Stigma and psychosocial problems in patients with epilepsy

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Abstract

Epilepsy, a prevalent neurological disorder, is characterized by chronic seizures resulting from abnormal electrical activity in the brain. Adequate medical treatment allows roughly 70% of patients to enjoy a seizure-free life. However, throughout history, epilepsy has acquired diverse interpretations due to the experienced seizures, transforming the condition from a clinical issue into a social stigma. Therefore, the aim of this review study is to review stigma and psychosocial problems in patients with epilepsy (PwE). For this reason, this study utilises sources from the last ten years and reports current data. As a result of the review, it was found that societal discrimination in PwE arises primarily from inadequate knowledge, misconceptions, and negative attitudes toward the condition. Other contributing factors were include patients’ lower levels of education and income, frequent seizures due to inadequate treatment, age at onset, duration of the disease, depressive symptoms, and lack of social support. Also, it was found that the stigma individuals with epilepsy face plays a pivotal role in exacerbating their psychosocial problems. Unfortunately, stigma and psychosocial challenges appear to be in a vicious circle, with an increase in one increasing the other. Stigmatized patients tended to isolate themselves from society, further increasing their likelihood of experiencing a depressive mood or psychiatric comorbidity. Consequently, individuals with epilepsy encounter difficulties in various domains such as marriage, work, education, and personal life. Considering these significant psychosocial burdens, it is essential to recognize that epilepsy surpasses its medical implications. Unfortunately, current efforts to reduce stigma remain insufficient, necessitating urgent and comprehensive measures to address this issue.

Keywords

Epilepsy, stigma, psychosocial problems, knowledge, attitude

Introduction

Epilepsy, a neurological disorder affecting approximately 70 million individuals worldwide, is characterized by seizures resulting from abnormal electrical discharges in the brain [1]. Regrettably, epilepsy is not solely recognized as a “medical condition” but is often burdened with prejudice, misconceptions, and a lack of
understanding, transforming it into a “social label” [2]. Seizures, which are unpredictable, uncontrollable, and often visually unappealing, contribute significantly to the discrimination faced by individuals with epilepsy. Throughout history, epilepsy has been met with fear, associated with mystical interpretations, and subjected to discrimination due to these seizures. Persistent beliefs that attribute epilepsy to being struck by the devil, possession by evil spirits, or divine wrath have endured for centuries [3]. Despite advances in understanding the pathophysiology of epilepsy and its identification as a neurological condition, dispelling false beliefs and biases has proven to be a more complex task. Even with substantial progress in medical treatment and seizure control, reports of bias and prejudice against epilepsy persist [4]. Notably, these prejudices and misconceptions are prevalent even in the most developed societies [5]. Such observations underscore how epilepsy is predominantly regarded in terms of its psychosocial dimensions rather than just its medical aspects. In essence, psychosocial challenges amplify the burden experienced by patients, alongside the medical problems they face [6]. Patient-related sociodemographic and clinical factors, coupled with incorrect handling during seizures, lack of accurate information, and perpetuated societal misconceptions, contribute to a sense of stigmatization and subsequent social isolation among individuals with epilepsy [7]. This indicates that “stigma” lies at the heart of the psychosocial difficulties encountered by patients.

**Epilepsy and stigma**

Stigma, initially characterized by Goffman [8] (1963) as an “undesirable difference, a mark of shame and disrepute, a blemish that distorts one’s social identity” can be classified into two forms: imposed stigma and felt stigma. Stigma manifests through discrimination, exclusion, and the imposition of a sense of being different by society. Felt stigma refers to an individual’s subjective experience of perceiving themselves as different due to their illness and the fear of potential social exclusion, even in the absence of direct discrimination [9]. Stigma plays a pivotal role in isolating individuals with epilepsy from society. This isolation exacerbates challenges in self-management and adaptation to the condition [10]. Moreover, stigma contributes to the development of psychiatric comorbidities, such as anxiety and depression, and has a detrimental impact on the overall quality of life. Numerous studies indicate anxiety rates among epilepsy patients ranging from 31% to 56% [11], while depression rates range from 27% to 34%, with stigma being identified as a root cause of these psychological issues [12].

The severity of stigma experienced by epilepsy patients can be attributed to two factors: patient-related and societal factors. Social factors primarily contribute to “enacted stigma” whereas patient factors are associated with “felt stigma” [4]. Stigma among epilepsy patients is intensified by the limited knowledge, misconceptions, prejudices, and negative attitudes prevalent in society. Particularly in underdeveloped and developing countries, patients endure formal or informal discrimination, which can be classified as imposed stigma [4]. Considering that approximately 80% of epilepsy patients live in these countries, the seriousness of the situation increases even more. In some studies conducted in the last decade, it has been observed that the belief that “Epilepsy is a mental illness, a mental health problem, caused by supernatural power, an infectious disease, occurs as a result of demon possession, and occurs as a result of the wrath of God” has been reported at very high rates (Table 1) [13–24]. There has been no serious positive development in knowledge and beliefs about epilepsy over time [25, 26]. Regrettably, individuals with epilepsy often face negative attitudes and discrimination from others. These negative attitudes are reflected in the reluctance to marry epilepsy patients, unwillingness to employ them, aversion to being in the same vicinity as them, and even discouragement of their children from playing with children who have epilepsy (Table 1). This direct discrimination imposed on individuals with epilepsy can be described as stigma. It is noteworthy that these societal attitudes align with the experiences shared by epilepsy patients themselves. Patients often report encountering various difficulties related to their condition in areas such as marriage, education, employment, and social interactions [27–29].

It would be incorrect to associate misconceptions and negative attitudes towards epilepsy solely with underdeveloped countries. Even in studies conducted in developed countries, it has been documented that inadequate knowledge and misconceptions surrounding epilepsy persist [53]. Addressing epilepsy-related
<table>
<thead>
<tr>
<th>Authors and year</th>
<th>Country</th>
<th>Sample</th>
<th>Results/Responses</th>
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</thead>
</table>
| Maiga et al. [16], 2014 | Mali | Community | • Epilepsy is contagious: 66%  
• Epilepsy is caused by a supernatural power: 53%  
• The first option for treatment is traditional healers: 63%  |
| Owolabi et al. [30], 2014 | Nigeria | Teachers | • The rate of those who would not want a child with epilepsy to be in their classroom: 25.5%  
• Children with epilepsy should be in separate classes: 60%  |
| Homi Bhesania et al. [13], 2014 | Pakistan | Teachers | • Epilepsy is contagious: 14.5%  
• Epilepsy causes mental retardation: 34.5%  
• Epilepsy is caused by a supernatural power: 10.9%  |
| Abulhamail et al. [31], 2014 | Saudi Arabia | Teachers | • Children with epilepsy may show abnormal behavior in the classroom: 47%  
• Children with epilepsy should be educated in separate classes: 28%  
• The intelligence level of children with epilepsy is lower than others: 25%  |
| Shehata and Mahran [32], 2014 | Egypt | Families with and without PwE | The answers belong to families of individuals with and without epilepsy, respectively:  
• Individuals with epilepsy should not marry: 21.9% vs. 4.1%  
• The rate of those who would not allow their child to marry someone with epilepsy: 90% vs. 75%  
• The rate of those who would not want to work in the same place as someone with epilepsy: 73% vs. 75%  |
| Ezeala-Adikaibe et al. [33], 2014 | Nigeria | Community | • Individuals with epilepsy should not marry: 28.5%  
• Should not have children: 42.8%  
• The rate of those who wouldn't marry someone with epilepsy: 80.3%  |
| Eze et al. [34], 2015 | Nigeria | Teachers | • Students with epilepsy cause some problems in the classroom: 86.3%  
• Children with epilepsy should be sent to private schools: 41.2%  
• The rate of those who would not want their own child to be in the same class as a child with epilepsy: 51.3%  |
| Al-Hashemi et al. [14], 2016 | Kuwait | Teachers | • Mental retardation develops in epilepsy patients: 15%  
• Epilepsy is contagious: 18%  
• Children with epilepsy should be educated in different classes: 52%  
• Individuals with epilepsy do not have equal employment rights like other people: 25%  |
| Karimi and Akbarian [17], 2016 | Iran | Family members of PwE | • Epilepsy is caused by supernatural powers: 8.1%  
• Individuals with epilepsy should not marry: 15.3%  
• Individuals with epilepsy have lower intelligence: 25%  |
| Gebrewold et al. [35], 2016 | Ethiopia | Teachers | • The rate of those who would not prefer to have a child with epilepsy in their class: 81%  
• The rate of those who would not let their child play with someone with epilepsy: 80%  
• The rate of those who would not allow their child to marry someone with epilepsy: 92.5%  |
| Masri et al. [18], 2017 | Jordan | Parents with PwE | • Epilepsy is a mental illness: 10%  
• The rate of those who would not allow their child to participate in sports activities: 59%  |
| Kaddumukasa et al. [36], 2018 | Uganda | Community | • Epilepsy is an infectious disease: 17%  
• The rate of those who would not let their child play with a child with epilepsy: 19.1%  
• The rate of those who would not allow a close relative to marry someone with epilepsy: 41.6%  |
<table>
<thead>
<tr>
<th>Authors and year</th>
<th>Country</th>
<th>Sample</th>
<th>Results/Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Al-Dossari et al. [19], 2018</td>
<td>Saudi Arabia</td>
<td>Community</td>
<td>- Cause of epilepsy possession by demons or an evil spirit: 46.5%</td>
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<td></td>
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<td></td>
<td>- Epilepsy is an infectious disease: 11.2%</td>
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<td>- Women with epilepsy should not marry: 13.7%</td>
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<tr>
<td>Kwanuka and Anyango Olyet [37], 2018</td>
<td>Uganda</td>
<td>Community</td>
<td>- The rate of those who would not allow their close relatives to marry someone with epilepsy: 13.4%</td>
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<td></td>
<td>- Individuals with epilepsy should not have children: 18.4%</td>
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<td>- The rate of those who would prefer traditional medicine or healers for the treatment of epilepsy: 52.1%</td>
</tr>
<tr>
<td>Panagariya et al. [38], 2019</td>
<td>India</td>
<td>Community</td>
<td>- Epilepsy is non-curable: 15%</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>- Would not marry persons with epilepsy: 81%</td>
</tr>
<tr>
<td>Ibinga et al. [20], 2019</td>
<td>Gabon</td>
<td>Teachers and health workers</td>
<td>- Epilepsy is an infectious disease: 27.5%</td>
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<td>- Domenic possession is the cause of epilepsy: 16%</td>
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<td>- The rate of those who stated that they would not send their child to school if they had epilepsy: 15%</td>
</tr>
<tr>
<td>Rani and Thomas [21], 2019</td>
<td>India</td>
<td>Parents with PwE</td>
<td>- Epilepsy is a mental disease: 52.5%</td>
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<td></td>
<td>- It is an infectious disease: 18%</td>
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<td></td>
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<td></td>
<td>- Developed due to evil spirits: 37.7%</td>
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<tr>
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<td></td>
<td>- The rate of people who believe that an object should be placed in the mouth while having a seizure: 88.5%</td>
</tr>
<tr>
<td>Panagariya et al. [38], 2019</td>
<td>Ethiopia</td>
<td>Community</td>
<td>- Epilepsy is caused by evil spirits: 49.8%</td>
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<td></td>
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<td>- The rate of those who would not want to hire someone with epilepsy: 94.2%</td>
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<td>- The rate of those who would not allow a member of their family to marry someone with epilepsy: 93.3%</td>
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<tr>
<td>Alamri and Al Thobaity [39], 2020</td>
<td>Saudi Arabia</td>
<td>Teachers</td>
<td>- Epilepsy is a mental disease: 59%</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>- The rate of those who would not allow their child to marry someone with epilepsy: 64%</td>
</tr>
<tr>
<td>Qiu et al. [40], 2020</td>
<td>China</td>
<td>Preschool staff</td>
<td>- The rate of those who would not let their child play with someone with epilepsy: 36.3%</td>
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<td>- The rate of those who believed that the activities of children with epilepsy should be limited: 41%</td>
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<td></td>
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<td>- The rate of those who do not prefer having children with epilepsy in their classroom: 70%</td>
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<tr>
<td>Wubetu et al. [41], 2020</td>
<td>Ethiopia</td>
<td>Community</td>
<td>- Individuals with epilepsy should be isolated: 12%</td>
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<td></td>
<td></td>
<td>- Individuals with epilepsy should not go to school: 75%</td>
</tr>
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<td></td>
<td></td>
<td></td>
<td>- The rate of those who would not want to hire someone with epilepsy: 57%</td>
</tr>
<tr>
<td>Tani and Adali [23], 2020</td>
<td>Morocco</td>
<td>Community</td>
<td>- Epilepsy is a dangerous disease: 32.2%</td>
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<td></td>
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<td>- Epilepsy develops as a result of possession: 15.4%</td>
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<td></td>
<td></td>
<td></td>
<td>- It is a psychiatric disease: 12.1%</td>
</tr>
<tr>
<td>Tirukelem et al. [24], 2021</td>
<td>Ethiopia</td>
<td>Community</td>
<td>- Epilepsy is god’s punishment: 16.9%</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>- Spirit possession is the cause of epilepsy: 45.8%</td>
</tr>
<tr>
<td>Shihata et al. [42], 2021</td>
<td>Saudi Arabia</td>
<td>Medical students</td>
<td>- Epilepsy is a mental disease: 43.5%</td>
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<td></td>
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<td></td>
<td>- The rate of those who wouldn’t marry someone with epilepsy: 45%</td>
</tr>
<tr>
<td>Hakami et al. [43], 2021</td>
<td>Saudi Arabia</td>
<td>University students</td>
<td>- Epilepsy is a mental disease: 20%</td>
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<td></td>
<td></td>
<td></td>
<td>- Epilepsy can be treated with traditional healers: 46%</td>
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<td></td>
<td>- Children with epilepsy should go to private schools: 16.5%</td>
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<td></td>
<td>- The rate of those who wouldn't marry someone with epilepsy: 78%</td>
</tr>
<tr>
<td>Molla et al. [15], 2021</td>
<td>Ethiopia</td>
<td>Community</td>
<td>- Epilepsy is the punishment for sins: 37.4%</td>
</tr>
</tbody>
</table>
Table 1. Results of some studies examining the knowledge and attitudes of individuals in the community about epilepsy (continued)

<table>
<thead>
<tr>
<th>Authors and year</th>
<th>Country</th>
<th>Sample</th>
<th>Results/Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yeni et al. [44], 2021</td>
<td>Turkiye</td>
<td>Medical students</td>
<td>• The rate of those who would not want to employ PwE: 36.6%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• The rate of those who wouldn't marry someone with epilepsy: 78.8%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• The rate of those would not allow their child to marry PwE: 26%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• The rate of those who wouldn't marry someone with epilepsy: 37%</td>
</tr>
<tr>
<td>Bin Abdulrahman et al. [45], 2022</td>
<td>Saudi Arabia</td>
<td>Medical students</td>
<td>• Epilepsy cannot be treated: 34%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• The rate of those who would not let their child play with PwE: 27.7%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• The rate of those who would not allow their child to marry someone with epilepsy: 23.8%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• The rate of people who believe that people with epilepsy should not work: 11.7%</td>
</tr>
<tr>
<td>Legesse et al. [46], 2022</td>
<td>Ethiopia</td>
<td>Community</td>
<td>• Epilepsy is caused by supernatural power: 58.6%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Epilepsy is a type of mental retardation: 59.6%</td>
</tr>
<tr>
<td>Ibrahim et al. [47], 2022</td>
<td>Sudan</td>
<td>Medical students</td>
<td>• Epilepsy is contagious: 1.7%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• It is a mental illness: 56%</td>
</tr>
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<td></td>
<td></td>
<td></td>
<td>• Cause of epilepsy is evil eye: 15.7%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Individuals with epilepsy should not have children: 20%</td>
</tr>
<tr>
<td>Alsuami et al. [48], 2022</td>
<td>Saudi Arabia</td>
<td>Teachers</td>
<td>• Epilepsy is a psychological disease: 10.6%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Children with epilepsy should be sent to private schools: 27.8%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• The rate of those who would not let their child play with PwE: 19.7%</td>
</tr>
<tr>
<td>Mustafa et al. [49], 2022</td>
<td>Sudan</td>
<td>Medical students</td>
<td>• There are psychological factors underlying epilepsy: 62.7%</td>
</tr>
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<td></td>
<td></td>
<td></td>
<td>• It is appropriate to use religious methods for treatment: 34.6%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Individuals with epilepsy should limit their sports or leisure activities: 42.1%</td>
</tr>
<tr>
<td>Abuhamdah et al. [50], 2022</td>
<td>Jordan</td>
<td>Community</td>
<td>• The rate of people who do not want to work in the same workplace with someone with epilepsy: 58.7%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Individuals with epilepsy should be isolated: 42%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• The rate of people who want to keep their child away from someone with epilepsy: 41%</td>
</tr>
<tr>
<td>Almarwani et al. [51], 2023</td>
<td>Saudi Arabia</td>
<td>Teachers</td>
<td>• The rate of those who do not feel competent in seizure intervention: 72.8%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Children with epilepsy negatively affect other children in the class: 19%</td>
</tr>
<tr>
<td>Javed et al. [52], 2023</td>
<td>Pakistan</td>
<td>Community</td>
<td>• Epilepsy develops as a result of possession: 51.7%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Epilepsy is a mental disease: 60.5%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Epilepsy is contagious: 50.1%</td>
</tr>
</tbody>
</table>

PwE: patients with epilepsy

stigma and reducing its social impact was identified as a priority area during the 2013 European Forum on Epilepsy Research. A subsequent publication arising from this meeting highlighted the importance of efforts to alleviate stigma and its burden on society [54]. Thus, while the extent of stigma towards epilepsy patients may vary across countries with different levels of development, it can be concluded that no country has reported a complete absence of stigma. This notion is further supported by a recent systematic review study which found that all 358 included studies have reported instances of stigma [4]. The prevalence of stigma among epilepsy patients and its effects are summarized in Table 2.

While patients may not face direct discrimination, they can still internalize feelings of stigma, perceiving themselves as different and potentially at risk of exclusion. This phenomenon is commonly referred to as “felt stigma”. Felt stigma can often be influenced by various sociodemographic and clinical
## Table 2. Examination of systematic reviews published about epilepsy and stigma in the last decades

<table>
<thead>
<tr>
<th>Authors and year</th>
<th>Sample</th>
<th>Aim</th>
<th>Results</th>
</tr>
</thead>
</table>
| Yang et al. [5], 2023 | A total of 47 research articles on adult individuals with epilepsy | Determining the rate of stigma felt by individuals with epilepsy and making comparisons between continents | • Overall perceived stigma rate is 48.4%  
• Stigma rates are 51.2% in Africa, 47.2% in Europe, 35.4% in Asia and 28.8% in the Middle East  
• There is no significant difference between continents in stigma rates |
| Baker et al. [55], 2018 | A total of 25 quantitative and 8 qualitative research articles conducted with adult epilepsy patients | Identifying predictors and consequences of stigma in adult individuals with epilepsy | • Stigma is related to sociodemographic, clinical and psychosocial factors  
• Cultural differences have an impact on stigma  
• Stigma impairs physical and psychological health  
• Increases anxiety and depression  
• Impairs disease self-management |
| Mayor et al. [7], 2022 | A total of 28 qualitative research articles conducted with adult individuals with epilepsy | Qualitatively synthesizing stigma in adult individuals with epilepsy | • Negative perceptions of epilepsy in society result in patients being rejected and discriminated against  
• Internalization of stigma causes negative self-perception and shame  
• Stigma negatively affects daily life and contributes to dependence on others  
• Individuals with epilepsy try to avoid stigmatization by hiding their disease and isolating themselves from society  
• Social support is helpful, but depends on the person receiving support’s perspective on epilepsy |
| Kaddumukasa et al. [36], 2018 | A total of 23 community-based quantitative research articles | Reviewing misconceptions and stigma surrounding epilepsy in sub-Saharan African countries | • Misconceptions and cultural beliefs about epilepsy are quite common  
• Very few studies (only two studies) are interventional studies aimed at reducing stigma  
• In order to reduce stigma, attempts should be made urgently to raise public awareness/education |
| Fite and Guta [56], 2021 | A total of 9 quantitative research articles conducted with adult individuals with epilepsy | To determine the prevalence of stigma and related factors in individuals with epilepsy living in Ethiopia | • Average stigma prevalence is 44.6%  
• Increased disease duration and seizure frequency are closely related to stigma  
• PwE require medical, social and psychological care |

Factors. These include the patient’s educational level, income level, age at disease onset, seizure frequency, disease duration, and the level of social support they receive [4]. Patients with lower levels of education may have limited knowledge about their condition, leading to the development of negative attitudes towards their own epilepsy. In a modeling study conducted by Yeni et al. [57] (2018), it was observed that knowledge level directly impacted attitudes, and these attitudes, in turn, affected the level of stigma experienced by epilepsy patients. Consequently, it can be inferred that the education level of the wider society influences the stigma imposed on individuals with epilepsy, while the educational level of the patient can impact the degree to which they personally experience stigma.

PwE face significant challenges, particularly in low-income countries. The main issues encountered include difficulty in accessing treatment, inadequate availability of antiepileptic drugs, limited access to specialized healthcare providers such as neurologists, and the presence of societal stigma stemming from negative attitudes towards epilepsy [58]. These collective challenges are often referred to as the “treatment gap” within the literature. Adversely impacting patients both medically and psychosocially, the treatment
gap compounds the effects of the disease. As the frequency of seizures increases, the psychosocial consequences intensify, further amplifying the stigma experienced by individuals with epilepsy [59]. Consequently, it becomes apparent that income level can play a direct or indirect role in shaping the level of stigma encountered by patients.

The presence of stigma is observed to be higher among patients with frequent seizures [56]. Increased seizure frequency not only intensifies the level of stigma but also has a negative impact on the individual’s health locus of control. Health locus of control can be categorized as internal and external. Research has shown that individuals with a predominant external locus of control tend to attribute their circumstances to luck and fate, perceiving themselves as having little influence over disease management and exhibiting poorer coping strategies [60]. It has been reported that epilepsy patients experiencing frequent seizures exhibit a more dominant external locus of control, are more prone to depression, and have a lower quality of life [61]. Although this suggests a potential association between stigma and locus of control, it is acknowledged that the available studies on this relationship are limited, necessitating further investigation [61–63].

The age at which epilepsy is diagnosed is another factor that is related to stigma. Research indicates a negative correlation between the age at diagnosis and the level of stigma experienced by patients [64–66]. As the age at diagnosis decreases, patients are more likely to be exposed to the effects of the disease, leading to an increase in the overall burden of the condition [4]. Factors such as seizures and the need for multiple medications contribute to the medical burden, while the impact on school, marriage, and work life adds to the social burden. The compounded medical and social burden exacerbates the level of stigma experienced by patients and can also lead to the development of psychiatric comorbidities.

Research suggests that the language used to refer to individuals with epilepsy can have an impact on the level of stigma they experience, in addition to sociodemographic and clinical factors. It has been reported that using the term “patients with epilepsy” instead of “epileptic patients” can help prevent labeling of individuals, foster a more positive societal attitude, and reduce the stigma associated with the condition [67–70]. This highlights the potential for patients to face various forms of formal or informal discrimination, including verbal and behavioral discrimination. Therefore, efforts should be made to raise awareness among both patients and society, improve knowledge around epilepsy, and foster positive attitudes.

Indeed, there exists a reciprocal relationship between stigma and psychosocial problems in individuals with epilepsy, forming a vicious circle. As the level of stigma increases, so does the likelihood of experiencing psychosocial challenges. Conversely, individuals who face difficulties in their social lives or encounter heightened depressive moods due to epilepsy may also experience an increase in stigmatization. To break free from this cycle, it is crucial to address and mitigate the stigma, its contributing factors, and the psychosocial problems it gives rise to in epilepsy patients.

Epilepsy and psychosocial problems

It would be inaccurate to claim that individuals with epilepsy have equal opportunities in social life. Epilepsy can have negative effects on various aspects of life such as employment, marriage, and academic pursuits. Even individuals who are seizure-free may face discrimination based solely on their diagnosis. The detrimental impact on social life can significantly impact the psychological well-being of patients. Psychosocial problems are more prevalent, particularly in underdeveloped and developing countries, and stigma is considered to be a significant contributing factor [36, 71, 72].

The work life of individuals who are discriminated against due to their epilepsy is one of the most affected social areas. Unfortunately, individuals with an epilepsy diagnosis often encounter challenges such as job rejections or dismissals [15, 22, 41]. As a result, the unemployment rate among individuals with epilepsy is significantly higher compared to that of healthy individuals. To avoid unemployment, many patients feel compelled to conceal their condition, which in turn leads to increased feelings of shame, guilt, and a higher likelihood of experiencing depressive moods [73].
Private life, as well as business life, is profoundly affected by epilepsy [29]. Numerous studies have revealed that individuals in society may not wish to marry those with epilepsy, and may even forbid their children from marrying someone with the condition (Table 1). This demonstrates a clear example of imposed stigma. Unfortunately, this negative attitude extends to education as well. The biases held by individuals in society, particularly teachers, have a significant detrimental impact on individuals with epilepsy. Negative beliefs, such as the misconception that people with epilepsy have low intelligence, pose a danger to other students, or should be educated separately, are still prevalent [14, 30, 31, 35, 48, 51]. It has been reported that individuals with epilepsy have a higher rate of dropping out of school or a lower rate of continuing to higher education, compared to their healthy peers or siblings [74, 75]. The psychosocial burden of the fear of exclusion and stigmatization by peers and educators compounds the medical burden of seizures, significantly impacting the educational lives of patients.

The challenges faced by individuals with epilepsy due to their diagnosis often lead to feelings of isolation and loneliness, which, in turn, increase the risk of psychiatric comorbidities such as anxiety and depression. In severe cases, individuals with stronger depressive moods may even attempt suicide if they lack sufficient coping mechanisms and social support. It has been reported that the risk of suicide among individuals with epilepsy is three times higher than in healthy individuals, with psychiatric comorbidity serving as an underlying cause [76]. The inclination towards suicide is particularly high among young adults who lack social support and face multiple psychosocial challenges. Therefore, precautions should be taken to address this issue [77]. Despite this, there is a significant lack of interventional studies aimed at reducing stigma in individuals with epilepsy or increasing public knowledge about the condition [36]. As a result, there is a pressing need for studies not only focused on measuring knowledge and attitudes but also on cultivating positive attitudes and reducing stigma. The lack of significant changes in societal knowledge and attitudes over time underscores the urgency of the situation.

Conclusions

Despite significant advances in the medical field over past centuries, stigma towards individuals with epilepsy remains prevalent. The stigma is rooted in insufficient knowledge, false beliefs, and negative attitudes held by individuals in society. It can be observed that sociodemographic and clinical characteristics of patients play a significant role in shaping the perceived stigma they face. Regardless of its form, stigma has a strong correlation with the psychosocial challenges experienced by patients. Despite numerous studies examining the issues faced by individuals with epilepsy, efforts to reduce or prevent stigma appear to be inadequate. Therefore, it is strongly recommended that future studies prioritize increasing awareness and knowledge within society, as well as focusing on strategies to reduce the stigma experienced by individuals with epilepsy.

Abbreviations

PwE: patients with epilepsy

Declarations

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