International Journal Of
Recent Scientific Research
ISSN: 0976-3031
Volume: 7(4) April -2016

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THE OFFICIAL PUBLICATION OF
INTERNATIONAL JOURNAL OF RECENT SCIENTIFIC RESEARCH (IJRSR)
http://www.recentscientific.com/ recentscientific@gmail.com

Available Online at http://www.recentscientific.com

ISSN: 0976-3031

International Journal of Recent Scientific Research
Vol. 7, Issue, 4, pp. 10565-10569, April, 2016

International Journal of Recent Scientific Research

Research Article

GRATIFICATION, PERCEIVED STRESS AND GENERALIZED EXPECTANCY OF PATIENTS WITH EPILEPSY

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ARTICLE INFO

Article History:

Received 29th January, 2016
Received in revised form
19th February, 2016
Accepted 25th March, 2016
Published online 28th April, 2016

Keywords:

Epilepsy, Seizure, QOL, Perceived stress, Life orientation

ABSTRACT

Epilepsy is a common medical and social disorder with unique characteristics. It is usually defined as a tendency to recurrent seizures and can have tremendous psycho social issues for patients. Epilepsy can have diverse and complex effect on the wellbeing of its sufferers. The aim of the study was to identify variables related to stress, Gratification and expectancies in person with epilepsy. The mean age of participants was 31.65 years in which mostly had seizures. The sample comprised of 40 diagnosed patients of epilepsy and 40 non epileptic by using the purposive sampling. To find out the impact of demographic and clinical variable on Gratification, Perceived stress and expectancies of epileptic patients, t test, ANOVA, and step wise regression analysis were applied. The results indicate that the epileptic patients scored lower on all domains of QOL or gratification (Physical, Psychological, Social and Environmental), optimism scale and Higher on perceived stress as compared to non epileptic. After ensuring the homogeneity of variance a 2X2 ANOVA was carried out to ascertain the main and interaction effect of the two factors (Sex and Nature of disease) under investigation. The results of ANOVA clearly revealed that the main effect and interaction effect of sex and nature of disease have been found statistically significant on gratification. In order to determine the significance of nature of disease, marital status and sex in predicting their quality of life step-wise multiple regression analysis was done. It is clear that nature of disease factor emerged as the best predictor of gratification in contributing 26 percent in the total variance followed by marital status and sex that contributed 14 percent and 10 percent of total variance. Examination of β revealed that the said predictors contributed negatively (β =-0.33 & -0.33 respectively) to quality of life.

INTRODUCTION

Epilepsy has been defined as "a disorder of the brain characterized by an enduring predisposition to generate epileptic seizures, and by the neurobiological, cognitive, psychological and social consequences of this condition. Factors contributing negatively to psychological well being include a sense of not being in control of one's life, feeling stigmatized, having problems related to quality of life such as co morbid depression and anxiety and problems connected with work, financial situation and stress inducing events in life (Jacoby A.1994, Baker GA.2000 and Hermann BP.*et al* 1999). Patients with epilepsy experience more problems in social functioning and psychological well being than peers in general and these are often considered to be even more handicapping than seizures themselves (Baker GA. 2005 and Mirnics Z. *et al*. 2001). Research has shown that people who reported higher levels of perceived stigma were more likely to report lower levels of self efficacy in dealing with epilepsy, long term health problems, injuries as a result of seizures, increased side effects from medications, non-adherence to anti-epileptic drug treatment and low satisfaction as patients (Suurmeijer T. *et al*.2001 and Joseph N, *et al*. 2011).

The situation of people with epilepsy in the developing countries remains even more problematic. India being a culturally diverse country with several religious practices has several misconceptions related to various illnesses, one of them being epilepsy. The misinterpretation of epilepsy often causes people with the condition being socially ostracized. Furthermore, as a consequence of both stigma and economic circumstances, most people with epilepsy do not receive the treatment they actually require. It is important that epilepsy is potentially curable and remission may be achieved in relatively large proportion of patients (Kwan, M.D. and Brodie, M.J. 2000). Brodie and Dichter (1996) showed that seizures can be completely controlled in 60–70% of patients. Adequate therapy

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improves medical and social prognosis of patients, possibility of every individual to implement his or her abilities. As demonstrated by several studies, quality of life (QOL) is worse in epileptic patients than in the general population. For instance, patients with epilepsy had significantly lower scores compared with healthy persons in six domains of the SF-36 in a prospective observational study of patients with partial or generalized epileptic seizures (Villeneuve, N. 2004, Wagner, A.K.*et al* 1996 and Wiebe, S.*et al* 1999). In many parts of the world, epilepsy continues to be viewed as witchcraft, contagious, and possession by devils and ancestral spirits (Austin JK.*et al* 2002). An Indian study reported that 15% of respondents believed epilepsy to be insanity, 40% believed that the child with epilepsy should not go to school or their children should not play with them and 66% objected in their children marrying someone who had epilepsy. Similar observations were found in a study from Taiwan which also reported that 31% of respondents believed that people with epilepsy should not be employed in jobs (Gambhir SK.*et al*. 1995 and Chung MY *et al*.1995).

Although there are numerous studies assessing the QOL of people with epilepsy from all over the world, but the study concern with stress, life orientation and QOL is very scanty and sparse in India. Quality of life, perceived stress and life orientation are a strong predictor of self perceived health status. It has been vividly found that epileptic patients are always unable to do their normal day to day works. It is necessary to ascertain the magnitude of the problem as a part of the systematic approach to challenges in epilepsy management. Thus, we conducted the present study in order to assess the gratification, stress and generalized expectancies in epilepsy in our region.

Objectives

1. To study the Quality of Life, perceived stress and life orientation among Epileptic and non Epileptic patients
2. To study the impact of gender on Quality of Life, Perceived Stress and Life Orientation
3. To study the impact of duration of disease on QOL, perceived stress and life orientation
4. To find out the impact of gender, marital status and nature of participants on Quality of Life

METHODOLOGY

The sample comprised of 40 diagnosed patients of epilepsy and 40 non epileptic by using the purposive sampling. The epileptic patients were taken from S.S. Hospital, B.H.U. Varanasi. All patients were interviewed for demographic and personal history. Demographic variables (Age, Sex, Education, Marital status) and Clinical variables (duration of disease, Onset of disease, Seizures severity and Seizures frequencies) were considered. For enrollment, inclusion criteria were age 18 years or older and Exclusion criteria were psychiatric co morbidity, any other organic lesion other than epilepsy. Those patients who were unable to communicate as well as comprehend the questions were not included in the research study. QOL, Perceived stress and Life orientation test were used for data collection.

Procedure

The participants were approached after taking permission from the respective hospitals and consent from the participants. The participants were given full information about the measures and the procedure of completing those questionnaires. There queries were effectively handled. Patients were assured that their confidentialities will be maintained. They were briefed that the information they will provide will be only used for research purpose. The subjects were asked to fill three scales i.e. Quality of life inventory, perceived stress scale and Life orientation test.

Measures

WHOQOL-26 Brief Hindi version: World health organization (1995) was developed this questionnaire to assess the QOL of an individual. The original scale contains 100 items, which assess six domains of QOL. The WHOQOL-BREF is a shorter version of the original WHO scale. The Hindi version of the scale used in this study was developed by Saxena, Chandiramani and Bhargava (1998). This scale contains 26 items, which measure four domains of QOL, namely physical health, psychological states, social relationships, and environment. Out of 26 items of the scale, only 24 items are scored. Items 1 and 2 are used as fillers, and not scored. The reliability (r = Cronbach's Alfa) of this scale was calculated and it ranges from .59 to .85. Confirmatory factor analysis (CFI) revealed a very high validity index of physical health (0.957), psychological states (0.982), social relationships (0.972) and environment (0.922) domains.

1. ***Perceived stress scale (****Cohen* ***et al 1983)–:*** Hindi version Perceived stress can be viewed as an outcome variable measuring the experienced level of stress as a function of objective stressful events, coping processes and personality factors. Group mean scores were used for comparisons and greater scores indicated higher perceived stress. Briefly, PSS is a global scale and identifies the factors influencing or influenced by stress appraisal. It is a 14 -item scale which measures the degree to which situations in one's life is appraised as stressful during the past month. There are seven negative and seven positive questions for which the subjects were required to choose from a scale of 5 alternatives 'never' 'almost never' 'sometimes' 'fairly often' 'very often' relating to their feeling of being stressed on a 0-4 scale. The 7 positive items were reverse scored and added up to the 7 negative items to get the total score. Co-efficient alpha reliability for PSS was 0.84 among adult population with a test-retest correlation of 0.85.
2. **Life orientation test (LOT-R)** - (Michale, F. Sheir & Charles, S. Carver; 1985). The Hindi version of life orientation test (LOT-RH) was used. It is revised version of the original LOT (Scheir & Carver; 1992). It comprises 10 items. A 10 item measure of optimism versus pessimism. Of the 10 items, 3 items measure optimism, 3 items measure pessimism and 4 items serve as fillers. Respondent rate each item on a 4 point scale such as 0 for strongly disagree, 1 for disagree, 2 for neutral, 3 for agree and 4 for strongly agree. The range

of the scale is 0-24 in which 0 indicates extreme pessimism and 24 indicates extreme optimism. Researchers who were interested in testing the potential difference between affirmation of optimism and disaffirmation of pessimism should compute separate sub tools of the relevant items.

RESULTS

The study group consisted of 40 Epileptic patients and 40 non epileptic of whom 20 were males and 20 were females in both groups with age ranging from 18 to 60 (mean age= 34.30 ± 13.16) years. Half of the participants were younger than 30 years (<30 years = 50%, and >30 years = 50%). Forty eight study subjects were belonging to semi urban area and thirty two were concern with urban area. Fifty-one respondents had graduate education while fourteen were elementary school educated and eleven were high school educated. 46.30% of the study subjects were married and 53.8 were unmarried. This is the scenario of demographic data. For measuring the significance differences between epileptic and non-epileptic on all domains of QOL, perceived stress and life orientation, Mean, SD and t test were calculated which is presented in table-1

Table 1 Mean, SD & t values of Epileptic and Non – Epileptic on different domains of Quality of life, Perceived Stress and Life orientation

S. N.	Measures	Epileptic (N=40)	Non epileptic (N=40)	t value
1	**Physical**	Mean =20.78 SD = 6.45	Mean = 27.25 SD = 5.13	**4.96****
2	**Psychological**	Mean = 18.35 SD = 4.84	Mean = 22.28 SD = 3.39	**4.20****
3	**Social**	Mean = 9.03 SD = 2.75	Mean = 11.25 SD = 2.51	**3.77****
4	**Environmental**	Mean = 25.10 SD = 4.88	Mean = 29.48 SD = 5.04	**3.94****
5	**Total QOL**	Mean = 73.25 SD = 15.17	Mean = 90.03 SD = 13.60	**5.20****
6	**Perceived stress**	Mean = 28.60 SD = 5.96	Mean = 25.78 SD = 5.77	**2.15****
7	**Optimism**	Mean = 6.18 SD = 3.12	Mean = 9.20 SD = 2.10	**5.08****
8	**Pessimism**	Mean = 6.50 SD = 2.88	Mean = 6.23 SD = 2.38	**0.46(NS)**

P<0.01

Epileptic patients show lower mean score on all domains of QOL and there is significant difference between epileptic and non epileptic on all domains such as physical, psychological, social and environmental (t=4.96, 4.20, 3.77and 3.94, df=78 respectively). Epileptic patients also scored low on optimism scale and high on perceived stress. In order to examine the impact of sex on Quality of Life, the 2 × 2 factorial ANOVA were calculated, which was displayed in Table 2.

Table 2 (Sex) X2(Nature) Factorial ANOVA regarding Quality of life

S.N.	Source of Variance	Sum of squares	df	Mean sum of squares	F value
1	Main effect of sex	2587.813	1	2587.813	**18.27****
2	Main effect of nature	5628.012	1	5628.012	**39.73****
3	Interaction Effect (Sex*Nature)	2844.113	1	2844.113	**20.08****

****P<.01,*P<.05**

The results for main effects are shown in table=3, which reveals that gender differences were found to be significant on whole QOL (p<0.01). Male epileptic patients scored higher (M=84.90, SD=10.04) as compared with females epileptic (M=61.60, SD=9.28) and marginal differences were found in normal male and female participants. The results also showed a significant Gender X Disease interaction for quality of life, F $_{1, 77}$ =20.08, P<0.01. It was found that male epileptic patients scored higher (M=84.90, SD=10.04) as compared with females epileptic (M=61.60, SD=9.28).

In order to ascertain the impact of marital status on different dimension of QOL, perceived stress and LOT, Mean, SD and t value were calculated and which is displayed in table-3

Table 3 Mean, SD and t value of Married and Unmarried participants with respect to their different domain of QOL, PSS and LOT

Measures	Unmarried	Married	t Value
Physical	Mean = 22.44 SD =5.989	Mean = 25.84 SD = 6.994	2.34*
Psychological	Mean = 19.19 SD = 4.130	Mean = 21.62 SD = 4.815	2.43**
Social	Mean = 9.86 SD = 2.816	Mean = 10.46 SD = 2.892	.937 (NS)
Environmental	Mean = 26.37 SD = 4.947	Mean = 28.35 SD = 5.765	1.65 (NS)
Total QOL	Mean = 77.88 SD = 15.132	Mean = 86.00 SD = 17.399	2.096**
Perceived Stress	Mean = 28.47 SD = 5.603	Mean = 25.70 SD = 6.180	2.09**
Optimism	Mean = 7.14 SD = 2.908	Mean = 8.32 SD = 3.127	1.755(NS)
Pessimism	Mean = 43 SD = 6.49	Mean = 37 SD = 6.22	.459(NS)

****P<.01,*P<.05**

Table reveals that unmarried patients had lower quality of health score in physical, psychological and social domain when compared with the married patients. Among them, energy/fatigue, emotional wellbeing, health discouragement, and social isolation parameters showed significantly low (t=2.34 & 2.43, p<0.01) and stress level shows significantly high (t= 2.09, p<0.01). In order to ascertain the impact of duration of disease on QOL, Perceived stress and Life orientation, the one way ANOVA was calculated and which is displayed in table-4

Table-4 One way ANOVA for QOL, PSS, LOT across Different Duration of the Disease

Measures	Groups	Sum of square	df	MSS	F
QOL: Total	Between Groups Within groups	5916.413 15908.074	3 76	1972.138 209.317	9.422**
PSS	Between Groups Within Groups	250.775 2595.412	3 76	83.592 34.150	2.448(NS)
Optimism	Between Groups Within Groups	193.411 541.776	3 76	64.470 7.129	9.044**
Pessimism	Between Groups Within Groups	6.378 540.109	3 76	2.126 7.107	.299(NS)

**P<0.01

Results reveals that 2-6 month sufferer epileptic patients scored better (Mean=77.14, SD=15.97) in comparison to 2 years and 3 years sufferer group (Mean=75.15, SD=14.34, Mean =70.65, SD=15.72 respectively) on whole quality of life. Chronic epileptic group scored high on perceived stress scale in comparison to recently suffered group. On optimism scale, recently suffered epileptic group scored high in comparison to 2 years sufferer and 3 years sufferer group. Table also reveals that there are significant difference among duration of disease on Whole QOL (F=9.42, P<0.01) and optimism scale (F=9.04, P<0.01). In order to determine the significance of participant's demographic status in predicting their quality of life step -wise multiple regression analysis was done. This was displayed in Table-5.

Table-5 Step wise multiple regression analysis using Quality of life as a criterion and nature of sample, marital status and sex as a predictors

	Criterion (QOL)						
Predictors	**R**	**R^2**	**R^2 change**	**B**	**Beta (β)**	**t**	**F**
Nature	.508	.258	.258	16.775	.588	7.01**	27.104**
Marital Status	.628	.394	.136	12.551	.354	4.21**	25.043**
Sex	.703	.494	.100	10.496	.318	3.88**	24.779**

**P<0.01

It is clear that demographic factors concern with nature of disease emerged as the best predictor of quality of life in patients which is contributing 26% in the total variance followed by marital status and sex that contributed 14% and 10% of total variance. Examination of β revealed that the nature of disease and marital status predictors contributed positively (β =0.59 & 0.35 respectively) and gender negatively to quality of life. The above patterns of findings suggest that epilepsy/non epilepsy and married /unmarried condition influence the quality of life.

DISCUSSION

Epileptic patients scored lower on all domains of quality of life such as physical, psychological, social and environmental and optimism scale as compared with normal and scored high on perceived stress scale which was supported by the study of Sridharan and Murthy (1999). Epilepsy is a chronic and serious neurological disorder with multifaceted uncertainties and stigmatization which have significant negative role in the QOL of those afflicted by the disorder. Elisabete *et al.*, 2006 have reported that epilepsy is a chronic condition with potential to affect significantly the broad range of aspects of quality of life. Osamu Kano *et al.*, 2011 have also found that Epilepsy can be associated with profound physical, psychological and social consequences and its impact on a person's quality of life can be greater than many other chronic diseases. The epilepsies are a complex group of disorders commonly associated with brain dysfunction, social isolation, and vocational difficulty. Each of these factors may contribute to increased prevalence of stress and poor QOL in epilepsy (Gus *et al.*, 2005).

The results of the study indicated a higher prevalence of psychological distress and poor QOL in females as compared with the males. This can be because of the reason that females have more family and children responsibilities and emotional intimacy as compared with males. Our culture also plays an important role in this, as it is believed that female tend to be more involved in personal relationships than male and suffer more when they are suffered from epilepsy. These social stressors result in more psychological distress in female as compared with male. Hormonal differences are usually cited as the major explanation. Compared to male, females experience much more fluctuation in hormone levels that are associated with stress about any disease such as epilepsy. Shakarishvilli *et al 2003* described that female gender was found to be a major determinant of the QOL in epileptics. Two Indian studies also reported similar findings (Thomas *et al* 2005 and Agarwal *et al.* 2006) In a European study on the QOL with epilepsy, female respondents had poorer energy/vitality, physical functioning, mental and general health (Buck *et al* 1999). Present study revealed that female patients had emotional and physical difficulties, had bodily pains, had difficulty in attention/concentration and were worried about seizures and medication effects. They also felt decreased social support and more social isolation compared to male counterparts.

Results also revealed that unmarried participants are more likely to have perceived stress and poor QOL as compared with married people. This could be because of the reason that most people, especially in rural areas, consider epilepsy as insanity and, therefore, do not marry. Duration of epilepsy, which might play an important role in QOL, was analyzed and it was found that patients with duration of more than 5 years had poor QOL. These patients had significant physical and emotional trauma which had limited their daily activities with poor attention/concentration with feeling of language dysfunction which was statistically significant. These patients also had seizure-worry, fatigability, memory disturbance and health discouragement. They were also worried about long-term side effects of antiepileptic drugs and had poor social support. Herodes *et al*, reported lower scores with shorter duration of epilepsy with significant effects on energy, emotional well being and bodily pain. Epilepsy is a chronic condition with potential to affect significantly the broad range of aspects of quality of life (Elisabete *et al.*, 2006). Epilepsy can be associated with profound physical, psychological and social consequences and its impact on a person's quality of life can be greater than that of many other chronic diseases (Osamu Kano *et al.*, 2011). The epilepsies are a complex group of disorders commonly associated with brain dysfunction, social isolation, and vocational difficulty. Each of these factors may contribute to increased perceived stress in epilepsy (Gus *et al.*, 2005). In this present study, we found a significant negative correlation between quality of life and perceived stress (p=.000) of epileptic patients. This result shows that impact of perceived stress on epileptic patient can lead to decreased quality of life. The three-time dimension theory developed by De-Leval, describes the dislocated temporal horizon of the stressful patient. It situates both depression and quality of life as part of a continuum in time rather than as independent phenomena.

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How to cite this article:

Gopal. Jee S and Mishra V.N.2016, Gratification, Perceived Stress and Generalized Expectancy of Patients with Epilepsy. *Int J Recent Sci Res.* 7(4), pp. 10565-10569.

ISSN 0976-3031
9 770976 303009 >