

## RESEARCH

# Subjective well-being and coping among people with schizophrenia and epilepsy

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## Abstract

**Background:** Schizophrenia and epilepsy are chronic and distressing disorders reported to occur together in a high percentage of patients. Consequently, people with schizophrenia and epilepsy are robbed of the opportunities that define a quality life: good jobs, safe housing, satisfactory health care and affiliation with a diverse group of people that may lead to decreased subjective well-being and poor coping resources and capability. There is paucity of data available on the subjective well-being and coping in these populations, particularly in Indian setting.

**Aim:** To study the subjective well-being and coping among people with schizophrenia and epilepsy.

**Materials and methods:** We evaluated 60 patients with diagnosis of schizophrenia and epilepsy (30 in each group) by following ICD-10 diagnostic criteria. Patient suffering from any comorbid psychiatric disorder including mental retardation, substance abuse, known other organic and neurological illness were excluded. We measured subjective well-being by using the Subjective Well-Being Inventory and coping strategies using the Coping Scale.

**Findings and conclusions:** Poor subjective well-being is prevalent in patients with schizophrenia and epilepsy; there is no difference found between both groups of patients on these parameters. In these subjects, coping strategies should be prompt so that well-being can be increased that may lead to improved quality of life by alleviating the suffering caused by schizophrenia and epilepsy.

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## Introduction

Schizophrenia and epilepsy are the chronic disorders that have affected people throughout history. According to the World Health Organization,[1] schizophrenia affects approximately 24 million people in the world with more than 50% not receiving the appropriate care; 90% of those untreated live in developing countries. In India the prevalence of schizophrenia is about three per 1000 individuals.[2] As far as epilepsy is concerned, about 50 million people worldwide have epilepsy and nearly 90% of epilepsy occurs in developing countries.[3] The global prevalence of epilepsy is generally taken as between five and ten cases per 1000 persons.[4,5] One in every 100 persons in India suffers from epilepsy, but the majority of the affected people remain untreated.[6] These two public health concerns have been found to be strongly correlated. Research on the relationship between schizophrenia and epilepsy revealed an eight times greater likelihood of schizophrenia occurring in patients with epilepsy, and a six times greater likelihood of epilepsy in those with

schizophrenia.[7] Both of them cause a significant decline in quality of life for the patient and impose a significant economic burden on society. The stigma and negative societal views attached to these disorders can make the diagnosis more distressing. The emergence of these disorders can devastate the lives of sufferers as well as their caregivers[8] via increasing distress, disability, reduce productivity and lowered quality of life. People with epilepsy are reported to perceive psychosocial adjustment as severe as perceived by patients having an impairing illness like schizophrenia in an earlier study from India.[9] Although treatment helps relieve many symptoms of schizophrenia and epilepsy, but some of the sufferers have to cope with symptoms throughout their lives. These struggles of ill persons in accepting and managing their illness can also affect negatively their well-being. Individuals may deal with the impact of the illness differently depending on their coping style; maladaptive coping style seems to make the situation more dreadful. Presence of high number of distressing factors in schizophrenia and epilepsy indicates a need for the

exploration of coping style along with subjective well-being of these patients, which are not well researched yet in Indian setting.

A recent study defines subjective well-being as “an umbrella term for different valuations that people make regarding their lives, the events happening to them, their body and minds, and circumstances in which they live.”[10] Diener and Locas[11] conceptualised subjective well-being as a broad construct, encompassing four specific and distinct components including (a) pleasant or positive well-being (e.g., joy, elation, happiness, mental health); (b) unpleasant affect or psychological distress (e.g., guilt, shame, sadness, anxiety, worry, anger, stress, depression); (c) life satisfaction (a global evaluation of one’s life); and (d) domain or situation satisfaction (e.g., work, family, leisure, health, finance, self). Epilepsy affected people often develop marked dysfunctions in many areas of life activities which could limit their socio-occupational functioning up to a great extent. Previous studies showed that there is a definite relationship between clinical variable like current seizure frequency and levels of anxiety and depression, perceived impact of epilepsy, perceived stigma, and marital and employment status. Another important variable like age at epilepsy onset may also have some relationship with psychosocial dysfunctions of these people.[12] In addition to those above issues people with epilepsy may also face a number of complex and interacting problems and barriers related to employment. Factors like gender, number of anti-epilepsy medications, seizure frequency, and reported interference in daily functioning created by seizures can be the best predictors of employment of these people.[13]

In last few decades medical and surgical care for patients with epilepsy has made tremendous strides. However, this progress has not always been followed by an improved subjective quality of life (QoL) of the individuals with epilepsy. Subjective well-being has been an important yardstick to measure one’s impression about his life and it becomes more important to people with some chronic problems. Due to chronic nature of the illness and unsupportive attitude of the society, epileptic patients often have lesser level of subjective sense of satisfaction than normal people. Previous studies have suggested that the negative effect of antagonistic societal attitude, e.g., social stigmatisation and less social support could limit the functionality and social interaction of the patients and this way patient’s self-efficacy, self-esteem and self-worth are deeply affected negatively. And eventually that could significantly affect the subjective well-being and quality of life of these people.[14,15]

Coping is a cognitive-behavioural process that unfolds in the context of a situation or condition perceived as personally relevant and challenging or that exceeds the individual’s resources to handle the particular

demand.[16] According to the theory of Folkman *et al.*,[17] there are two broad ways of coping—problem-focused and emotion-focused. Problem-focused coping seeks to change the troubled person-environment relationship by acting on the environment or oneself. Emotion focused coping refers to efforts undertaken to regulate stressful emotions.[18] Hence, coping can take many forms, it may be growth-oriented (e.g., problem-solving of issues impeding one’s functioning, thinking positively about the possibilities available in the future) or negatively weighted (e.g., avoiding certain situations, catastrophising), or it can encompass both forms simultaneously.[19]

Living with chronic illness or illnesses is a tremendous challenge and it seems plausible that emergence of these disorders often bring negative effect on sufferer’s coping abilities and well-being. Hence, it is very important to make their lives as unproblematic as possible so that they feel more confident and use their adaptive potential against these adverse illnesses. That can be achieved by increasing their coping capabilities that may finally result in improved well-being. To understand this phenomenon, the present study had been taken up to find out the subjective well-being and coping style of persons with schizophrenia and epilepsy. The investigators expected that the findings would provide useful information and in broadening their outlook from the point of view of professionals working in the field of schizophrenia and epilepsy.

## Method

The researchers decided to keep the sample size 30 in each group i.e. the patients’ group with epilepsy and patients’ group with schizophrenia. To be included in the study informed consent was made a prerequisite for all the participants. Patients between ages of 18 to 60 years of either sex and diagnosed as suffering from schizophrenia or epilepsy according to the tenth revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10) Diagnostic Criteria for Research (DCR)[20] were included in the study. Duration of illness needed to be of equal or more than one year. Patients suffering from any comorbid psychiatric disorder, mental retardation, substance abuse, known organic or neurological illness were excluded in the study.

## Research design

The study design was cross-sectional. Consecutive patients fulfilling the aforementioned criteria were recruited.

**Setting:** The study of conducted in Central Institute of Psychiatry, Ranchi, India, a tertiary psychiatric institute having postgraduate teaching facilities in all the relevant discipline related to psychiatry viz. clinical psychology,

psychiatric social work and psychiatric nursing etc. in addition to psychiatry itself.

**Subjects:** The sample base was the patients attending the outpatient department (OPD) of the said institute.

**Duration of study:** The study was conducted during January to June 2003.

**Tools of the study:** The diagnosis was made by the senior residents/consultants in charge of the OPD and was confirmed by the researchers by applying ICD-10 DCR criteria.[20]

To measure the subjective well-being and coping, the following tools were used –

**Subjective Well-Being Inventory:**

This assessment inventory was prepared and used by Sell and Nagpal.[21] Each question given in the questionnaire represents the feeling of the interviewee and he/she is supposed to tick the best alternative among the options given. In case the interviewee finds no choice to select the alternative then he/she can tick the approximate solution among the options. There were forty items in this inventory.

**Coping scale:** Scale derived from coping scale by Carver *et al.*[22] There were total 14 items viz. planning, suppression, active coping etc. The total 14 items were divided into two parts i.e. active coping and passive coping.

**Statistical measures:** The data collected were analysed using statistical package for social sciences (SPSS) 10.0 for Windows 98. Descriptive statistics including mean, standard deviation (SD), and percentage were applied to describe the characteristic of the sample studied. To examine group differences t test and  $\chi^2$  were employed.

**Table 1. Group differences in socio-demographic variables**

| Variable                 | Epilepsy (n=30) |       | Schizophrenia (n=30) |       | Analysis |    |
|--------------------------|-----------------|-------|----------------------|-------|----------|----|
|                          | Mean            | SD    | Mean                 | SD    | T        | p  |
| Age (years)              | 31.5            | 10.29 | 31.8                 | 10.17 | 1.47     | ns |
| Total years of education | 11.00           | 3.90  | 10.90                | 4.68  | 1.62     | ns |
| Variable                 | n               | %     | n                    | %     | $\chi^2$ | P  |
| Sex                      |                 |       |                      |       |          |    |
| Males                    | 26              | 86.7  | 27                   | 90    | .162     | ns |
| Females                  | 4               | 13.3  | 3                    | 10    |          |    |
| Occupation               |                 |       |                      |       |          |    |
| Employed                 | 5               | 16.7  | 8                    | 26.7  | .251     | ns |
| Unemployed               | 16              | 53.3  | 10                   | 33.3  |          |    |
| Others                   | 9               | 30.0  | 12                   | 40.0  |          |    |

n=number, SD=standard deviation, ns=non significant

**Table 2. Group differences in the subjective well-being**

| Domains                         | Epilepsy |      | Schizophrenia |      | Analysis |    |
|---------------------------------|----------|------|---------------|------|----------|----|
|                                 | Mean     | SD   | Mean          | SD   | t        | p  |
| Family background               | 15.96    | 3.15 | 16.30         | 2.57 | .44      | ns |
| Emotional adjustment            | 28.93    | 4.10 | 27.63         | 5.72 | .54      | ns |
| Interpersonal adjustment        | 9.56     | 1.94 | 10.30         | 2.01 | 1.43     | ns |
| Vocational adjustment           | 4.40     | .96  | 4.50          | 90   | .41      | ns |
| Financial adjustment            | 2.10     | .65  | 2.31          | 1.66 | 1.36     | ns |
| Medicine and medical management | 12.36    | 2.95 | 10.16         | 2.50 | 1.87     | ns |

SD=standard deviation, ns=non significant

**Table 3. Group differences in coping strategies**

| Domain   | Epilepsy n= 30 |      | Schizophrenia n=30 |      | Analysis |       |
|--|----------------|------|--------------------|------|----------|-------|
|  | Mean           | SD   | Mean               | SD   | t        | p     |
| Active coping                                  | 2.07           | 1.05 | 2.20               | .97  | .51      | ns    |
| Planning                                       | 2.37           | 1.0  | 2.10               | .92  | 1.47     | ns    |
| Suppression of completing activities           | 2.47           | .97  | 1.97               | .85  | 2.11*    | < 0.5 |
| Restraint coping                               | 2.10           | .88  | 2.40               | .81  | 1.37     | ns    |
| Seeking social support for instrumental reason | 1.50           | .82  | 1.90               | .88  | 1.62     | ns    |
| Seeking social support for emotional reason    | 1.97           | .85  | 2.00               | .90  | 1.5      | ns    |
| Positive reinterpretation                      | 2.47           | 1.10 | 2.47               | .89  | .00      | ns    |
| Acceptance                                     | 2.23           | 1.19 | 2.13               | .97  | .36      | ns    |
| Turning to religion                            | 2.60           | 1.06 | 2.46               | .93  | .51      | ns    |
| Venting of emotional                           | 2.13           | 1.10 | 2.03               | .85  | .51      | ns    |
| Denial   | 1.97           | 1.06 | 1.86               | 1.10 | .39      | ns    |

\*p < 0.5, SD=standard deviation, ns=not significant

**Results**

The epilepsy and schizophrenia groups constituted 86.7% and 90% male respectively (table 1). There were no significant difference between the mean ages, total years of education and occupational status of patients with epilepsy and schizophrenia (table 1). There was no significant difference between the groups (epilepsy and schizophrenia) on any of the sub-domain of subjective well-being (table 2). The epilepsy and schizophrenia

groups significantly differed in the following items: suppression of completing activities and alcohol-drug disengagement (table 3).

## Discussion

The present study has explored the subjective well-being and coping of people with epilepsy in comparison to people with schizophrenia. The main reason for considering schizophrenia a control group has been because this disorder like that of epilepsy is known to have severe course and progression and is attached with social stigma.

The present study has shown the degree of compromise in emotional adjustment in people with epilepsy to be comparable to those with people with schizophrenia. Much of the literature bears sufficient evidence for the role of emotional factors in epilepsy. Previous studies[23-26] showed that emotional problems and adjustment were major concern in most of the epileptics. Many studies have shown people with epilepsy to have poor emotional adjustment. The present study has shown that the degree of compromise in emotional adjustment in people with epilepsy to be comparable to those with people with schizophrenia. This finding suggests the need for assessment of emotional functioning in people with epilepsy as a clinical routine. In the same direction, a future study is needed to compare the emotional adjustment in people with epilepsy and schizophrenia and the effect of intervention strategies focusing this aspect of functioning.

Current findings show that there is no significant difference in the area of interpersonal adjustment between these two groups (epilepsy and schizophrenia). Dodrill *et al.*,[23] in a study of chronic epileptic people, reported significantly difficulty in the area of interpersonal adjustment.

The findings of the study show that there is no significant difference in the area of vocational adjustment between these two groups. Earlier findings[27-29] have shown that vocational adjustment is related to control of seizure either by surgery or medication. Seidman-Ripley *et al.*[28] reported 24% reduction in vocational disability for those who had complete seizure relief. Jacoby *et al.*[30] indicated that rates of employment among subjects (epileptic patients) were comparable with those of general population. They also reported low levels of distress in epilepsy. It has also been found that presence of job is linked to being married.[31]

Current findings show that there is no significant difference in the area of financial maladjustment between these two groups. Previous findings[32,33] show that improvement in financial condition may be result of relief from seizure.

Findings of the study also show that there is no significant difference in subjective well-being in the area of family background between these two groups. Most of the studies[23,24,28,34] have reported low scores in subjective well-being in the area of family background indicating major difficulties. We can say that in both conditions severe psychosocial adjustment problems are present. In a study done by Lau *et al.*,[35] findings show that social factors are more important predictors of psychosocial adjustment in epilepsy than medical factors.

There are several reasons which might explain why the patients' with schizophrenia and epilepsy scored poorly on subjective well-being and coping scales, including the unpredictable nature of epilepsy that affects all dimensions (physical, psychological and social) of the sufferer's life. People with the diagnosis of epilepsy are at greater risk for different social as well as other problems including marriage, education and daily activities. Patients diagnosed with schizophrenia also exhibit positive, negative and mood symptoms as well as experience cognitive and functional impairments.[36] Persons with epilepsy are more likely to report never being married than those without epilepsy. Social support, especially from marriage, may buffer the negative impact of stressful events and chronic health conditions.[37] Despite significant advances in the pharmacotherapy, noncompliance, particularly in long-term treatment, remains a major problem in schizophrenia.[38] Present finding may also seems to infer that poor coping mechanism and subjective well-being can lead to poor treatment compliance.

## Limitations and future direction

1. Clinical variables related to subjective well-being has not been examined.
2. Assessment of depression and anxiety in epilepsy patients has also not been examined.
3. The exploration of severity of schizophrenic psychopathology has not been done.
4. In future, subjective well-being and its predictors need to be examined in epilepsy patients, new and old, treated and untreated.
5. Effect of interventional strategies needs to be examined in the future.

## Conclusion

Schizophrenia and epilepsy are chronic and disabling illnesses; moreover schizophrenia co-occurring with epilepsy or vice versa is highly prevalent and associated with a wide range of adverse outcomes. In addition, poor subjective well-being in this population seems to be associated with less effective self-care, more severe physical symptoms, greater functional impairment and

disability as well as increased healthcare utilisation and expenditure. Moreover, poor coping make it more difficult to treat the illness, since poor coping may make sufferers not to take care of themselves and follow prescribed treatment. So it is important to elicit level of subjective well-being and coping among them earliest to prevent them from adverse effect that may lead to avail effective existing treatment. The findings of this study are quite encouraging as early identification and appropriate treatment of psychological factors in the ills can positively influence medical outcome and quality of life.

### Further Reading

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