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# Social and Psychological Issues in Patients with Epilepsy

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## 1. Introduction

### 1.1 Background and purpose

Patients with epilepsy commonly have associated psychological, psychiatric and social issues. The objective is to look into the psychosocial problems that are encountered by the patients with epilepsy.

### 1.2 Methods

The literature on psychosocial issues of patients with epilepsy will be reviewed. The differences of the issues between the two genders are also explored. We also would like to look into the literature regarding the differences in the social and psychological issues in the western countries as compared to the Asian countries.

### 1.3 Results

A high number of patients with epilepsy have depressive illness and psychosis. They also have higher rate of suicidal attempts or ideation. They also have negative social skills and impaired coping mechanisms. Unemployment and higher anxiety states are more frequent for women with epilepsy as compared to men with epilepsy. Female patients have more difficulty finding life partners and have higher rate of divorce compared with males. Women with epilepsy rarely use constructive coping methods, and thus have poor psychosocial status and adjustment within the family and society.

### 1.4 Conclusions

Patients with epilepsy have higher risk of psychiatric problems with behavioural changes. Female patients tend to have more mood disorders and social problems in comparison to male patients.

## 2. Epileptic patients with social and psychological issues

Epilepsy is a common illness in the world. Epilepsy affects 50 million people worldwide. (1) Epilepsy is a chronic illness. The disease results 1% of days lost to ill health globally. (2) Epilepsy is characterised as recurrent, intermittent seizures unprovoked by any acute medical condition or transient brain disorder. (2) Epilepsy is the fourth most common neurologic disease. (3) One in 26 people develops epilepsy during the lifetime. (3)

Epilepsy is one of the most common serious neurological diseases in childhood. (4) Epilepsy is ranked second in a range of health conditions.(5) The incidence of epilepsy is slightly higher in male patients with epilepsy.(6)

Patients with epilepsy commonly have multiple psychological, psychiatric and social problems due to their illness. (7, 8, 9) and also due to medication. There is significant psychological and social impact of epilepsy.(1)

Epilepsy is associated with increased mortality, including increased risk of sudden unexpected death. (2) Epilepsy can also result in morbidity which may be physical occurring directly from seizures. (2) The patients can also have cognitive delay, speech difficulties, language difficulties or learning disabilities. (2) Epilepsy can also result in aggressive behaviour or psychosocial issues.(2)

Patients frequently have poor knowledge of epilepsy. (10) Thus, they are more prone to having low self-esteem.

Epileptic patients feel stigmatised by the society and they develop social maladjustment as well. (11) They have multiple social problems such as social withdrawal, ostracism and low self-esteem. (7, 12) These issues may be due to attitude and perception of the society. (7) People with epilepsy are wrongly perceived as having mental health and also being antisocial. (1)

Twenty-five percent of adults having epilepsy describe social stigma as a result of their epilepsy (1) The patients fear rejection from their peers and from other people. (1) Many a times, they feel lonely (1) and feel being outcast from society.

Stigma is associated with poor psychosocial health outcomes in people with epilepsy. (13) Epilepsy stigma can be categorised into internalized, interpersonal, and institutional. (14) The stigma is based on misunderstandings and wrong conception that are present for many years. (1) Despite modernisation of society, there are still wrong concepts and ideas about patients with epilepsy, resulting in difficult social environment for the patients. (14)

Some people may have wrong beliefs and stereotypes with negative expectations of patients with epilepsy. (5) There is an association between stigma and poor quality of life. (14)

However, there are some improvements in public attitudes towards epilepsy as compared to before. (14, 15) A study in France showed that there is improvement of public attitudes towards epilepsy. (16)

The majority of people in the public in France who participated in the survey felt that people with epilepsy should have the opportunity to get married and that children with epilepsy should be allowed to go to school with others. (16) However, there are still gaps of wrong beliefs and knowledge among the men, elderly and people from the lower educational group.(16)

In a Middle Eastern country Jordan, a study was done where 16,044 people from different areas in the country were interviewed with questionnaire. (17) Eighty-eight percent of the people interviewed had knowledge about epilepsy. (17) About 85% of the people surveyed, believed that epilepsy is a neurological disease. (17)

Around 80% of the participants in Jordan thought that there is loss of consciousness with epilepsy. (17) The younger participants and those with higher education had more knowledge on causes and symptoms of epilepsy with statistically significance. (17)

The Jordanian participants also believed that people with epilepsy are able to have children and to have high educational level, such as degrees. (17) However, about 10% of respondents had negative attitudes, and believed that patients with epilepsy have mental disorder. (17)

A large proportion of Jordanian participants (88.5%) objected to the marriage of epileptic patients with epilepsy to the participants' children. (17) One third of the respondents believed that epilepsy is more serious compared to diabetes mellitus and hypertension. (17) The knowledge and attitudes of Jordanians towards epilepsy is almost similar to the results from Asia. However the results are more negative than results from the West.(17)

There was a study done in New Zealand. (15) A survey of community knowledge and attitudes toward epilepsy was carried out. (15) Telephone interviews were conducted on 400 people aged more than 17 years old from a provincial town.(15) Attitudes toward people with epilepsy were favorable.(15) Ninety-five percent of the participants had knowledge about epilepsy.(15)

The respondents who were less knowledgeable were the younger people, the people with less education and lower socioeconomic status with those of Maori or non-European ethnicity.(15) Only 5% of the respondents objected to their children marrying an epileptic patient. (15) Less positive attitudes were found among the older people. (15) People in New Zealand have good knowledge of epilepsy.(15) The attitudes of New Zealanders to epilepsy are positive.(15)

There was another study done in Hungary with recruitment of 1000 respondents from the general public who interviewed with questionnaire in 1994 and in 2000. (18) The participants had prejudice towards employment of patients with epilepsy.(18) However, in recent years, there was a significant decrease in stigmatisation towards regarding marriage of people with epilepsy.(18) There could be culture-specific characteristics of understanding epilepsy.(18)

The patients, relatives and the general public may have misunderstanding or wrong conception about the disease and therefore, have unnecessary fear about the disease and consequences of disease and therapy. (7) One study reported that social skills are inversely proportionate to depression and negative social skills are inversely associated with anxiety. (19)

Financial issue is a major problem for the patients. (20) Most epileptic live with their parents, foster homes or institutions as reported by a Dutch study. (21) The longer the duration of epilepsy is, the worse the psychological issues are. (22) They have impaired quality of life, such as loneliness. (23)

Epileptic patients have poor education and achievement later on in life. (21) Patients who have epilepsy at school age have worse learning achievement. (21)

Learning disorders are disorders that interfere with academic performance or with daily activities that require reading, writing or mathematical skills in subjects with a normal intelligence quotient. (4)

Learning disorders are more common in children with epilepsy than in the general population. (4) Therefore, the risk of cognitive impairment in children with epilepsy is high. (4) Learning disorders are affected by the type of epileptic syndrome, the age of onset and the antiepileptic treatment.(4)

Even some children who have relatively benign form of epilepsy such as, benign childhood epilepsy with centrotemporal spikes (BECTS), they have delayed reading, counting or spelling ability by about one academic year. (24)

Some children with BECTS have poorer drawing and visuo-spatial skills and visuo-spatial memory compared to children of normal population.(24) However, their verbal functions and memory remain intact.(24)

Adolescent patients with epilepsy have more depression, anhedonia, social anxiety and obsessive symptoms than patients in general population of same age group. (25) They have low self-esteem. (10) Generally, higher seizure frequency is associated with low self-esteem. (25)

Patients with tonic-clonic seizures have higher levels of depression. (25) Poor knowledge of epilepsy is significantly associated with higher level of depression, lower self-esteem and higher level of social anxiety. (25)

They have problems with finding their self-identity. (13) They also are more prone to being stigmatized by the society. (13) There are significant negative attitudes in the adolescent public globally worldwide, resulting in loneliness and social avoidance in school. (1)

Vocational issue is common in epileptic patients, as they have high unemployment rates and frequently work in underpaid jobs. (7) One of the reasons for employment problems of patients with epilepsy is the attitude of employers. (26)

The problem is worse in the female patients as they have a higher rate of unemployment. (27) Epileptic patients have difficulty in finding life partners or have children. (21) There is a tendency for them to be single. (7) They also have difficulties in achieving independence in their life. (7)

A study was done in South Korea regarding employment of people with epilepsy. (28) People with epilepsy have higher rate of unemployment (five times higher) at around 30% compared to general population. (28) The people with epilepsy who are unemployed have significantly lower quality of life than the employed ones. (28)

The employability of people with epilepsy was influenced by the frequency and severity of seizures, age at onset, interseizure psychosocial disabilities including self-esteem, personality, and problem-solving style and social discrimination. (28) There was stigmatization and misconception in employment of people with epilepsy. (28)

Nearly one quarter of the participants thought that they were treated unfairly at work or when trying to look for jobs. (28) More than half of those who disclosed their disease to employers said that they were refused jobs due to their illness. (28) About 75% of the patients mentioned that they did not reveal their disease when applying for job. (28)

There was a study done in United Kingdom looking at the attitudes of employers to people with epilepsy. (26) There were 204 respondents. (26) Nearly one quarter of the participants had experience of employing patients with epilepsy. (26) Sixteen percent considered that there were no jobs in their company suitable for people with epilepsy. (26) About 20% of the respondents thought that by employing people with epilepsy, it would be "a major issue." (26)

Employers believed that patients with epilepsy, even when in remission, should inform the condition of their illness to the employer. (26) Seizure severity and frequency are important when employers consider epileptic patients for employment, as half of the employers are worried of work-related accidents. (26) They are willing to give flexible working hours to epileptic patients. (26) Company size and type of company influence employability of people with epilepsy. (26)

Epilepsy is associated with reduced quality of life. (29) Patients with epilepsy generally have impaired coping skills or mechanisms especially female patients. (30) Patients who have seizures that are well controlled have better coping skills and better quality of life. (21) However, socioeconomic status can be an additional protective factor. (29)

Important predictors of good outcome are good quality of life at the beginning and few side effects of therapy. (29) Significant predictors of poor outcome were poor health perception and presence of depression. (29)

Patients on antiepileptic medications, also have worse social functioning. (21) Emotional problems are prevalent in the patients in the West and in Asia. (7, 11) Education plays an important role in assisting the patients cope with their illness. (30) In an interesting study in Holland, patients with epilepsy cope well with their epilepsy despite having worse psychosocial consequences than general population. (21)

A high number of patients with epilepsy have depressive illness (31) and psychosis. They also have problems with interpersonal relationship. (7) They also have higher rate of suicidal attempts or ideation. (32, 33)

Suicide in people with epilepsy is about four times more common than healthy people. (32) The major risk factors for suicidal ideation in epilepsy are depression and psychiatric symptoms. (33) Male patients with temporal lobe epilepsy have higher risk for suicidal behaviour. (34)

Patients with epilepsy are more anxious. (35) Different types of epilepsy can present with different types of psychiatric disorders. (19) Patients who suffer from juvenile myoclonic epilepsy tend to have anxiety and mood disorders. (19) Patients with mesial temporal sclerosis more commonly have psychotic disorders. (19)

Male patients with epilepsy have less sexual desire and lower erectile function compared to normal population. (36) They have higher sex hormone binding globulin levels and lower dehydroepiandrosterone level. (36)

There are gender-specific issues with regards to patients with epilepsy. Worsening anxiety is more frequent for women with epilepsy. (27) Female patients tend to have more mood disorders and social problems in comparison to male patients. (27)

Women with epilepsy have more comorbidities. (27) Female patients with epilepsy have more difficulty finding life partners compared with male patients. (27) They have more problems with marriage and therefore have increased risk of divorce. (27)

Female patients with epilepsy have increased risk of seizure at certain phases of menstrual cycle. (6) There is an increase in seizures during the second half of the menstrual cycle. (37) During menopause, about 40% of women report worsening of their seizure disorder, 27% improve, and a third had no change. (38) Hormone replacement therapy in postmenopausal women can also worsen the seizures. (6)

In a study in India, female patients with epilepsy in India between 15-40 years old had little quality of life. (30) Female patients have more difficulty finding life partners and have higher rate of divorce compared with males. Women with epilepsy rarely use constructive coping methods and they use less problem solving techniques. (30) As a result there is poor psychosocial status and adjustment within the family and society.

Epilepsy and the anticonvulsant therapy have effect on female reproductive function such as menstruation and fertility. (39) Both the disease and medication can cause menstrual disorder and infertility. (39) There is also an increase in polycystic ovaries and hyperandrogenism associated with sodium valproate therapy. (40)

In another recent study in India, 38.4% of 375 women with epilepsy had infertility. (41) The most common causes of infertility were treatment with numerous antiepileptic drugs, older age, and lower education. (41)

This association between low education and was in contrast to the observations from population studies where higher education status is associated with lower fertility. (41) A study in Great Britain showed that women with treated epilepsy from 25 to 39 years of age had 33% reduction in fertility. (42)

Antiepileptic medication which are liver-enzyme inducers, reduce the serum concentration of bioactive sex steroids. (43) Anticonvulsant treatment such as sodium valproate, which is liver enzyme inhibitor, increases the serum concentration of androgens. (43)

There can also be potential drug interaction between antiepileptic drugs and oral contraceptive pills. (44) This drug interaction can cause worsening of frequency of seizure or unplanned pregnancies. (44) There are potential drug interactions between the combined oral contraceptive pills and liver microsomal-inducing anti-epileptic medication such as, phenytoin, barbiturates, carbamazepine, topiramate (at dose >200 mg daily), oxcarbazepine and lamotrigine. (37) Antiepileptic medication which are liver-enzyme inducers, reduce the serum concentration of bioactive sex steroids. (43)

Nonenzyme-inducing AEDs (sodium valproate, benzodiazepines, ethosuximide and levetiracetam) do not show drug interaction with the combined oral contraceptive pill. (38) Anticonvulsant treatment such as sodium valproate, which is liver enzyme inhibitor, increases the serum concentration of androgens. (43)

There are no contraindications to the use of non-hormonal methods of contraception in women with epilepsy. (38)

There is also a decrease in childbirth rates in patients with epilepsy. (41) The childbirth rate in female patients with epilepsy is 25% lower compared to women in the general population. (39) Female patients with epilepsy have reduced sexual interest. (45) In some female patients with epilepsy, the desire and arousal phases may be inhibited. (38)

As for treatment during pregnancy, the teratogenic risks of anticonvulsant drugs such as spina bifida and the seizure control of the pregnant mothers need to be balanced. (6) Pre-conception counselling should be given to women with epilepsy who are thinking about getting pregnant. (37) Female patients with epilepsy should be informed about certain issues, including methods and consequences of prenatal screening, labour, breast feeding and care of a child. (37)

Preconceptional folic acid (at least 0.4 mg) is given to prevent major congenital malformations in the babies of women with epilepsy who are taking anticonvulsant medications. (46) During pregnancy, the lowest effective dose of the most appropriate anticonvulsant drug should be given. (37) There is more teratogenesis with sodium valproate is than carbamazepine. (37) The combination of sodium valproate and lamotrigine is especially teratogenic. (37)

Pregnancy probably causes increased amount in the clearance and decreased concentration of lamotrigine, phenytoin, and to a lesser extent carbamazepine. (46) Pregnancy possibly decreases the concentration of levetiracetam and the active oxcarbazepine metabolite, the monohydroxy derivative. (46)

The majority of infants are delivered healthy with no increased risk of obstetric complications in female patients with epilepsy. (37) Monitoring of lamotrigine, carbamazepine, and phenytoin levels during pregnancy should be considered. (46) Monitoring of levetiracetam and oxcarbazepine (as monohydroxy derivative) levels may be considered. (46)

Breastfeeding is not contraindicated in babies of female patients with epilepsy. (37) The antiepileptic medication concentration in breast milk follows the plasma concentration curve. (37) The total amount of drug transferred to babies via breast milk is much smaller than the amount transferred via the placenta during pregnancy. (37) However, repeated administration of lamotrigine via breast milk may lead to accumulation in the baby. (37)

Primidone and levetiracetam probably transfer into breast milk in amounts that may be clinically important. (46) Sodium valproate, phenobarbital, phenytoin, and carbamazepine probably are not transferred into breast milk in clinically important amounts. (46)

The risk of the child being harmed depends on the type of seizure and its severity and frequency.(38) The risk is small if the mothers and caregivers are trained in safety precautions.(38)

Female patients with epilepsy may have problems with bone health. (37) Women with epilepsy are at increased risk of fractures, osteoporosis and osteomalacia.(37)

In a study in Zimbabwe, it is uncertain whether epileptic patients living in the rural areas have more disability compared to the urban location. (47) In another African country, Nigeria, epilepsy is considered as a stigmatizing disease. (48) The Nigerian patients who have epilepsy face social discrimination in the areas of employment, marriage, housing and education similar to patients from other parts of the world. (48)

Patients with epilepsy need proper and adequate management. Management of psychosocial problems of epileptic patients includes adequate counseling therapy. (11) Social support is beneficial for patients with epilepsy as they have problems with social integration. (49)

Formation of social support groups will benefit the patients. (11) Social support groups can provide assistance in terms of important emotional and social support. (23) These groups can provide resources for the patient in helping them communicate with the society. (23)

This is a good type of professional support given to patients. (33) This support can be given as an addition to conventional therapy. (23) This will help improve patients' quality of life. (33)

Family counseling will also be helpful. (7) Social network and access to information about epilepsy should be given to patients. (25) Educational campaigns are necessary to improve public perception about epilepsy.(17)

Psychosocial interventions are important for the patients. (50) Psychosocial interventions are useful to increase self-mastery and promote positive adjustment to a diagnosis, which therefore will improve the patients' quality of life.(29)

A study which was done on adolescent patients with epilepsy showed that educational intervention can lead to improvement in knowledge of illness and attitude to the disease with statistical significance. (10) The patients enjoyed the sessions and found them invaluable. (10)

To be able to assist people with epilepsy, doctors should be aware of social resources and social welfare systems that are available for the patients. (49) Medical doctors should also perform thorough screening of epilepsy patients for depression and other psychiatric problems. (33) If they have any psychiatric issues, they need to be given treatment early and managed appropriately.

Proper treatment should be given to these patients to reduce suicidal behaviour. (33) In summary, rehabilitation in epilepsy is important in prevention and treatment of psychosocial disorders. (7)

Epilepsy self-management interventions which address issues such as, health care needs, medical adherence, depression, anxiety, employment, and sleep problems have been investigated. (51) Programmes such as, self-management programmes involving face-to-face individual or group meetings led by an epilepsy professional can be organized.(51)

Sessions that focus on education sessions such as, managing disability and leading a healthy lifestyle can be done. (51) Emotional coping strategies and emotional self-management can also be organized. (51)

### 3. Conclusion

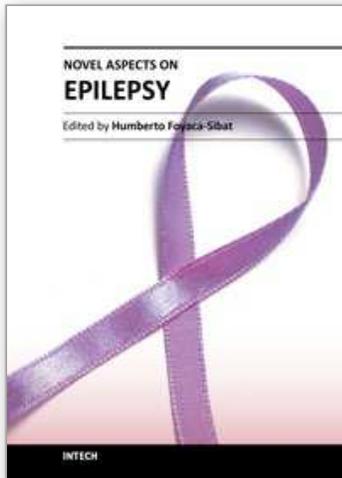
In conclusion, patients with epilepsy irrespective of location in the world generally have numerous psychosocial problems related to disease and treatment. Women with epilepsy have more mood disturbance and social problems compared to male patients.

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This book covers novel aspects of epilepsy without ignoring its foundation and therefore, apart from the classic issues that cannot be missing in any book about epilepsy, we introduced novel aspects related with epilepsy and neurocysticercosis as a leading cause of epilepsy in developing countries. We are looking forward with confidence and pride in the vital role that this book has to play for a new vision and mission. Therefore, we introduce novel aspects of epilepsy related to its impact on reproductive functions, oral health and epilepsy secondary to tuberous sclerosis, mitochondrial disorders and lisosomal storage disorders.

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