications by authors on stigma in children with epilepsy were analyzed. The authors of the publications in the SSCI, the SCI-EXPANDED, and the ESCI databases in WOS were examined. A total of 3,940 authors wrote and published 883 articles, including 38 authors who published 5 or more related articles.

The author who published the most on stigma in children with epilepsy was Joan K Austin from Indiana University Faculty of Nursing. The second most published author is Gretchen L Birbeck from the University of Rochester. The third most published author was Ann Jacoby from the University of Liverpool (Figure 3).

Lotka's law reveals the quantitative distribution of the publications of authors contributing to the literature on a particular subject in that field. This is a study to examine the scientific productivity of the authors. Lotka's law predicts that 70% of the authors who publish on a subject contribute to the subject with one publication, 15% with two publications, and 7% with three publications.[25] Analysis of articles on stigma in children with epilepsy using Lotka's law revealed that 87.5% of the authors contributed only one article (n=3,446), 0.86% produced two articles (n=340), and 0.21% produced three articles (n=81). It was observed that the distribution of authors in the study did not follow Lotka's law (Figure 4).

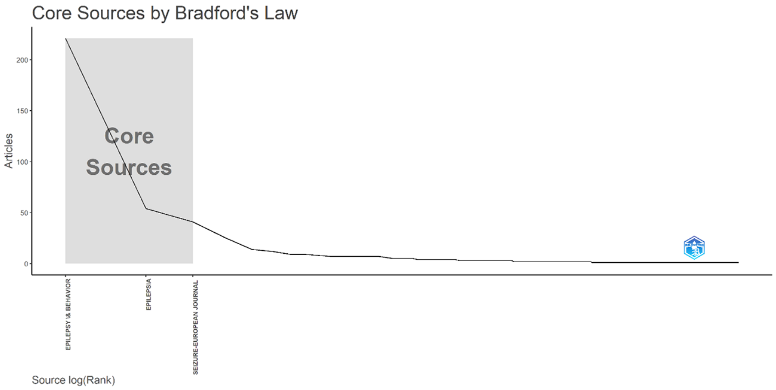

Figure 2. Bradford’s law

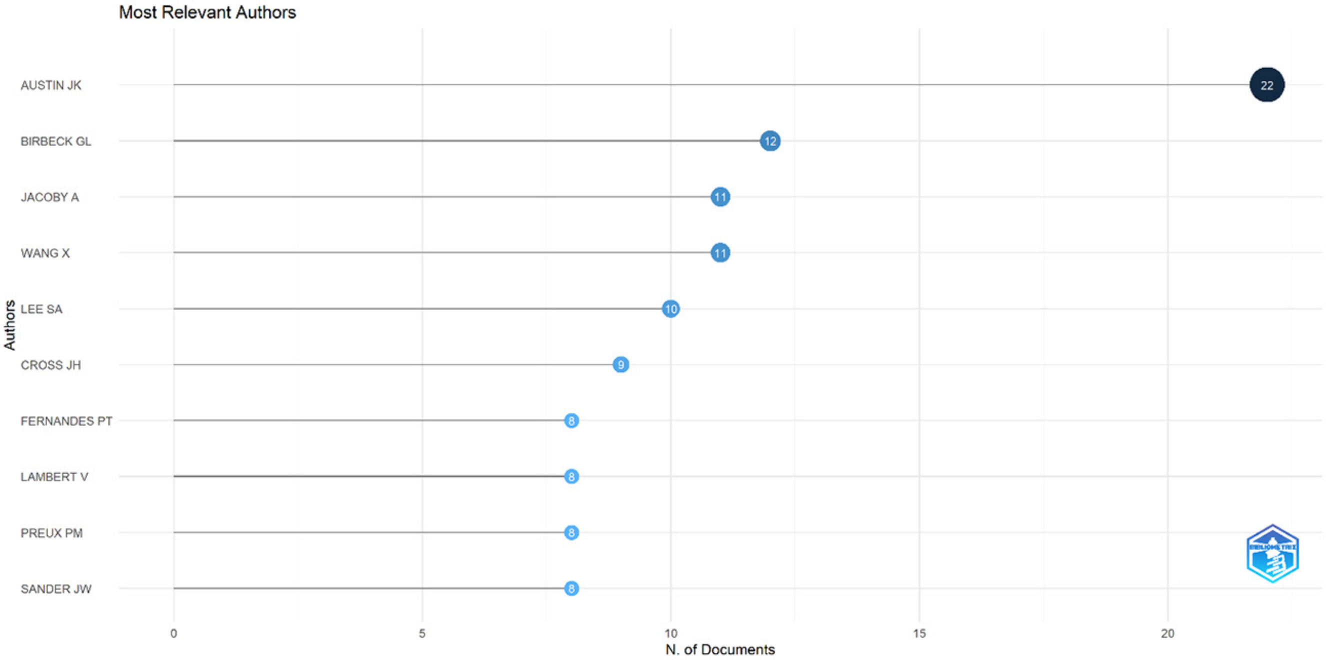

Figure 3. Most relevant authors

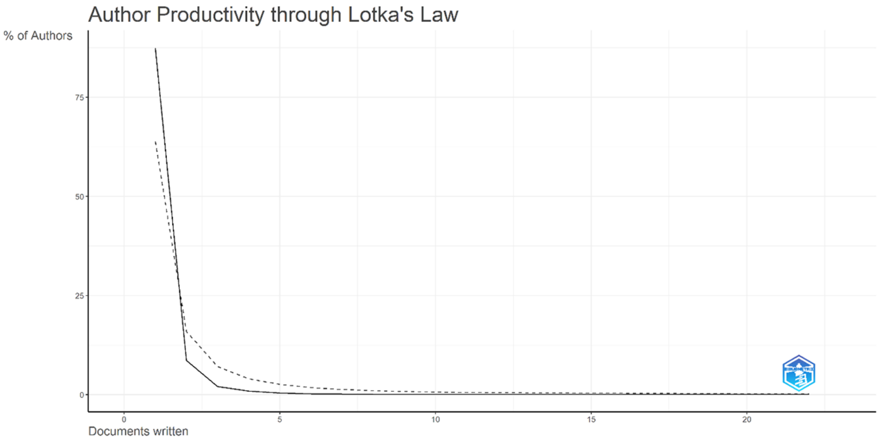

Figure 4. Author productivity through Lotka’s law

When most relevant affiliations were analyzed (Figure 5), the University of Liverpool (n=46) was at the top. This was followed by Makerere University (n=35), All India Institute of Medical Sciences (n=34), Indiana University (n=34), University of California, Los Angeles (n=31), and Harvard Medical School (n=29).

Analysis of scientific publications by country showed that the leading 10 countries (Figure 6) were: the United States of America (USA) (n=189), United Kingdom (n=71), Canada (n=64), China (n=36), Netherlands (n=31), India (n=28), France (n=25), Germany (n=25), Italy (n=25), Australia (n=25).

When inter-country cooperation on stigma in children with epilepsy was analyzed, it was observed that the greatest cooperation was between the USA and the United Kingdom (n=33), followed by USA-Canada (n=19), United Kingdom-Netherlands (n=16), USA-Zambia (n=13), Netherlands-Belgium (n=11), United Kingdom-Italy (n=11), United Kingdom-Kenya (n=11), USA-Uganda (n=11), USA-Ireland (n=10), United Kingdom-Brazil (n=9) (Figure 7).

Bibliometric Analysis of Keyword and Trend Topic Analyses

The most frequently used words in this study were children (n=307), stigma (n=199), quality of life (n=136), people (n=124), adolescents (n=119), knowledge (n=107), epilepsy (n=94), impact (n=91), attitudes (n=77), prevalence (n=73). Factor analysis of the keywords used in publications on stigma in children with epilepsy was performed. In the selected analysis, two clusters were identified, and words such as stigma, perceived stigma, quality of life, perceptions, childhood epilepsy, knowledge, risk factors, seizures, epilepsy, management, public awareness, and public attitudes formed the large group. In the second small group, the words seizure, disorders, anxiety, and depression came together (Figure 8).

In this study, the keywords in multiple studies on stigma in children with epilepsy were analyzed with VOSviewer. When the color and distribution of the boxes in this figure were examined, it was seen that such as anxiety, depression, childhood, risk factors, communication, and family were grouped together with the keyword epilepsy. In blue, words like discrimination, perceived stigma, disclosure, social supports, and parents were grouped together with the keyword stigma (Figure 9). This study also investigated the trend in the words used in stigma studies in children with epilepsy over the years. This revealed that the concepts used have changed over time (Figure 10).

DISCUSSION

In this study, it was observed that publications on stigma in children with epilepsy increased over the years from 1980 to 2024, with an annual growth rate of 8.12%. It was noteworthy that only 48 of the articles published by 3,940 researchers were single-authored, while the others were multi-authored. The fact that the number of citations of each of the studies in this study was 26.41 shows the scientific value of the studies. Although the number of articles published on stigma in children with epilepsy has increased over the years, it was also noteworthy that the number of publications was not high enough, considering the importance of the subject.

Epilepsy affects 50 million people worldwide, of which approximately 20% are children. Three scientific publications by country were analyzed, it was noteworthy that most publications were made in developed countries, and only India was among the top 10 countries from underdeveloped or developing countries. When the relevant literature was examined, it was reported that the prevalence of epilepsy was higher in underdeveloped and developing countries than in developed countries.[3] The examination of the findings in this study necessitates more research on this subject in underdeveloped or developing countries. One of the pleasing results obtained in this study is the increase in cooperation between developed and developing countries, indicated by the countries of the co-authors.

In this study, the most frequently used words were children, stigma, quality of life, people, adolescents, knowledge, epilepsy, impact, attitudes, and prevalence. Stigma negatively affects the quality of life in individuals with epilepsy.[8,9,14,26,27] The World Health

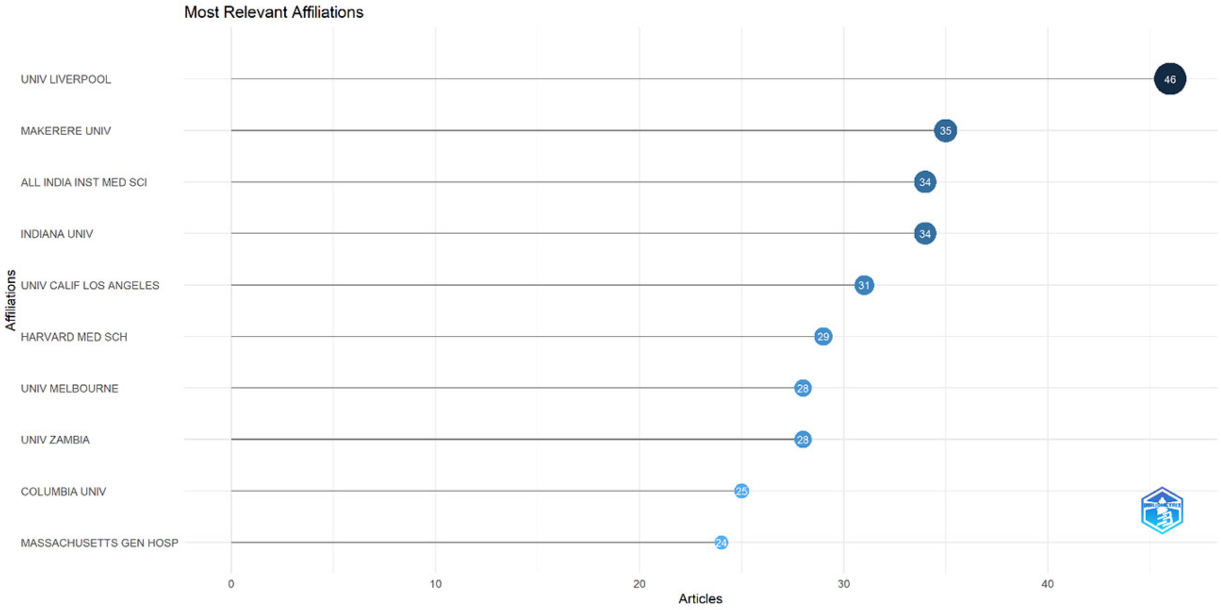

Figure 5. Most relevant affiliations

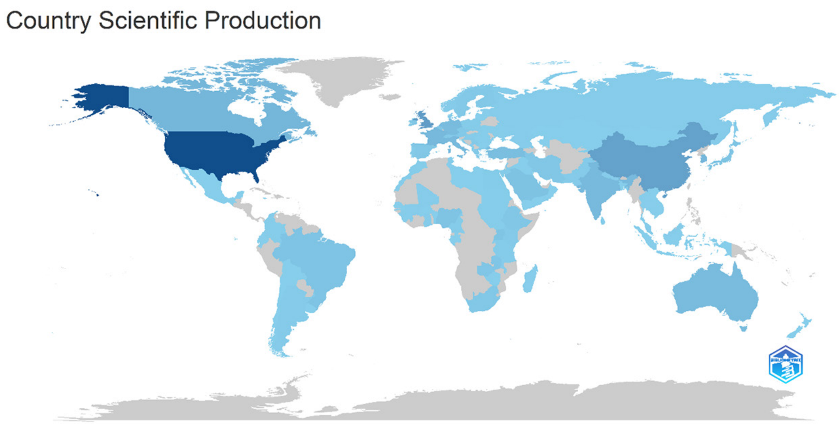

Figure 6. Country scientific production

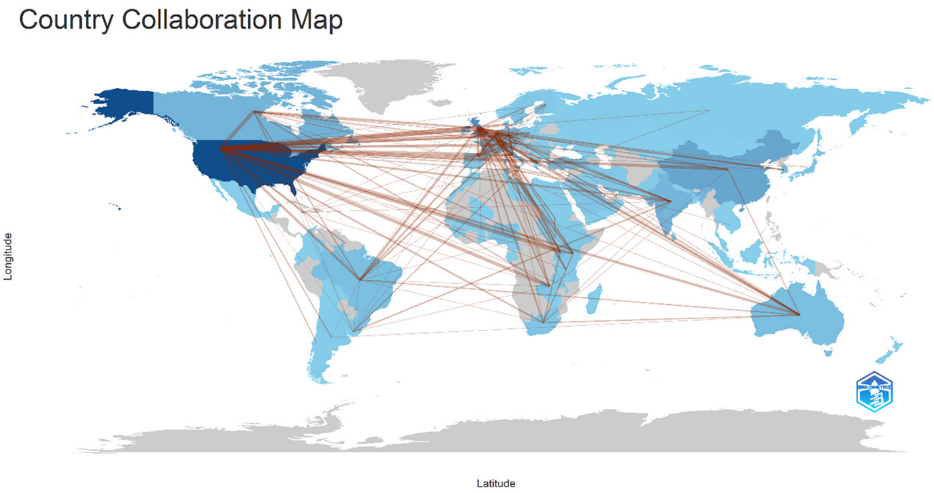

Figure 7. Country collaboration map

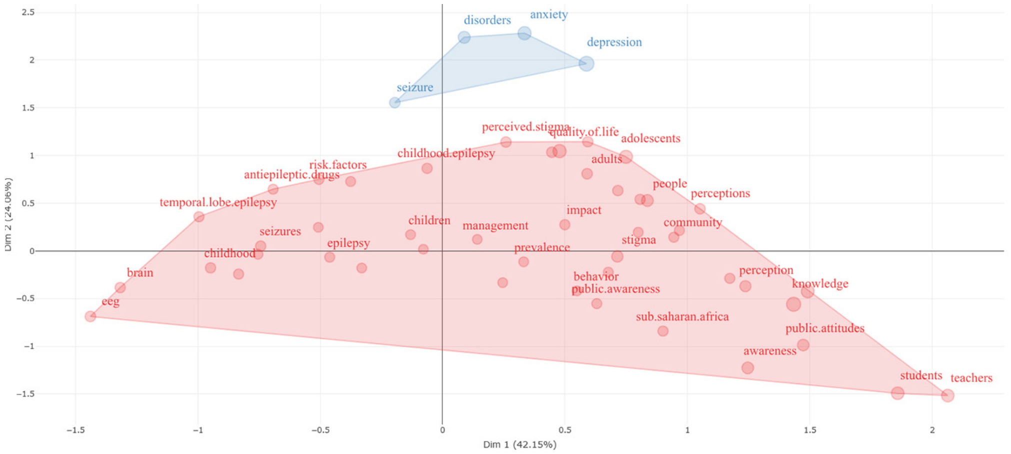

Figure 8. Keyword plus conceptual structure map of keywords

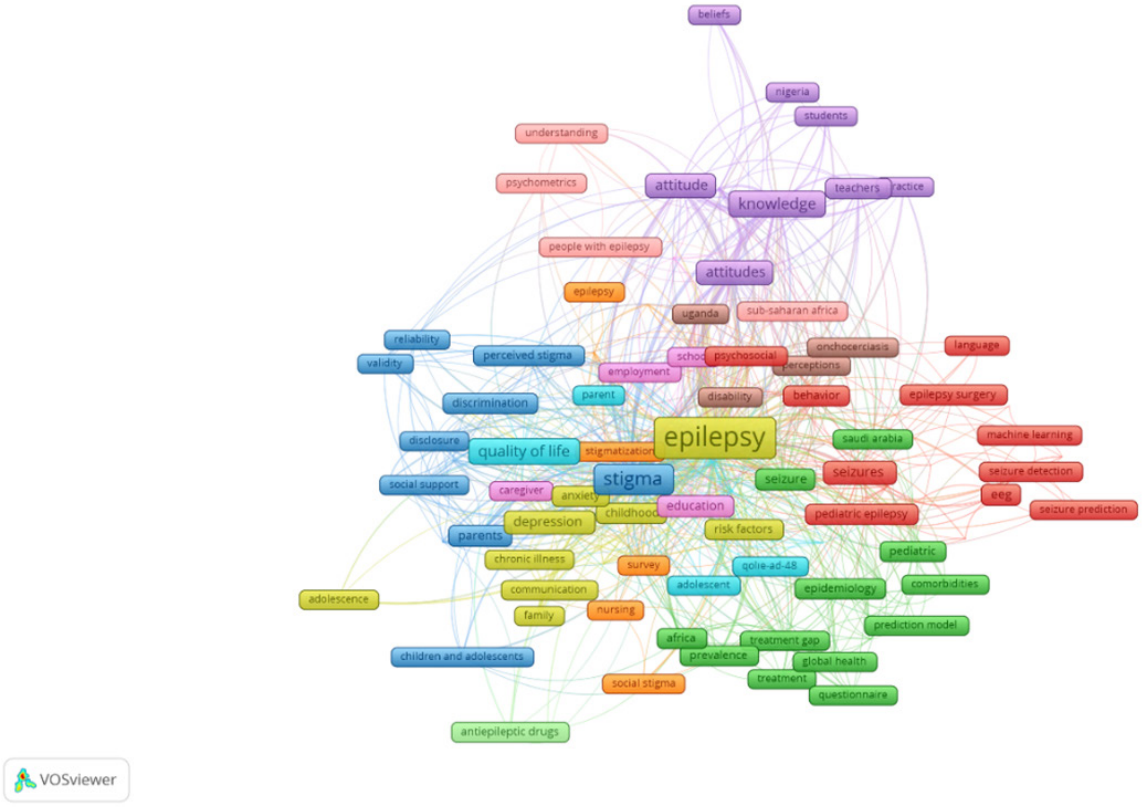

Figure 9. Authors keywords collaboration

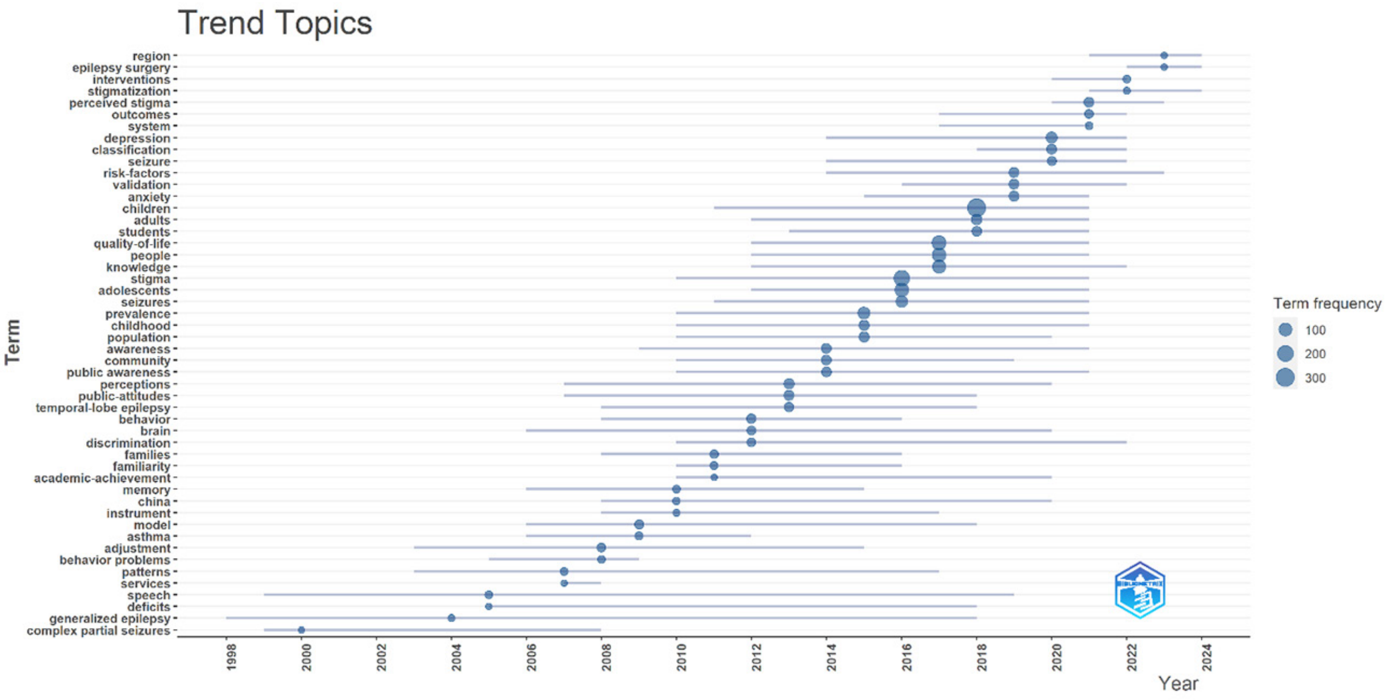

Figure 10. Trend topics

Organization defined quality of life as a state of complete physical, mental, and social well-being, not just the absence of disease or disability.[28] It states that quality of life in individuals with epilepsy depends on factors such as the type of epilepsy, frequency of seizures, whether seizures are controlled, antiepileptic drugs, as well as personal, social, or environmental factors.[29]

Children with epilepsy face low academic performance and school dropout due to bullying, alienation, and stigmatization.[30] The presence of stigma in children with epilepsy has negative consequences for both children and their families. Reducing stigma is important for successful epilepsy treatments.[31]

When the relevant literature is reviewed, difficulties such as educational barriers, stigma, and lack of access to treatment have been reported in many parts of the world for years. Efforts have been made to increase access to epilepsy treatment, especially in underdeveloped and developing countries where access to treatment is more limited. Difficulty in accessing treatment in epilepsy is not only a problem in low-income and developing countries. Difficulties in accessing treatment can also be seen in individuals with epilepsy living in developed countries.[32] Lack of knowledge about epilepsy negatively affects individuals with epilepsy and their families more significantly. The attitudes of the individuals who make up the society, consisting of erroneous thoughts, feelings and behaviors about epilepsy, increase the burden of stigma on individuals with epilepsy and their families.[33]

There is a comorbidity observed in individuals with epilepsy. Internalizing problems such as anxiety and depression, and psychiatric disorders such as autism spectrum disorder, and attention deficit hyperactivity disorder, are more common in children with epilepsy than previously thought. Although the common pathophysiology is not easily explained, these psychiatric disorders seen in children with epilepsy cause the picture to become more complex and may complicate treatment.[34]

Lack of accurate knowledge about epilepsy is associated with superstitions (e.g., madness and demons) in various civilizations.[35] Such devaluations often lead to stigmatization of people with epilepsy and carry a psychosocial burden.[12] The unpredictable nature of seizures can cause feelings of unhappiness, loneliness, hopelessness, low self-esteem and self-blame in people with epilepsy, which can lead to social isolation and stigmatization.[36]

It is known that individuals with advantageous social support cope better with difficulties.[37] It has been observed that the stigma felt in individuals with epilepsy has a negative relationship with the self-efficacy level. Identifying and strengthening the self-efficacy of children with epilepsy will facilitate the management of the disease.[38]

High levels of self-efficacy and social support are needed to achieve positive results in the treatment and management of epilepsy. In this way, their quality of life can be enhanced through positive effects in their academic and social lives. The stigma associated with epilepsy can be an obstacle for individuals with epilepsy to access treatment. Therefore, providing training aimed at increasing social awareness that epilepsy is a medical syndrome and that it is a treatable disease can help eliminate the factors that negatively affect the treatment of epilepsy.[39]

Table 2. Most cited articles[12,23,24,40-46]

No	Paper (DOI)	Author	PY	Journal	Total citations	TC per year
1	The global burden and stigma of epilepsy (10.1016/j.yebeh.2007.12.019)	De Boer et al.[12]	2008	Epilepsy and Behavior	573	33.71
2	The consequences of refractory epilepsy and its treatment (10.1016/j.yebeh.2014.05.031)	Laxer et al.[24]	2014	Epilepsy and Behavior	464	42.18
3	Epilepsy and social identity: the stigma of a chronic neurological disorder (10.1016/S1474-4422(05)01014-8)	Jacoby et al.[23]	2005	The Lancet Neurology	363	18.15
4	Global disparities in the epilepsy treatment gap: a systematic review (10.2471/BLT.09.064147)	Meyer et al.[40]	2010	Bulletin of the World Health Organization	307	20.46
5	A multivariate approach for patient-specific EEG seizure detection using empirical wavelet transform (10.1109/TBME.2017.2650259)	Bhattacharyya and Pachori[41]	2017	EEE Transactions on Biomedical Engineering	295	36.875
6	Periventricular heterotopia: an X-linked dominant epilepsy locus causing aberrant cerebral cortical development (10.1016/S0896-6273(00)80025-2)	Ekşioğlu et al.[42]	1996	Neuron	255	8.79
7	PI3K/AKT pathway mutations cause a spectrum of brain malformations from megalencephaly to focal cortical dysplasia (10.1093/brain/awv045)	Jansen et al.[43]	2015	Brain	251	25.1
8	Working, declarative and procedural memory in specific language impairment (10.1016/j.cortex.2011.06.001)	Lum et al.[44]	2012	Cortex	236	18.15
9	The treatment of epilepsy in developing countries: where do we go from here? (N/A)	Scott et al.[45]	2001	Bulletin of the World Health Organization	219	9.12
10	The fra(X) syndrome - neurological, electrophysiological, and neuropathological abnormalities (10.1002/ajmg.1320380267)	Wisniewski et al.[46]	1991	American Journal of Medical Genetics	203	5.97

Study Limitations

The principal limitations of this research are that databases such as Scopus, EMBASE, PubMed, Google Scholar, and Dimensions were not screened. Additionally, because the search terms were applied in English, a more comprehensive evaluation was not possible.

CONCLUSION

In this study, in which the issue of stigma in children with epilepsy was examined by bibliometric analysis, the fact that terms such as stigma and quality of life have been included more in studies since 2010 indicates that epilepsy, which is a neurological disease, should be handled with a holistic approach in both childhood and adolescence. Decreased stigma related to epilepsy, increased self-efficacy, and social support increase the quality of life. It is clear that increased knowledge and awareness of the child, family, friends, school, teachers, and other people about epilepsy facilitates epilepsy treatment.

When the relevant literature was examined, it was observed that researchers from underdeveloped or developing countries published fewer on stigma in children with epilepsy. Although there is a need for more publications on this subject in these countries, it is also noteworthy that more comparative studies involving individuals from different cultures are necessary. In addition, it is thought that comparative studies on stigma in girls and boys with epilepsy would be useful in the context of gender. In this study, it was observed that intervention for stigma in children with epilepsy has been researched in recent years, and there is a need for further study in the future.

Ethics

Ethics Committee Approval: No ethics committee permission was required for bibliometric analysis.

Informed Consent: Patient consent was not required.

Footnotes

Authorship Contributions

Concept: K.M.K., H.A., Design: K.M.K., H.A., Data Collection or Processing: K.M.K., Analysis or Interpretation: K.M.K., Literature Search: K.M.K., H.A., Writing: K.M.K., H.A.

Conflict of Interest: No conflict of interest was declared by the authors.

Financial Disclosure: The authors declared that this study received no financial support.

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