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Mental Health Nursing

ASSESSMENT OF BURDEN AND EMOTIONAL DISTRESS AMONG PRIMARY CARE GIVERS OF ELDERLY WITH MENTAL HEALTH ISSUES

Mrs. Chitra Bora* Nursing Tutor, LGB Regional Institute of Mental Health, Tezpur, Assam, India. *Corresponding Author

Baruah Arunjyoti Professor & Head, Psychiatric Nursing, LGB Regional Institute of Mental Health, Tezpur, Assam, India

ABSTRACT Elderly populations are at risk of developing mental disorders. 14% of adults aged 60 years or over live with a mental disorder. The caregivers of any person with mental illness experiences stress & anxiety as the illness tends to be chronic and need long term care. **Objectives:** To assess the burden and emotional distress of primary caregivers of elderly with mental health issues, to find out the association of burden and emotional distress with selected socio demographic and clinical variables and to determine the relationship between burden and emotional distress. **Methodology:** Descriptive research design was adopted. 83 primary caregivers of elderly diagnosed with mental health issues attending Geriatric Mental Health unit of a tertiary mental health care Institute of North East region of India were selected using purposive sampling technique. Data collection tools were Zarit burden Interview and Kessler Psychological Distress Scale. **Results:** 61.4% elderly aged 60 years to 70 years and 56.6% caregivers age 18 to 40 years. 41.0% elderly's diagnosis was F30 – F39. 74.7% of care givers experienced little or no burden and 53% likely to be well. A higher level of caregiver burden was associated with higher level of emotional distress among the caregivers (Pearson correlation coefficient: 0.501; p=0.1). There was no significant difference of burden in three diagnostic groups F00-F09, F20-F29 and F30-F39 (F=0.878; p=0.5). **Conclusion:** The study conclude that majority of care givers experienced little or no burden and no emotional distress.

KEYWORDS : Burden, Emotional distress, Primary care giver, Elderly with mental health issues

INTRODUCTION:

Ageing populations are increasing in worldwide. The proportion of the world's older adults is estimated to almost double from about 12% to 22% between 2015 and 2050. Elderly populations are at risk of developing mental disorders, neurological disorders or substance use problems as well as physical health problems. Over 20% of adults aged 60 and over suffer from a mental or neurological disorder and 6.6% of all disability among people over 60 years is attributed to mental and neurological disorders. The most common mental and neurological disorders in this age group are dementia and depression, which affect approximately 5% and 7% of the world's older population, respectively. Anxiety disorders affect 3.8% of the older population, substance use problems affect almost 1%. Substance abuse problems among older people are often overlooked or misdiagnosed.[1] The National Mental Health Survey, 2016 reported that life time prevalence of mental morbidity in adults aged 60 and above 60 years was 15.11% and current prevalence was 10.90%.[2] The caregivers of any person with mental illness experiences stress & anxiety as the illness tends to be chronic and need long term care. A study on care giving burden among family caregivers of elderly conducted by Suneetha found that 70 percent of the respondents are moderately burdened due to care giving to their elderly relative followed by 20 percent having severe to very severe burdened and a less 10 percent caregivers of elderly were experienced none to mild burden.[3] Brinda et al. found the cost and burden of informal caregiving are high in rural Indian community and highlighted the need for support to informal caregivers for management of dependent older people with chronic disabling diseases by multidisciplinary community teams.[4]Bharathy et al. study on burden and its associated factors among the caregivers of the older adults highlighted that caregivers had physical strain especially in relation to lifting, ambulating and meeting toilet needs of older adults and financial crisis to meet the health needs of the older adults.

Caregivers were disturbed emotionally in relation to poor prognosis and fear of losing the loved one. It also leads to sleep disturbances among the caregivers. The continuous stress of care giving burden may affect the physical and mental health of the caregivers.[5]There is a high prevalence of psychological morbidity and burden of care among family care givers providing care for persons with mental illness[6]. The prevalence of anxiety and depression among caregivers of psychiatric patients is high. [7,8,9]. Shikimoto et al. [10] findings indicated that the psychological distress of the caregivers is quite high. Vaingankar et al. study found that 8.8% informal caregivers of older adult exhibited psychiatric morbidity [11]. A qualitative study on the experiences of caregivers of adults with mental illness identified that caregivers' experiences stress and worry and negative emotions like anger, guilt, resentment, sadness, devastation, ambivalence, and embarrassment due to care giving responsibility.[12] Cheng et al. [13] study findings indicated that caregivers' psychological health and care burden influenced their quality of life. Burden on caregivers of elderly psychiatric patients is significantly higher than that of caregivers of elderly medical patients. [14,15] There is paucity of evidences on burden and emotional distress among caregivers of elderly with mental health issues in north east region of India. Therefore, this study is undertaken with an aim to describe the burden and emotional distress of caregivers of elderly with mental health issues. The objectives of the study were to assess the burden and emotional distress of primary caregivers of elderly with mental health issues, to find out the association of burden and emotional distress with selected socio demographic and clinical variables and to determine the relationship between burden and emotional distress.

MATERIALS AND METHODOLOGY

Quantitative research approach and descriptive research design was adopted. The population was the primary caregiver of elderly diagnosed with mental health issues attending Geriatric Mental Health unit of a tertiary mental health care Institute of North East region of India. In this study, elderly with mental health issues refers elderly whose age 60 or above 60 years attending geriatric mental health unit (GMHU) of Tertiary Mental Health care institute with any mental health issues which leads to psychological disturbances and diagnosed by psychiatrist as mental and behavioral disorders as per International Classification of Diseases 10(ICD 10). All category of mental health issues were included to evaluate the burden of caregivers in the major diagnostic groups of mental disorders. Primary care giver refers to any individual, family member or relatives of elderly with any mental health issues who provide care at home and attending geriatric mental health unit with the elderly. Caregivers whose age between 18 to 59 years without any diagnosed mental illness were selected as sample. Caregivers of elderly with diagnosed mental disorder and with severe chronic physical illness were not taken as sample. Purposive sampling technique was used and sample size was 83. Sample size was determined based on the number of patients attending in GMHU in one year. Socio demographic data sheet was developed to collect the socio demographic details of caregiver & clinical details of elderly with mental health issues. In this study burden refers to strain and difficulties experienced by the primary care giver due to the responsibility to care of elderly with mental health issues and measured by Zarit burden Interview (ZBI) and emotional distress refers to the emotional states of the primary care giver of elderly with mental health issues which was measured by Kessler Psychological Distress Scale. (K10). Tools were translated in to Assamese language and validated. Ethical clearance was obtained from institution Ethics committee. (No:LGB/ACA/ETC/2560/07/Vol.II/3207/3693, Dated 28th June'2023). After obtaining ethical clearance formal permission

was obtained from the concerned authorities to conduct the study at Geriatric Mental Health unit. Written informed consent was obtained from the caregivers of the elderly with mental health issues. Data was collected from Jan 2024 to December 2024. Analysis was done in SPSS version 25 based on objectives.

RESULTS

Table -1: Socio Demographic & Clinical Variables Of Elderly n=83

Variables		Percentage (f)
Age in years	60 to 70	61.4(51)
	Above 70	38.6(32)
Diagnosis	F00 to F09 (Organic, including symptomatic, mental disorders)	21.7(18)
	F10 to F19 (Mental and behavioural disorders due to psychoactive substance use)	1.2(1)
	F20 -F29 (Schizophrenia, schizotypal and delusional disorders)	32.5 (27)
	F30-F39 (Mood disorders)	41.0(34)
	F40-F49 (Neurotic, stress-related and somatoform disorders)	3.6(3)
Gender	Male	53(44)
	Female	47(39)
Ability in activities of daily living	Independent	51.8(43)
	Need assistant	38.6(32)
	Unable to perform	9.6(8)
Financial status	Pensioner	26.5(22)
	Dependant on children/relatives	56.6(47)
	Self sufficient	16.9(14)

Table-2: Sociodemographic Variables Of Primary Caregivers n=83

Variables		Percentage (f)
Age in years	18-40	56.6 (47)
	41 -59	43.4 (36)
Caregiver gender	Male	53(44)
	Female	47(39)
Relationship with elderly	Son	47(39)
	Spouse	14.5(12)
	Daughter	18.1(15)
	Siblings	3.6(3)
	Others	16.9(14)
Duration of stay with elderly	Less than 5 years	9.6(8)
	More than 5 years	90.4(75)
Duration of care to elderly	Less than 1 years	27.7(23)
	Above 1 year	72.3(60)
Time spent per day to care elderly	Less than 6 hours/ day	83.1(69)
	Above 6 hours	16.9(14)
Presence of alternative caregiver	Yes	12(10)
	No	88(73)
Education	Primary school certificate	13.2(11)
	Middle school	21.7(18)
	High school	18.1(15)
	Graduate	19.3(16)
	profession	27.7(23)
Occupation	Unemployed	12(12)
	Daily wage worker	6(6)
	Cultivator	7.2(6)
	Private service	13.3(11)
	Govt. service	10.8(9)
	Housewife	20.5(17)
	others	30.1(25)
Marital status	Married	74.4(62)
	Unmarried	24.1(20)
	Widow	1.2(1)
Type of family	Nuclear	41(34)
	Joint	59(49)
Family income	Less than Rs.6174	8.4(7)
	6175-18496	413(4)
	18497-30830	30.1(25)
	30831-46128	12(10)
	46129-61662	7.2(6)
	61663-123321	1.2(1)

Table 3: Burden And Emotional Distress Of Primary Caregivers n=83

Variables		Percentage (f)
Burden	0-21(Little or no burden)	74.7(62)
	21-40(Mild to moderate burden)	16.9(14)
	41-60 moderate to severe burden	7.2(6)
	61-88 Severe burden	1.2(1)
Emotional distress	10-19 (Likely to be well)	53(44)
	20-24 (Likely to have a mild disorder)	14.5(12)
	25-29(Likely to have moderate disorder)	16.9(14)
	30-50(Likely to have severe disorder)	15.7(13)

Table 3 depicted the burden and emotional distress of the primary caregivers of elderly with mental health issues. Majority of caregivers have little or no burden and no emotional distress that is 74.7% and 53% respectively. 14.5% have mild distress,16.9% have moderate distress and 15.7% have severe distress. 16.9% have mild to moderate burden. 7.2% have moderate to severe burden and 1.2% care givers experiences severe burden.

Association Of Burden And Emotional Distress With Selected Socio Demographic And Clinical Variables

Chi square test showed no significant association of emotional distress and burden with any sociodemographic variables of caregivers and clinical variables of elderly with mental health issues at 0.05 level of significant.

Relationship Between Burden And Emotional Distress

Pearson correlation coefficient between emotional distress and Burden was positive (r = 0.501) at 0.01 level of significant.

Evaluation Of Burden Between The Three Different Diagnostic Groups F00-F09, F20-F29 and F30-F39

One way ANOVA was used to compare burden in three major diagnostic groups. The results revealed there was no significant difference of the caregiver's burden between the organic including symptomatic mental disorders, schizophrenia, schizotypal and delusional disorders and mood disorders (F=0.878; p=0.5). The mean and standard deviation of burden score in organic including symptomatic mental disorders (F00-F09) was 19.11 (±16.240) which was highest and denotes little or no burden. Lowest mean score 13.74(±11.603) was found in F30-F39 (Mood disorders) and 14.70(±15.694) was the mean score of burden in schizophrenia, schizotypal and delusional disorders(F20-F29). Post hoc comparisons using the Tukey HSD test shows there was no significant difference of burden of caregivers found between the three diagnostic groups.

DISCUSSION:

This study was aimed to assess the burden and emotional distress of primary caregivers of elderly with mental health issues. The findings revealed that majority (61.4%) of elderly age between 60 to 70 years, 44% elderly were male. 41% elderly belonged to the diagnosis category of F30 to F39. Ozen et al.[16] study also supported this study by majority of elderly psychiatric person aged 60-69 and type of psychiatric disorder were 21.3% bipolar and 31.3% were depression. Another study by Bala et al.[17] found most common age group is 65-69 years and in contrast majority were female and bipolar disorder was present in only 6% of elderly. Many evidences found depression and anxiety disorders are more prevalence in elderly population. [16.17,18] Elderly need assistant in activities of daily activities (ADL) was 32% and 8% elderly were unable to perform ADL. Most of the elderly that is 47% were financially dependent on children's or relatives. Elderly individual need assistant in ADL and need financial support due to declining physical health which is normal changes in ageing process.

The results of this study showed that majority that is 56.6% caregivers

age between 18 to 40 years and majority of the participants were male (53%). Majority that is 47% participants relationship with elderly was son. Majority of the caregivers stays more than 5 years with the elderly and 72.3% caregivers taking care of elderly more than one year and 83.1% caregivers spent less than 6 hours to care the elderly with mental health issues. Only 12% caregivers have alternative caregivers. Study conducted by Ozen et al. [16] found majority caregivers of age between 40 years to 59 years. Evidence [7,16] reported majority were female caregiver which is contrast to this study findings. Many studies found majority caregivers relation with elderly was child.[16]

This study found that 74.7% caregivers have little or no burden, 16.9% have mild to moderate burden,7.2% have moderate to severe burden and 1.2% caregivers' experiences severe burden. Bala et al.[17] study on caregivers of elderly psychiatric patient found majority caregivers experience the mild to moderate burden (52%), moderate to severe burden was present in 24% of the caregivers and severe burden was seen in 13 % of the caregivers. Ozen et al. [16] study on elderly psychiatric patients care givers found 55% caregivers had average burden. In our study majority caregivers were son, daughters and spouses. So, the majority participants of the study may perceive as their responsibility to take care of their love one instead of considering as burden. In contrast a systematic review and meta-analysis revealed that nearly one third of the caregivers experienced burden when taking care of individuals with mental illness.[18]

The present study found that 53% caregivers have no emotional distress,14.5% have mild distress,16.9% have moderate distress and 15.7% have severe distress. The research study on psychological distress of caregivers of dementia revealed similar findings that is majority (73.8%) sample experienced no psychological distress and 26.2% of the sample experienced psychological distress. [19]

The results revealed that there is no significant association of emotional distress and burden with any sociodemographic variables of caregivers and clinical variables of elderly with mental health issues. Aline et al. study revealed that age was statistically correlated to being burdened in the same way gender was correlated to emotional distress.[20] A review by Shah et al. found that the production of burden in carers is related to gender, age, health status, ethnic and cultural affiliation, lack of social support, coping style, in addition to the stressors of the disorder itself.[21]

This study showed positive relationship between emotional distress and burden which indicated that higher the emotional distress and higher the burden and vice versa. Research highlighted that perceived caregiver burden significantly predicts the psychological distress of people with dementia.[19]

The present study result reveals that there is no a significant difference of the caregiver's burden in the three major diagnostic group of mental health issues of elderly. So, it can be interpretated that caregiver experienced burden irrespective of the type of mental health disorders. The burden is higher in the organic, including symptomatic, mental disorders than schizophrenia, schizotypal and delusional disorders and mood disorders. Lesser burden was found in mood disorders in this study. The present study results show caregivers experienced little or no burden in three major diagnostic group of mental disorders.

This study was conducted in a selected tertiary mental health care institute. Sample size was less which was determined based on the number of patients attending in Geriatric Mental Health Unit in one year. There is a relationship between the burden of caregivers and the methods of coping with stress. The caregivers' ways of coping with stress were not investigated. So, this study results may not be generalized.

CONCLUSION

The study conclude that majority of care givers experienced no burden (74.7%) and no emotional distress (53%). There is a positive correlation between emotional distress and burden of caregivers of elderly with mental health issue and no significant difference of burden in organic, including symptomatic mental disorders, schizophrenia, schizotypal and delusional disorders and mood disorders. The study findings shows that emotional distress can increase caregiver's burden. So, strategies or interventions can be developed to reduce emotional distress and caregiving burden of caregivers of elderly with mental health issues.

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