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RELATIONSHIP BETWEEN PSYCHOSOCIAL FACTORS AND DISABILITY IN WOMEN WITH EPILEPSY

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Abstract: *Most of the neurological and psychiatric disorders bring special concerns for women and epilepsy is no exception. Along with its impact on normal functioning due to unpredictable nature of attacks and traumatic manifestations, the psychosocial factors exacerbate the condition leading to disability. The aim of the study was to examine the relationship between the psychosocial factors and functioning and social disability. A sample of 150 women with epilepsy was selected from the out patient departments of NIMHANS through random method. A quantitative, descriptive research design was adopted. WHODAS II[1] was used along with socio-demographic profile schedule. Analysis was done using SPSS 15 with descriptive statistics, Pearson's correlation coefficient and multiple regression analysis. The mean age was 29.05 years (SD [±] 8.24). A majority of them (67.3%) were non-earning members. Frequent seizure attacks were observed with 20.7% of the subjects (repeating in a short span of less than a week). The women showed high mean score on the domains of participation in society and total disability on WHO DAS-2. The Stepwise Multiple Regression Analysis showed that women with higher age group, poor family relationship, frequent seizure attack, and financial difficulties were predicted to be the factors causing disability. To reduce the disability and enhance the functioning it is essential to initiate a comprehensive and evidence based psychosocial intervention modalities. Thus Social Work intervention should emphasize the holistic approach of the health and well-being of women with epilepsy.*

Key words: *Women, Epilepsy, Psychosocial, Functioning, Disability*

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INTRODUCTION:

Most of the neurological and psychiatric disorders bring special concerns for women and epilepsy is no exception. Epilepsy has been considered both as medical diagnosis and a social label[1]. Along with its impact on normal functioning due to unpredictable nature of attacks and traumatic manifestation, the psychosocial factors exacerbate the condition leading to disability.

The studies on women with epilepsy have predominantly concentrated on the biological, psychological, and health related quality of life issues whereas studies on psychosocial factors due to epilepsy and its impact on functioning and disability are scant. The current research attempted to study these factors, thereby guiding the helping professionals in restoring impaired abilities, exploring resources and preventing further dysfunction.

SUBJECTS AND METHODS:

Aim:

To examine the relationship between the psychosocial factors and functioning and social disability

Objectives:

1. To assess extent of disability among women with epilepsy
2. To identify the predictors of psychosocial factors influencing the functioning and disability in women with epilepsy

Participants:

After approval by the Institute Ethics Committee and following informed consent from the women with epilepsy as well as their family members about the purpose of the study, a sample of 150 was drawn randomly, based on inclusion and exclusion criteria from Neurology out patient department of NIMHANS. The inclusion criteria were women aged between 18 and 45 years, diagnosed to have general tonic-clonic seizure (GTCS) and partial seizures and with the duration of above one year and below ten years. Exclusion criteria included women with epilepsy who have psychiatric illness and/or mental retardation, diagnosed to have refractory (uncontrollable) epilepsy and women with other physical disabilities.

Research Design:

The study was adopted a quantitative, descriptive, correlational research design.

Research Tools:

A semi structured interview schedule was administered to collect socio-demographic data and to assess the level of social and functional disability WHO DAS-2 was used[1]. The socio-demographic data was content validated by internal experts as study relevant illness details and psychosocial variables were included.

The WHODAS II has been developed to assess the activity limitations and participation restrictions experienced by an individual irrespective of medical diagnosis. It is a practical and multidimensional questionnaire for measuring level of functioning/disability across a variety of conditions and treatment interventions. This instrument is based on an international classification system, is cross-culturally applicable, and treats all disorders at parity when determining level of functioning. The advantage of the WHODAS-2 is that, it assesses functioning/disability at the individual level instead of the disorder-specific level. Respondents are asked to state the level of difficulty experienced taking into consideration how they usually do the activity, including the use of any assistive devices and/or the help of a person. The scale has 36 items with 6 domains which is extensively used in Indian setting and has been translated to Kannada, a local language. An informed consent was taken from the respondents before collecting the data.

Analysis of data:

Data obtained was analysed using SPSS 15 with descriptive statistics, Pearson's correlation coefficient and stepwise multiple regression analysis. It was decided that $P < 0.05$ would be used to test significance levels.

Results:

Descriptive:

Table: 1 Personal Profile of the subjects *(n=150)*:

Variable	Number	Percentage
Age		
18-26 years	67	44.7
27-35 years	50	33.3
36-45 years	33	22.0
Education		
PUC/ Graduation/Post Graduation	39	26
Primary / High School	84	56
Illiterate	27	18
Marital Status		

Married	104	69.3
Others	46	30.7
Occupation		
Earning women	49	32.7
Non-earning women	101	67.3
Family Income (Rs/m)		
Below 1700	94	62.6
1700-2699	25	16.7
2700 & Above	31	20.7

The age profile of the respondents showed that 65 of them (45%) belonged to the age group of 18-26 and 33 percent and 22 percent belonged to the 27-35 and 36-45 age groups respectively. The mean age of the respondents was 29.05 years (SD [±] 8.24). Of the 150 subjects, 84 (56%) of the women with epilepsy were primary and high school educated, 39 i.e., 26% had completed either pre-university course or graduation or professional course and 27 (18%) were illiterate. A majority of the 104 respondents were married (69.3%), where as 46 (30.7%) were in the categories of single and widow. In terms of occupation, a majority of the 101 (67.3%) women represented non-earning member category which included homemakers and students whereas 49 were working (32.7%). It was found that a majority of 94 subjects (62.6%) belonged to the income group of Rs.1700 and below which is considered as below the poverty line in the standard income level followed in NIMHANS. There were 25 of the families (16.7%) having an income of Rs. 1700-2699 while 31 of them (20.7%) had Rs. 2700 and above.

Table: 2 Clinical Characteristics of the Respondents *(n=150):*

Variable	**Number**	**Percentage**
Diagnosis		
GTCS	117	78
Partial Seizures	33	22
Duration of Illness		
1-5 years	45	30
6-10 years	105	70
Frequency of Attacks		
Very frequent	31	20.7
Frequent	33	22
Rare	36	24
Very rare	50	33.3

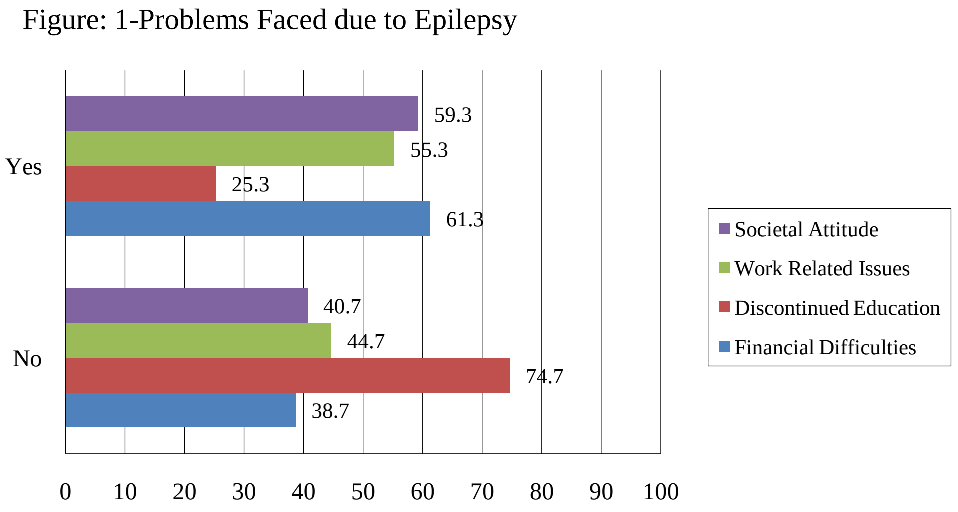
The clinical condition in terms of diagnosis revealed that a large number of 117 respondents (78%) had the diagnosis of General Tonic Clonic Seizure (GTCS) while 22 percent were diagnosed to have Complex Partial Seizure (CPS). A majority of 105 women (70%) suffer from this illness from past 6-10 years and nearly one third of the women (45, i.e., 30%) have epilepsy from 1 to 5 years. The frequency of the seizure highlights a very frequent seizure attacks (repeating in a short span of less than a week) with 31 subjects (20.7%), 33 (22%) of them experienced it once in three months, 36 of them (24%) got fewer attacks in a whole year and 50 subjects (33.3%) did not have an attack for more than a year.

Table: 3 Treatment Adherence *(n=150)*

Variable	Number	Percentage
Medication		
Monotherapy	89	59.3
Polytherapy	61	40.7
Compliance		
Regular	110	73.3
Irregular	40	26.7

It is evident form the data that all 150 respondents were on anti-epileptic drug (AED) treatment out of which 89 (59.3%) were only on one type of medicine (mono therapy) while other 61 (40.75) were prescribed more than one AED (poly therapy). Among the subjects, a large number of 110 (73.3%) reported being regular and 40 (26.7%) were irregular.

Figure: 1 Problem Faced Due to Epilepsy



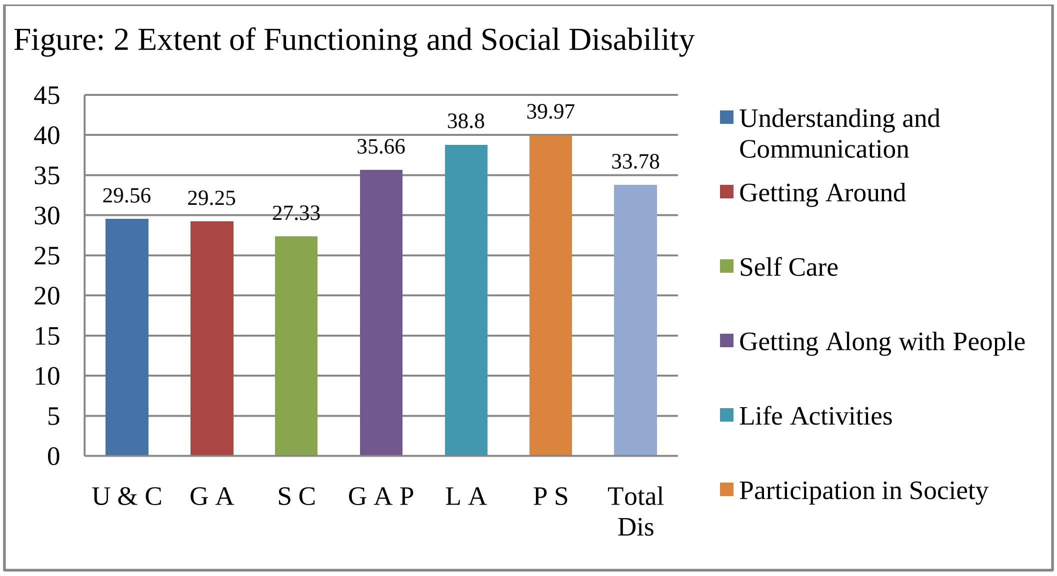
The above figure explains the various types of difficulties that the women with epilepsy have been facing because of their illness status. Though this section was in an open-ended question format, the researcher has taken frequency of most common answers and grouped them into above-mentioned four categories.

Due to their illness, of the 150 respondents, 92 (61.3%) had mentioned that they are facing financial difficulties and 37 (25%) of them had discontinued their education. Regarding problems in the work area, keeping their ability to perform as a yardstick researcher had included women who were employed, homemakers and students among whom 82 (55.3%) felt that they experience difficulties while concentrating on studies, working near fire or water, taking up responsibilities not matching their education, occurrence of attack while working leading to frequent job changes etc. In terms of societal attitude 89 of the subjects (59.3%) felt that the people around them express some amount of negative attitude towards the illness and towards the subjects per se, generally by their own family members or relatives and sometimes from professionals and/or public.

Extent of Functioning and Social Disability:

International Classification of Functioning, Disability and Health (ICF), the medical model views disability as a problem of the person, directly caused by disease, trauma or other health condition that requires medical care provided in the form of individual treatment by professionals. Management of the disability is aimed at cure or the individual’s adjustment and behaviour change. However, the social model of disability sees the issue mainly as a socially created problem and a matter related to the full integration of individuals into society.

Figure: 2 Extent of Functioning and Social Disability:



While assessing the disability a few categories of people were excluded namely women with psychiatric illness, refractory epilepsy, mental retardation and other physical disability or ailments. This was decided based on the extensive literature survey which pointed out a clear cut contribution of these factors on disability of people with epilepsy. Thus disability score in the present study depicts the disability only due to epilepsy without any other co-morbid conditions. The above diagram on level of functioning and disability represented its score in percentages. It got that the 'Participation in Society' (PS) domain had obtained maximum mean score, i.e., 39.97 (SD=26.15). The mean ± SD score on domain 'Life Activities' (LA) was slightly below (38.30 ± 30.67) than the abovementioned domain. The 'Getting Along with People' (GAP) domain had the mean score as 35.66 (SD=25.38). The domain 'Understanding and Communicating' (U&C) had the mean score of 29.56 (SD=23.58), which is close to the mean ± SD score of domain 'Getting Around' (GA) (29.25±22.66). The domain 'Self Care' (SC) has observed the least mean score among all the domains, i.e., 27.33 ± 20.93 and the mean score of 'Total Disability' (Total D) found to be 33.78 (SD=20.80). Thus it could be understood that epilepsy alone has a great bearing in causing disability and problems in social functioning for women with epilepsy.

Table: 4 Multiple Regression Analysis of Psychosocial Factors and Total Disability:

Sl. No	Variables Selected	Multiple R	R^2	Adjusted R^2	B	't' Value	P Value
1.	Education	0.259	0.067	0.034	12.261	2.565	0.011
2.	Frequent seizures	0.368	0.136	0.093	11.554	2.826	0.005
3.	Family Relationship	0.372	0.139	0.115	14.357	3.097	0.002
4.	Availability of Support	0.466	0.217	0.178	11.177	2.486	0.014
5.	Financial Difficulties	0.494	0.244	0.201	7.899	2.255	0.026

$P < 0.05$

In order to find out the most contributing background variables among the independent variables stepwise multiple regression analysis was used. The total disability score was considered as dependent variable where as demographic variables namely occupation, relationship in the family and illness details such as frequency of attacks, availability of support and financial difficulties were independent variables. Using this analysis method, it has been found that important variables identified as predictor variables namely, education (illiterate) poor family relationship, frequent seizure attacks, inadequate support and financial difficulties, which were, contributed 24.4 percent of the variance.

DISCUSSION:

Descriptive:

The age of women with epilepsy was distributed between 18-45 years with the mean age being 29.05 in the present study. The age-specific prevalence rates of epilepsy in a study by Radhakrishnan et al, like in other studies from developing countries peaked in the second decade.[2] A majority of 69.3% women were married. The present study indicated higher marriage rate among the respondents which could be attributed to the social pressure and cultural beliefs existing in India. Mani *et al*., observed that in rural areas of India subjects with epilepsy or mental retardation often marry arranged marriages as usual, beget children and lead a normal life generally free from societal discrimination. Marriage in such instances is considered a social insurance[3]. Most of the respondents (56%) were either primary or high school educated and a small proportion of the respondents (18%) were illiterate. In their study, ‘The impact of epilepsy from patient’s perspective’, Fisher *et al*., reported that performance in school was singled out as an activity adversely affected by epilepsy, more so than job performance, driving a car or relationships with family. [4]

In terms of occupation majority of the women were housewives (67.3%) and some were students. Only a small portion of women (32.7%) had income generating occupation ranging from software professionals to coolie. In India, majority of the women in general population are homemakers, so this is reflected in the present study. The presence of continuing seizures is seen as a major factor in employability.[5] The family income was below Rs. 1,700/- per month for majority of the respondents (62.6%), which has been considered as below poverty line. In the present study it is observed that majority of the families have been migrated from other states and rural areas in search of jobs and this group constituted of painters, auto drivers or coolies who fell under below poverty line category. Danesi *et al*., in his study reports that compared to the control population, epileptics were more often in the low income group (earning less than N1, 000 [Nigerian naira] per annum) and were found less frequently in the medium and higher income groups.[6]

Clinical Characteristics:

The duration of illness was 6-10 years with 70% women which was supported by a study by *Shalini et al*., wherein the duration of illness ranged from 1 to 27 years and chronicity of illness and protracted treatment did have adverse affect on QOL.[7] The frequency of seizure was almost equally distributed and little more than one third of them reported very rare attacks. According to a study by Leidy *et al*., among those who have persistent seizures have the most remarkable differences appearing in mental health, physical functioning, social activities, general health perception and epilepsy specific concerns such as seizure worry, medication effects, health discouragements and work, driving and social functioning.[8]

Treatment Adherence:

More than half of the respondents were on mono therapy (59.3%) and remaining on polytherapy (40.7%). The need for providing the quality of therapeutic care is mandatory but varies for each country, as every health system is likely to have its own characteristics.[9] Majority of the respondents were on regular medication (73.3%) still, a small portion of them were non-compliant to drugs. Estimates suggest that 30% to 60% of patients with epilepsy are not adherent to their drug regiments.[10]

Problem Faced Due to Epilepsy

More than half of them (61.3%) had experienced financial difficulties, 25% had discontinued their education, some had issues related to their work, and of unhealthy societal attitude more of a negative one. In a study on the psychosocial aspects of epilepsy in the UK it has been found that 70% of people with newly diagnosed epilepsy expected to experience stigma and discrimination at work.[11]

Extent of Functioning and Disability:

The respondents expressed that they faced difficulty in understanding and communicating, getting around, getting along with people, life activities and participation in society. Thus it could be understood that epilepsy as a condition has contributed greatly to the disease induced disability and problems in social functioning in women with epilepsy. In view of Drazkowski, people with seizures experience restrictions in many areas of life, including participation in social situations, recreational activities, employment, and driving.[12]

Relationship between Psychosocial Factors and Functioning and disability:

The predictor variables namely, education (illiterate) poor family relationship, frequent seizure attacks, inadequate support and financial difficulties, which were, contributed 24.4 percent of the variance. Although the fundamentals of epilepsy are similar for both males and females, the clinical management of epilepsy in women should take into consideration a variety of factors including, age, relationships, diagnosis and characterization, female specific syndromes, the influence of female hormones, hormonal contraceptives and hormonal replacement therapy, the cosmetic side effects of epilepsy treatment, fertility, pregnancy and child care along with social and cultural issues.[13]

IMPLICATIONS:

While attempting to understand the functioning and disability in women it might be argued that there are certain conditions or disorders which are unique to women; occur more commonly in women; have different risk factors for women; or follow a different course in women relative to men. Various psychosocial problems demand professional intervention and Psychiatric Social Worker becomes a valuable member in the treatment team. Their varied role includes individual, family, community level interventions and working on advocacy for the welfare of the people with epilepsy. Thus multiple psychosocial factors as well as unnecessary long term disability may be avoided and mainly therapy will result in reducing disease induced disability there by ensuring adequate support leading to better quality of life among women with epilepsy.

LIMITATIONS:

The sample size was small hence generalization may be difficult. The study has taken only women as study sample. The comparison study with men would have given a clearer understanding of women's issues.

RECOMMENDATIONS:

For the specific group of women with epilepsy there are different areas from psychosocial point of view. So those areas could be identified and studied.

Epilepsy is most commonly spoken but less understood from psychosocial point of view. The initiatives on developing Indianised intervention packages are needed; be it psycho educational or issue specific interventions.

CONCLUSION:

The present study adds a new perspective to the psychosocial issues of women with epilepsy by assessing the disability caused due to this illness. Some of the earlier studies have identified the disability experienced by the women with epilepsy when they have added symptoms or co-morbid conditions like depression, anxiety or personality problems and/or psychological distress. But the present study exposed to the fact that despite controlling these variables which adds on to the disability in women, they still experience disease induced disability. It warrants a psychosocial intervention approach. The goals of psychiatric social workers while intervening with women with epilepsy could be restoration of impaired abilities of the individuals, exploration of individual and social resources and prevention of social dysfunction.

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