ORIGNAL RESEARCH PAPER

Anxiety Depression and Burden among the Caregivers of Persons with Neurological Illness

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ABSTRACT

Background: Studies have shown that caregivers of the persons with neurological illness have high levels of psychological distress, depression and caregiver's burden. **The aim of the study** was to find out anxiety, depression and caregiver's burden among the caregivers of persons with neurological illness (PWNI). **Method**: Thirty caregivers of PWNI attending the Centre of Rehabilitation Sciences, LGB Regional Institute of Mental Health, Tezpur, Assam were selected using purposive sampling technique for the present study. Socio-demographic and clinical data sheet, Zarit Burden Interview Scale and The Hospital Anxiety and Depression Scale were used. **Results:** The results shown that in Hospital Anxiety and Depression Scale, 26.6% of the caregivers' scores were in the abnormal range in the domain of depression. While in the domain of anxiety, 16.6% scored in the abnormal range. In Zarit Burden of Scale, 13.3% of the caregivers were having little or no burden, 26.6% of the caregivers were having mild to moderate level of burden, 20% were having moderate to severe burden and 30% were having a severe burden of care. Care burden has significant positive correlation with depression ($r= .124$, $p\leq 0.01$ and anxiety ($r= .124$, $p\leq 0.05$). **Conclusion**: Caregivers of PWNI have been found to be at higher risk of mental health problems and care burden. The importance of addressing the burden of caregivers involved in the care of PWNI need to be taken into consideration while providing treatment and rehabilitation of PWNI.

Keywords: Anxiety, depression, burden, neurological illness

INTRODUCTION

The caregivers of individuals with a neurological illness continue to experience high levels of stress and burden. This burden of care can lead to a breakdown among the caregivers themselves, affecting their social and psychological functioning. Caregivers of the PWNI have shown high levels of psychological distress, depression increased rates of physiological illness and various social, personal and financial problems.[1-4] They also experience burden, social isolation and compromised their physical health and psychological well being.[5-8] Providing care to an individual diagnosed with Alzheimer's disease, stroke, cancer, motor neuron disease (MND), multiple sclerosis (MS) and Parkinson's disease (PD) can cause significant psychological distress during the course of their care giving and can affect their quality of life and well being.[8,9,10] In spite of neurological conditions being one of the most common causes of disability, very few studies have addressed the impact of these conditions on the caregivers in the Indian, especially in the north east part.

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The current study aims at assessment of the anxiety, depression, and burden of care among the caregivers of the persons with neurological illness and to find relationship between these study variables.

METHODOLOGY

The present study was a descriptive study. The research setting was at the Centre of Rehabilitation Sciences, Lokopriya Gopinath Regional Institute of Mental Health, Tezpur, Assam, India. The subjects were the caregivers of those PWNI attending the centre. In the present study 30 participants were included in the research study using purposive sampling, Caregiver of either sex, who had given consent for the study, between the age range of 16 to 65 years of age, staying together and providing care to person with neurological illness for at least 6 months were included in the study. They were explained about the purpose and the procedures of the study and written informed consent were obtained from all participants. Respondents were informed about the confidentiality and they were given choice to withdraw from the study at any stage. Sufficient opportunity was given to the participants to contact the investigator for any clarification if needed. The study was approved by the ethical committee of LGBRIMH, Tezpur.

Tools used for the study

1. **Socio-demographic and Clinical Data Sheet**: Semi-structured data sheet to assess age, sex, relationship, education, religion etc.
2. **Zarit Burden Interview**[11]: To measures the subjective burden among caregivers The scale is a 22-item self-report inventory and each question is scored on a 5 point Likert scale ranging from - never to nearly always present and classify into four range that is little or no burden (score between 0-21), mild to moderate burden (score between 21-40), moderate to severe burden (score between 41-60), severe burden (score between 61-88).The internal consistency of the scale is good (Cronbach's alpha = 0.83 and 0.89).
3. **Hospital Anxiety and Depression Scale (HADS**) was originally developed by Zigmond and Snaith[12] which measures anxiety and depression. The scale consists of 14 items, seven of the items are related to anxiety and seven are related to depression. The cut-off point of 8/21 is for anxiety or depression. For anxiety (HADS-A) this gave a specificity of 0.78 and a sensitivity of 0.9. For depression (HADS-D) this gave a specificity of 0.79 and a sensitivity of 0.83. The scale measures the anxiety and depression on the basis of total score in which 0-7 normal range, 8-10 borderline abnormal range and 11- 21 is in the abnormal range.

Statistical Analysis: An appropriate statistical measure was used for data analysis with the help of SPSS version 18. Descriptive statistics and Pearson's correlation was used for the analysis of data.

RESULTS

The mean age of the caregivers was 48.36 and the standard deviation (SD) was 7.56. In the study it was found that majority of the caregivers were female (66%), spouses (70%), homemaker by occupation (62%) belong to Hindu religion (90%), majority of the respondents (56.7%) were from rural area, followed by 23.3% were from semi-urban area and 20.0% were from urban area. Majority of the respondents (43.3%) belong to upper socioeconomic status, about 33.3% of respondents belong to low middle socioeconomic background and 23.3% of respondents were from upper middle socioeconomic status. In clinical profile of the patients, 80% of them were having stroke, 6.6% of the patients were having motor neuron disorders and 13.3% of them were having Parkinson disorder. The mean age of the patients was 54.36 and the standard deviation (SD) is 8.56. In the study it was found that majority of the caregivers were male (76%).

In hospital anxiety and depression scale, 60% of the caregivers scored in the normal range, 13.3% of the caregivers scored in borderline range and 26.6% of the caregivers scored in abnormal range in the domain of depression (table1). While in the domain of anxiety, 66.6% scored in normal range, 16.6% scored in borderline range and 16.6 scored in the abnormal range in anxiety (table 1). In Zarit burden of scale, 13.3% of the caregivers were having little or no burden, 26.6% of the caregivers were having mild to moderate level of burden, 20% were having moderate to severe burden and 30% were having severe burden of care(table 2). In the study it was found that care burden has a significant positive correlation with depression (r= .124, p≤ 0.01 and anxiety (r= .124, p≤ 0.05) (table 3).

Table: 1 Depression and anxiety among caregivers of PWNI

	Normal	**Borderline**	**Abnormal**
Depression	18(60%)	4(13.3%)	8(26.6%)
Anxiety	20(66.6)	5(16.6%)	5(16.6%)

Table: 2 Care burden among caregivers of PWNI

Burden of Care			
Little or No	**Mild to Moderate**	**Moderate to Severe**	**Severe**
4(13.3%)	8(26.6%)	6(20%)	12(40%)

Table: 3 Correlation between burden, anxiety and depression

Variables	**Depression**	**Anxiety**
Care burden	.124**	178*

*p≤.05, **p≤.01

DISCUSSION

In the present study it was found that in hospital anxiety and depression scale 26.6% of the caregivers scores in abnormal range in the domain of depression. While in the domain of anxiety, 16.6% of the caregivers scored in the abnormal range in anxiety. The present finding is consistent with the other studies.[7, 13] Balhara et al.[13] found that caring for the patients with stroke can manifests as increased rate of anxiety and depression among caregivers. Verma et al.[7] also reported caregivers with neurological illness reported high level of depression and anxiety. They stated that the caregivers, especially female caregivers, have higher level of anxiety and depression.

Peters et al.[8] stated that caregivers for people with a chronic illness are at risk of experiencing physical, emotional, and psychological problems. Studies have shown that providing care to an individual diagnosed with Alzheimer’s disease, stroke, cancer, or a neurological condition such as motor neuron disease (MND), multiple sclerosis (MS), Parkinson's disease (PD) can adversely affect the caregivers, resulting in stress, strain ,burden and poor quality of life.[8-10, 14-15] Vitaliano et al.[16] reported that one-third of the caregivers reported mild to moderate levels of depression or anxiety. Muscroft and Bowl[17] reported that 18–47% of caregivers develop depression while providing care to a person with mental illness. Depression, anxiety and burnout are the common mental health issues in caregiver while providing care.

In the present study caregivers reported care burden in dealing with persons with neurological illness, 40% of them had a severe burden of care, 26.6% of the caregivers had mild to moderate level of burden, 20% of them had moderate to severe burden and 13.3% of the caregivers had little or no burden. Many studies have reported that caregivers experience high levels of stress and burden in providing care to person with chronic and neurological illness [18-21] and it has an impact on their physical and psychological well-being.[22-23]

In the study it was found that care burden has a positive correlation with depression (r= .124, p≤ 0.01 and anxiety (r= .124, p≤ 0.05). Various studies have concluded that that care giving for individuals with a chronic condition would affect a caregiver's physical, psychological, and social life, resulting in poor physical health, social isolation, and increased stress and burden.[24-27] Romero-Moreno et al. (28) examined the moderating effect of self-efficacy in managing feelings of distress and burden and it was associated with high subjective stress and poor psychological well-being, including anxiety and depression among caregivers. Care giving to PWNI can have an adverse effect on caregivers that can lead to a risk of psychiatric morbidity and other physical health-related problems.[24, 29-31]

There were certain limitations in the study. The study sample size was small; hence the finding cannot be generalized. The study looked only at depression and anxiety, other mental health issues were not taken into consideration. The present study does not include the components of social support which is considered as the mediating factor of burden and stress among the caregivers.

CONCLUSION

Caregivers of persons with neurological disorders have been at higher risk of mental health problems. Moderate to severe level of Care burden is present among the caregivers of neurological illness. Results from this study add to the body of knowledge on caregiver anxiety, depression and burden from north-east context. The above study can help us in planning adequate psychosocial intervention for the caregivers. Psychiatric Social Worker can help in formulating and providing specific psychiatric social work intervention at family level.

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