



Improving public stigma, sociocultural beliefs, and social identity for people with epilepsy in the Aseer region of Saudi Arabia



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ABSTRACT

Differences in the sociocultural practice and biases against people with epilepsy (PWE) largely contribute to the development of stigmatization. In this study, we evaluated factors that impact stigma for PWE involved in evolution and maintenance to report changes in the public awareness and cultural practices. We performed a cross-sectional study in which data were collected from a self-administered electronic survey composed of 33 items targeting the population in the Aseer region. Feedback response was obtained from 937 respondents. Of these, 921 participants (98.3%) had heard or read about the disorder previously. Approximately 84.8% believed that epilepsy was one of the brain disorders. 95.8% disagreed that epilepsy was due to a contagious disease. However, 40.1% of the responders were convinced that it was the result of a spiritual reason. Still, more than 9% believed treating PWE should be approached spiritually. About 75% felt that epilepsy could be the results of a test delivered by God. In addition to the clinical impact from seizures in PWE, it carries a social label and public stigma that influences one's social prognosis. Raising awareness through campaigns would improve the knowledge and practices of the population and hence provide a healthier environment for PWE, alleviating feelings of stigma, and improving their quality of life.

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1. Introduction

Epilepsy is a common neurologic condition, affecting more than 70 million individuals worldwide in people of all ages regardless of geographic, social, and ethnic boundaries [1,2]. However, drug-resistant seizures are experienced in more than one-third of patients, with higher rates of patients who experience psychiatric comorbidity, resulting in a lower quality of life [3]. Patients with epilepsy (PWE) live under the assumption that, at any given time,

they may not be able to function normally. To be engaged in their usual daily activities, such as driving, they must rely on someone to take care of them during their outgoing tasks. They may suffer loneliness, helplessness, and impaired self-esteem and self-efficacy with reduced life satisfaction [4]. Therefore, epilepsy is often associated with psychological dysfunction in addition to somatic effects from seizures, leading to consequences linked to stigma that could influence one's social network [5].

PWE suffer from a loss of independence, underemployment, and decreased engagement in physical activities and in spending their leisure time. Stigmatization creates a large group of stressors that challenges individuals and negatively affects their social interactions and identity, particularly for those living in low-income countries. Therefore, the available conceptual, psychosocial, and economic resources highly influence the ability to withstand stress imposed by stigma. Unfortunately, there remains less optimism

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regarding the social prognosis of PWE compared to the clinical outcome on seizure reduction [6].

Stigma is defined as “an undesired differentness”, and currently, this represents “underlying disgrace, negative stereotypes, harsh judgments, social disapproval, and isolation” [7]. Individuals with a stigmatizing trait will experience stereotypes, discriminatory behavior, and inferiority. Goffman stated that stigmatized people may try to remove such a “contaminated social identity”; however, the normal status they desire cannot easily be reacquired. Thus, stigma may produce a lifelong identity for PWE and others that can stigmatize people for years [6,8].

The stigmatizing nature of epilepsy includes labeling, stereotyping, and separation from the community. One of the dominant cultural beliefs is labeling them “epileptic” and linking this term to a negative stereotype including perception of PWE as dangerous people with a mental illness [9]. This attitude encourages the social processes that lead to their isolation and stigmatization. PWE subsequently suffer a loss of social status and discrimination in the workplace and educational institutions. Consequently, this creates a social distance and a more introverted personality, making PWE at risk for developing emotional stress. These practices and feelings worsen a benign course of illness, adding to functional loss and creating social withdrawal that reinforces feelings of being stigmatized [7,10]. As a result, stigma can not be easily measured, yet is a vital contributor to the burden from the illness and one of the crucial predictors of associated psychological distress [11].

PWE require support from their families, friends, co-workers, and the surrounding community, with its members showing a high level of functionality to help them engage in a safe and healthy environment and not to punish them indirectly by keeping them in isolation. They should have equal-opportunity provisions and legal protections that restrict or mitigate discriminatory behavior against them. National and international campaigns ought to take action by raising people’s awareness through education programs talking about the disorder and the correct management actions during seizures as well as help to alleviate the stigma and improve patients’ lives [12,13]. The goal of our study was to evaluate the factors that impact stigma associated with epilepsy and address evolutionary and maintenance issues involved in PWE. We also addressed changes in public awareness, cultural practices, and religious beliefs toward PWE.

2. Materials and methods

This was a cross-sectional study conducted between March 2020 and June 2020. We intended to collect data from a survey by interviewing subjects in the target population. However, due to the COVID-19 pandemic, we collected data as a self-completed questionnaire that was disseminated through social media. Participants from both genders of the general population in the Aseer region older than 14 years old were included, while individuals below the age of 14 and PWE were excluded. The study was approved by the local Ethics Committee, and informed consent was obtained, including an explanation of the confidentiality issues and instructions to complete the questionnaire form and guarantee voluntary participation and confidentiality for all participants.

The questionnaire was translated into Arabic to evaluate the factors influencing and maintaining stigma in PWE with the desire to decrease discrimination and stigmatization. The questionnaire consisted of 33 questions. Questions were adapted and modified from previous reports in the literature [13–19]. The form was revised, and the final modified version was conducted for reliability and validated for use. Thirty-three questions were categorized into four groups verifying the general knowledge about epilepsy, factors enforcing epilepsy stigma, the different stereotypes of epi-

lepsy based on socio-cultural beliefs, and episodes of discrimination against PWE. Additionally, five questions collected information about the demographic data of the responders. We compared our data with previous studies covering the same region and assessed the factors stigmatizing PWE.

All responses, numerical values, and demographic data were analyzed and presented as percentages. The data were entered and calculated using the Statistical Package for the Social Sciences (SPSS) software (version 25, IBM Inc., Chicago, IL, USA). The frequency distribution was calculated, in addition to using Pearson’s chi-squared test, considering *p*-values < 0.05 as significant.

3. Results

3.1. Demographic data of the study population

A total of 937 individuals participated in this study. The majority of responders were Saudis (98.6%) with a mean age (\pm SD) of 31.24 \pm 11.85 years. Around half of the participants (45.9%) were in the age group between 21–30 years old, while only 0.5% were older than 60 years. More than half of the subjects were women (58.3%). About two-thirds of the participants had no family history of epilepsy, and 43.8% had a high monthly income (Table 1). As shown in Fig. 1, there was variation in the level of education. The majority (80%) of participants had a university degree, either a bachelor (70.44%) or post-graduate education (9.61%), compared to less than 1.0% with no education (0.11%) or completion of primary education (0.64%).

3.2. Public knowledge about epilepsy

Almost all participants (98.3%) had heard about epilepsy, more than one-third from the surrounding community or from friends. Almost 10% less had educational institutions as a secondary source of information, according to respondents. Reading relevant books, magazines, and newspapers were the least common sources.

Regarding treatment approaches to PWE, 9.6% believe they should be treated only with spiritual modalities, such as the recitation of the Qur’an, Ruqya (exorcism), and prayers. Three-quarters of participants supported these modalities as an additional way of treatment alongside pharmacotherapy. Around half of the participants claim that therapies such as herbal remedies, massages, barefoot walking on sand, cauterization, acupuncture, meditation,

Table 1
Demographic data of the responding population.

| Category | n | % | |
|------------------------------|------------------------|-----|------|
| Age (years) | 16–17 | 57 | 6.1 |
| | 18–20 | 87 | 9.3 |
| | 21–30 | 430 | 45.9 |
| | 31–40 | 134 | 14.3 |
| | 41–50 | 162 | 17.3 |
| | 51–60 | 62 | 6.6 |
| | More than 60 | 5 | 0.5 |
| Age in years (mean \pm SD) | 31.24 \pm 11.85 | | |
| Gender | Males | 391 | 41.7 |
| | Females | 546 | 58.3 |
| Nationality | Saudi | 924 | 98.6 |
| | Non-Saudi | 13 | 1.4 |
| Socioeconomic status | High | 410 | 43.8 |
| | Average | 502 | 53.6 |
| | Low | 25 | 2.7 |
| Educational level | Postgraduate | 90 | 9.6 |
| | Bachelor’s degree | 660 | 70.4 |
| | Secondary school | 167 | 17.8 |
| | Below secondary school | 20 | 2.2 |
| Family history of epilepsy | Yes | 343 | 36.6 |
| | No | 594 | 63.4 |

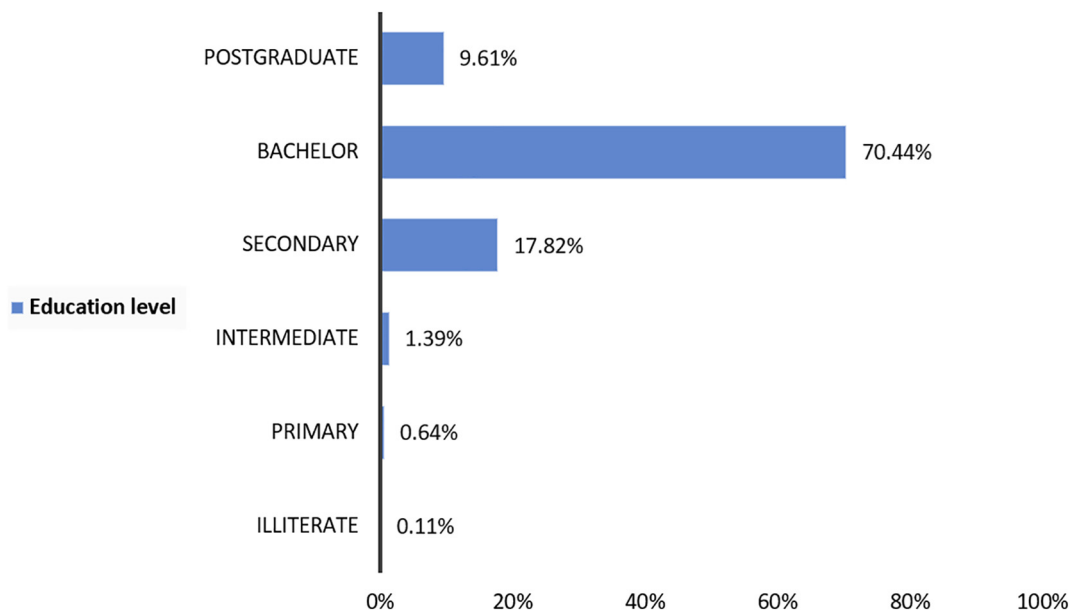


Fig. 1. Proportions of the respondents' education levels.

etc. could be beneficial in addition to pharmacological medications. Only 3% were convinced that traditional treatment with medication alone was effective (Table 2).

When asked about the causes of epilepsy, 84.8% considered it one of the nervous disorders, where less than one-half believed it was either a mental illness or due to an inherited condition (40.1% and 40.3, respectively), and only 0.5% thought that it was an infectious disease (Fig. 2).

3.3. Public attitudes towards epilepsy

To know more about public attitudes toward epilepsy, responders answered several questions presented in Table 3. More than one-half (53%) of participants agreed they would hire a PWE if they were an employer, while 42.7% would do so when the PWE was seizure-free for at least 2 years. Approximately 1 in 4 participants would either marry or permit their daughters/sons to marry a PWE. This increased marginally if the patient was seizure-free for

Table 2
The general population knowledge regarding epilepsy.

| Question | n | % |
|---|--|----------|
| Have you ever heard about epilepsy? | Yes | 921 98.3 |
| | No | 16 1.7 |
| What is the source of your information on epilepsy? | Relatives/friends | 307 32.8 |
| | Relative with epilepsy | 141 15 |
| | Internet/TV | 165 17.6 |
| | Physician | 75 8 |
| | School/college | 194 20.7 |
| | Others (books, magazines, newspapers, etc.) | 55 5.9 |
| How do you think epilepsy should be treated? | Spiritual healing | 90 9.6 |
| | Medication with spiritual healing | 696 74.3 |
| | Traditional therapies only | 29 3.1 |
| | Medication with traditional therapies | 464 49.5 |
| | I don't believe in spiritual healing | 151 16.1 |
| | I don't believe in traditional therapies or other modalities | 444 47.4 |

2 years. Most of the responders (91%) opposed the idea that epilepsy could be divine punishment, but two-thirds felt it could be a type of test and affliction from a spiritual reason (40.1%).

Half of the respondents confessed that society stigmatizes epilepsy patients. Over 30% thought that PWE could be stigmatized due to accidents that occurred in their home or workplace, lacked dedication, and were a healthcare burden. We found that 15% assumed that epilepsy patients were violent or harmful individuals, while 1 in 5 were of the opinion that PWE had accompanying disabilities with a contagious and genetic disease.

On the other hand, more than 40% were of the opinion that patients could have normal mental abilities with no ailments, succeed in normal life, marriage, and other relationships, have a career, and practice social and physical activities like their healthy counterparts.

There was a statistically significant association between a higher education level and correct beliefs about epilepsy, such as epilepsy being due to a neurological or genetic disorder ($p = 0.007$ and 0.001 , respectively), and not an infectious disease ($p < 0.001$). In addition, this group felt that epilepsy patients are not violent and harmful ($p = 0.029$) and can have a normal and successful life ($p = 0.02$ and 0.043 , respectively). Interestingly, a higher percentage of participants who agreed to hire epilepsy patients was noted in the mid to higher education level groups ($p < 0.0001$).

4. Discussion

Stigma is defined by Goffman as 'an attribute which is deeply discrediting' [8], where stigmatized individuals becomes less desirable in their communities, resulting in their rejection and isolation. Currently, the impact and burdens born by PWE as a neurological disorder transgresses the clinical aspects to include associated stigma [20]. For example, preliminary research reported that marriage and employment rates were lower in PWE, in addition to a higher under-employment rate compared to the general population [10,12,21–32]. However, stigma is a social construct of identity, and its forms can vary over communities, despite epilepsy being a stigmatizing disease in most of them [32]. Our study conducted in Saudi Arabia reports the knowledge and attitudes observed in a general population assessing changes in perception.

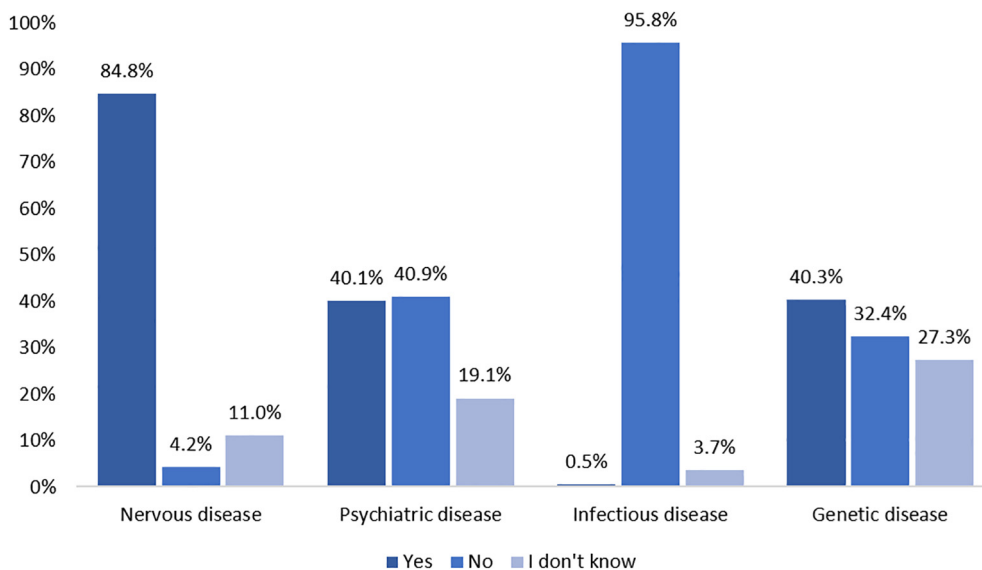


Fig. 2. The proportion of participants responses on the etiology of epilepsy.

The current findings in addition to the previous reports from the Kingdom of Saudi Arabia over the years will help in establishing a culturally-based scale to longitudinally assess stigma in the Saudi community.

Saudi Arabia has dramatically improved in recent years to incorporate sustainable development plans, with the general population witnessing considerable changes in different aspects of life [33–35]. The change in the educational level of respondents in addition to the socioeconomic status reflects the encouragement and the successful investment by the government. Comparing results obtained from a previous study in the Aseer region in 2016 [19], the proportions of those with a bachelors degree or higher were considerably more in the current survey. Regarding several studies conducted in the Jeddah, Al-Kharj, Riyadh, Majmaah, and Qassim governorates [13,18,36–38], a noticeable growth in the population’s monthly income was also observed.

Significant progress was shown in understanding epilepsy, its clinical aspects, etiology, risk factors, genetic background, and therapeutic options among respondents. The percentage of knowledgeable respondents of epilepsy rose in comparison to other studies from different cities in Saudi [13,18,19,36–41]. This could reflect the differences in participant’s level of education imparting greater awareness of the disorder.

The percentage of participants with some knowledge of epilepsy was comparable to reports from other Arab countries including Kuwait (97.6%) [42], the United Arab Emirates (UAE, 75% and 97%) [43,44], and Jordan (88%) [45]. Other countries reporting on attitudes and knowledge toward PWE include Iran (76.6%) [46], China (93%) [47], Greece (94%) [48], United States (US, 90%–95% over a five-year period) [49], Taiwan (87%) [50], Turkey (81%) [51], New Zealand (95%) [52], Germany (94.8%) [53], and Ethiopia (97.1% in rural and 92.3% in urban areas) [17], but lower than Cameroon in studies reported in 2009 and 2013 (99.3% and 99.6%, respectively) [54,55].

The healthcare system also witnessed an improvement in the Kingdom despite the fact that physicians were a source of information in only 5% in a study from Jeddah a year before [13]. This was slightly higher in the current report. Consequently, this suggest hospitals and physicians could contribute to increasing awareness of PWE addition to referring to specialists who can provide a higher level of care. As well, relatives and friends’ personal experiences had an impact on the Saudi community regarding PWE [39], and

therefore, public education and awareness programs must be increased.

Regarding the respondents’ thoughts about the best options for epilepsy treatment, fortunately, the majority of them did believe in the importance of medical care for patients, considering spiritual rituals and adjunctive therapies as an additional option to treatment with medication. Still, some respondents were convinced that the efficacy of standard treatment modlaties should rely mostly on religious beliefs and practices rather than medication use.

The proportion suggesting spirituality as a primary focus of management was much lower compared with results obtained from other cities in Saudi Arabia [13,18,19,36,37,39,40,56], sub-Saharan African countries [57], UAE [43,44], and Kuwait [42]. Research has indicated that prayer practice, which is one of the major aspects of Muslims worship, plays a significant role in therapeutic modalities [58].

The knowledge of the population improved over the years in Saudi Arabia, as the percentage of individuals who thought that epilepsy was a contagious disorder fluctuated with a noticeable decrease in different regions of the Kingdom [13,18,19,36–38,59]. Particularly, in the same city; Aseer, reporting 21.2% in 2016 [19], dropped dramatically to only 0.5% in this study. This finding indicates the enhancement in the understanding of the disease correcting misperceptions associated with its etiology among the general population. On the other hand, some misconceptions and myths still exist in the community. It is generally believed that epilepsy is a result of God’s test or punishment, demonic possession (evil spirits), magical works, envy, or an evil eye [13,18,19,36–40,56]. Unfortunately, these thoughts are of cultural and religious connection with the community [38,60], which makes them surprisingly that they were also popular even among educated individuals [39]. This could be a possible explanation for the belief in both traditional and religious-based treatment for PWE.

Social stigma related to epilepsy can affect a patients’ life in several aspects due to the associated seizures and complications of the disorder. A notable proportion in the present study agreed they would hire PWE if they were in charge, which is consistent with recent Saudi [13,40] and UAE [44] findings. Although many societies show their acceptance and belief in equal opportunity for employing PWE, unemployment and underemployment was still found to be considerable. The possible reasons behind such dis-

Table 3
Percentage of public attitudes and believes towards epilepsy patients.

| | No | Yes | Yes, if they have been free of Seizures > 2 Years | | |
|---|-------|---------------|---|------------------|--------------|
| If you were a manager, would you hire a patient with epilepsy? | 4.3 | 53.0 | 42.7 | | |
| Would you marry or let your son or daughter marry a patient with epilepsy? | 39.0 | 27.6 | 33.4 | | |
| Do you think that epilepsy is a kind of test and affliction? | 13.1 | 75.1 | 11.7 | | |
| Do you think that epilepsy is a punishment for the patient? | 91.0 | 1.2 | 7.8 | | |
| Do you think that epilepsy may be because of a spiritual reason, such as the eye, magic, demons, and touch? | 30.0 | 40.1 | 29.9 | | |
| | Agree | Totally agree | Disagree | Totally disagree | I don't know |
| Do you think that epilepsy patients may cause accidents at home, work, or other places? | 30.4 | 0.0 | 59.0 | 0.0 | 10.6 |
| Do you think that epilepsy patients are committed to their work? | 36.4 | 0.0 | 27.5 | 0.0 | 35.8 |
| Do you think that epilepsy patients are a heavy burden for insurance companies? | 42.5 | 0.0 | 16.8 | 0.0 | 40.7 |
| Do you think that epilepsy patients are violent or harmful individuals? | 15.0 | 0.0 | 3.1 | 0.0 | 81.8 |
| Do you think that epilepsy patients have disabilities with a contagious or hereditary disorder? | 22.5 | 0.0 | 9.1 | 0.0 | 68.4 |
| Do you think that the mental abilities of epilepsy patients are similar to other forms? | 41.0 | 38.2 | 2.3 | 0.7 | 17.7 |
| Do you think that epilepsy patients have psychological disturbances? | 25.7 | 5.1 | 36.4 | 0.0 | 32.8 |
| Do you think that epilepsy patients may succeed in their life and work similar to other people? | 46.1 | 46.0 | 1.4 | 0.0 | 6.5 |
| Do you think that epilepsy patients can live a normal life like other people? | 49.0 | 37.6 | 0.0 | 5.0 | 8.4 |
| Do you think that a child with epilepsy should play with your/other children? | 53.6 | 34.4 | 0.0 | 3.3 | 8.8 |
| Do you think that it's scary to see someone seize in front of you? | 40.4 | 23.4 | 0.0 | 26.9 | 9.3 |
| | No | Yes | I don't know | | |
| Do you think society stigmatizes treats epilepsy patients? | 37.1 | 51.2 | 11.6 | | |
| Do you think that epilepsy patients can have normal marriages and relationships like other people? | 51.5 | 35.6 | 12.8 | | |
| Do you think that epilepsy patients can work in the military sector? | 9.3 | 82.6 | 8.1 | | |
| Do you think that epilepsy patients can get a job like other persons? | 26.3 | 67.0 | 6.7 | | |
| Do you think that epilepsy patients should be allowed to drive a car? | 7.9 | 85.6 | 6.5 | | |
| Do you think that epilepsy patients can participate in daily routines like playing sports? | 56.4 | 30.0 | 13.7 | | |

crimination could be due to the nature of the unpredictable and paroxysmal features of the disease, where concern exists that PWE may lead to accidents in the workplace, lack commitment, and have higher financial costs to employ (e.g., paid sick leaves and healthcare insurance costs).

Additionally, the general belief in the psychological and mental ability of the patients is one of the major obstacles that can limit their opportunities to have a job in different sectors or have normal relationships including marriage, like healthy individuals. Another challenge for PWE to marry stems from social stigmatization. The percentage of respondents who agreed they would marry or allow the marriage of their offspring to PWE was considerably lower than those reported in Qassim [38], Al-Kharj [18], Majmaah [37], and Jeddah [15], and developed countries, such as Austria [61], and New Zealand [52]. However, this was higher than prior studies in Aseer [19], Taif [41], and other Saudi regions [13,36] and remained higher compared to other populations, including Greece [48], Jordan [44], the UAE [45], and Egypt [62]. These contradictions could be due to the impact of local traditions, where marriage is mostly arranged and authorized by the parents. The fear of transmitting the disease to children in addition to the associated social and economic commitments are major factors in the social status for epilepsy patients [13,63]. Surprisingly, all of our respondents would permit their children to play and interact with other children who have epilepsy, which is inconsistent with other local and worldwide trends [13,15,17–19,36–38,42,44–46,48,52,61,62,64]. This positive attitude reflects a significant enhancement in the rooted sociocultural stigma in our cohort.

The ability of PWE to practice daily activities, such as driving a car, has been a considerable issue globally, where the challenge is to find a balance between viability and safety exists [65,66]. Although it is a primary concern, a large proportion of respondents did believe in the feasibility of PWE to drive, which is greater than recently reported in Saudi Arabia [13,15,56] and consistent with a study in Taif City [41]. On the other hand, only one-third of the respondents thought that patients could participate in sporting activities. A much higher percentage was found in Jeddah [13], Taif [41], and the UAE [44]. This finding could indicate a gap in understanding restrictions and proper precautions required for PWE. This probably reflects concerns over potential risk of injuries that could be sustained from breakthrough seizures in addition to limited consensus on the topic to provide individualized recommendations. Recent findings suggest that seizures are rarely detrimental when triggered by exercise during common sporting events with the exception of dangerous sports including scuba diving and skydiving [67].

5. Conclusions and recommendations

This study demonstrated that the level of education and awareness regarding epilepsy in the Saudi population living in Aseer city has improved over time. Our findings could aid in designing targeted awareness programs and workshops focusing on the most common misconceptions and negative attitudes toward epilepsy patients. This requires the collaboration of several government agencies and local institutions to ensure that steps are taken to tackle these issues and prevent further deterioration. Seminars to heighten awareness in schools and universities and in the local community on epilepsy and its causes, methods of treatment, seizure control, and associated economic and societal consequences would be beneficial. PWE should be encouraged to exercise by clarifying the associated advantages on the mental and physical state of the patients, to counterbalance PWE who experience depression and being overweight. Finally, we advocate for creating special training programs that prepare epilepsy patients for the labor mar-

ket to assist them in a successful married life would be of value, in addition to enacting regulations that protect their civil rights.

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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