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Stress and Well Being of Primary Care Givers of Elderly with Psychosis: A Descriptive Study

Ms. Rashmi Sonowal[1], Mrs. Chitra Bora[2], Dr. Pallavi Talukdar[3]

[1]Nursing Tutor, Mental Health Nursing, RINPS
[2,3]Nursing Tutor, Mental Health Nursing, LGBRIMH

ABSTRACT

Aging population is increasing in the world, with 1 in 6 people expected to be over 60 years of age by 2030. Elderly individuals are at risk for mental, neurological, or substance use disorders as well as physical health issues. Primary caregivers of elderly with psychosis often face significant stress, impacting their physical, mental, and social well-being. The primary objectives of the study are to assess stress and well-being of primary caregivers of elderly with psychosis and to determine the relationship between stress and wellbeing of the primary caregivers.

Methodology: Quantitative research approach and descriptive research design was used. The population was the primary caregivers of elderly diagnosed with psychosis. The study was conducted at Geriatric Mental Health Unit of a Tertiary Mental Health Care Institute of North East Region of India. 51 caregivers were selected through purposive sampling technique. Data collection tools were Kingston Caregiver Stress Scale and Caregiver Well-Being Scale.

Results: The study results revealed that 45.1% (f=23) of the primary caregivers of elderly with psychosis had severe stress, 37.3% (f=19) of the primary caregivers had moderate stress and 9% (f=17.6) of the primary caregivers had mild stress. A statistically significant association was found between caregiver stress with family income [<0.05 level (***p*** =0.01)], and the elderly's functional ability in activities of daily living (***p***=0.04). A significant association was also found between caregiver well-being and the functional ability of elderly in activities of daily living (***p***=0.02). A negative correlation was observed between stress and well-being (r=-0.58, ***p***<0.01).

Conclusion: The study concludes that majority of primary caregivers of elderly with psychosis experienced severe stress and there is negative correlation between stress and well-being of the primary caregivers of elderly with psychosis

Keywords: Primary caregivers, Stress, Well-being, Elderly, Psychosis

INTRODUCTION

Aging population is increasing day by day in the world. It has been estimated that by 2030, globally 1 in 6 people will be older i.e. 60 years or over.[1,2] Elderly persons are at risk of developing mental disorders, neurological disorders or substance use problems as well as other physical health conditions.[2,3,4] The lifetime prevalence of schizophrenia is about 1%, but in older adults, it ranges from 0.1% to 0.5%. Additionally, 0.14% of people over 60 years have schizoaffective disorder. Delusional disorder affects an estimated 0.03% of older adults.[5, 6,7] Primary caregivers take responsibilities of an elderly individual's

physical, social, and financial need to ensure their quality of life. Research studies highlighted that caregivers of elderly with psychosis often face caregiving stress.[8, 9, 10, 11, 12] The ongoing stress of caregiving can have significant impact on the caregiver's physical, mental and social aspects of life.[13, 14, 15, 16, 17, 18] So, the researcher felt the need to assess the stress and well being among primary care givers of elderly with psychosis. The study findings will be helpful to design supportive interventions for the primary caregivers of elderly with psychosis, to reduce the stress experienced by caregivers and to improve the overall well being.

The study was done with following threefold objectives: First, it sought to describe the levels of stress and wellbeing of primary caregivers of elderly with psychosis. Second, the study aimed to find out the association between stress and wellbeing with selected with selected socio demographic variables and clinical variables. Finally, it intended to determine the relationship between stress and wellbeing of primary caregivers of elderly with psychosis.

MATERIALS AND METHODS

A descriptive, quantitative research approach and cross-sectional design was used in the study. A total of 51 primary caregivers of elderly diagnosed with F20–F29, who had been living with them for at least 6 months, were selected through purposive sampling from the Geriatric Mental Health OPD at a Tertiary Mental Health Institute in Tezpur, Assam. Sample size calculation made as per data collected from OPD. In 2022, the total cases of F20-F29 were 208 in 12 months. A tentative sample size of 51 was estimated for a 3-month data collection period. The data collection was done from 21st March 2024 till 21st May 2024 by using socio-demographic proforma, Kingston Caregiver Stress Scale and Caregiver Well-Being Scale (CWBS) shorter version. The primary caregivers who have any diagnosed mental disorder and severe chronic physical illness were excluded.

1. **Socio demographic proforma:** A self-structured socio-demographic proforma was developed for the purpose of assessing the socio-demographic variables of the primary caregivers and clinical variables of the elderly with psychosis.
2. **Kingston Caregiver Stress Scale (KCSS):** The Kingston Caregiver Stress Scale (KCSS) was used to assess the stress among the primary caregivers of elderly with psychosis. The possible score range is between 10-50. Any mean scale ranging from 10 to 14 are considered as mild stress, a score of 15-23 are considered moderate stress and a score from 24 to 50 are considered as severe stress. The test-retest reliability for full scale was 0.89.[19] The tool was translated to Assamese language following WHO translation guidelines. The calculated reliability of Assamese version of Kingston Caregiver Stress Scale (KCSS) in the current study was found to be 0.767.
3. **Caregiver well being scale (CWBS):** The Caregiver Well-Being Scale (CWBS) shorter version was used to assess the well-being of primary caregivers of elderly with psychosis. It focused on assessing caregiver's basic human needs and their satisfaction with daily living activities. Higher mean scores indicate better well-being among caregivers. The scale demonstrates good reliability, with Cronbach's alpha values of 0.73 for Basic Human Needs, 0.74 for Activities of Daily Living, and an overall coefficient of 0.83.[20] The tool was translated to Assamese language following WHO translation guidelines. The calculated reliability of Assamese version of Caregiver Well-Being Scale (CWBS) shorter version in the current study was found to be 0.874.

Ethical consideration:

Before beginning of the study, approval for conducting the study was obtained from the Scientific Advisory Committee (No. LGB/ACA/SAC/2589/15/3408). Ethical clearance was granted by the Institutional Ethical Committee, ensuring that the research adhered to the necessary ethical standards (No. LGB/ACA/ETC/2560/07/Vol.II/3207/3669). In addition, formal permission was secured from the relevant authorities of the Tertiary Mental Health Care Institute where the study was conducted (LGB/ACA/ETC/2560/07/Vol.II/3207/3669). Informed consent was obtained from the participants before data collection. Anonymity and confidentiality of the participants was also maintained.

Analysis was done based on the objectives of the study. Appropriate descriptive i.e. mean, standard deviation, percentage, frequency, range and inferential statistics i.e. Karl Pearson correlation co-efficient and Chi-square were used to analyse the data with the help of SPSS version 20.

RESULTS:

Description of sociodemographic variables of primary caregivers of elderly with psychosis:

The result showed that the primary caregiver's age ranges from 18 years to 59 years and the mean and standard deviation of age were 36.84 ± 10.63. Among the 51 primary caregivers majority of primary caregivers, i.e. 68.4% (f=35) were male, 31.4% (f=16) were female. 41.2% (f=21) of the primary caregivers were unemployed, 7.8% (f=4) were daily wage earner, 3.9% (f=2) were cultivator, 33.3% (f-=17) were private job employee, 3.9% (f=2) were government employee, 7.8% (f=4) were doing business and 2% (f=1) were engaged in other occupation. The result revealed that, among the 51 primary caregivers majority of primary caregivers majority i.e. 70.6% (f=36) of the primary caregivers were married, 27.5% (f=14) were unmarried and 2% (f=1) of the primary caregivers were widow.

Majority of the primary caregivers i.e. 72.5% (f=37) were stayed with the patient for more than 2 years, 7.8% (f=4) were stayed for 2 years, 7.8% (f=4) were stayed for 1 year and 11.8% (f=6) were stayed for 6 months with the elderly with psychosis. Majority of the primary caregivers i.e. 70.6% (f=36) gave care to the elderly with psychosis for more than 2 years, 7.8% (f=4) gave care to the elderly with psychosis for 2 years, 7.8% (f=4) gave care to the elderly with psychosis for 1 year and 13.7% (f=7) gave care to the elderly with psychosis for 6 months.

Table-1: Frequency and percentage distribution of sociodemographic variables of primary caregivers of elderly with psychosis:

n=51

VARIABLE		**FREQUENCY (f) and PERCENTAGE (%)**
Sex	Male	35 (68.6%)
	Female	16 (31.4%)
Occupation	Unemployed	21 (41.2%)
	Daily wage earner	4 (7.8%)
	Cultivator	2 (3.9%)
	Private service	17 (33.3%)
	Govt. service	2 (3.9%)
	Business	4 (7.8%)
	Others	1 (2.0%)

Marital status	Married	36 (70.6%)
	Unmarried	14 (27.5%)
	Widow	1 (2.0%)
Duration of Stay with the elderly	6 months	6 (11.8)
	1 year	4 (7.8%)
	2 years	4 (7.8%)
	More than 2 years	37 (72.5%)
Duration of care to the elderly	6 months	7 (13.7%)
	1 year	4 (7.8%)
	2 years	4 (7.8%)
	More than 2 years	36 (70.6%)
Presence of physical/mental and behavioural disorder in the family	Yes	15 (29.4%)
	No	36 (70.6%)

Description of sociodemographic and clinical variables of elderly with psychosis:

The result revealed that, majority of the elderly, i.e. 52.9% (f=27) were diagnosed with F20, 7.8% (f=4) were diagnosed with F22, 2.0% (f=1) were diagnosed with F25 and 37.3% (f=19) were diagnosed with F29. Gender wise majority i.e. 58.8% (f=30) of the elderly were female and 41.2% (f=21) were male. Most of the elderly i.e. 43.1% (f=22) of the elderly could perform their daily activities under supervision, 41.2% (f=21) of the elderly could perform their daily activities independently, 15.7% (f=8) of the elderly needed assistance to perform their daily activities of daily living.

Table-2: Frequency and percentage distribution of sociodemographic and clinical variables of elderly with psychosis:

n=51

VARIABLES		**FREQUENCY (f) and PERCENTAGE (%)**
Diagnosis	F20	27 (52.9%)
	F22	4 (7.8%)
	F25	1 (2.0%)
	F29	19 (37.3%)
Gender	Male	21 (41.2%)
	Female	30 (58.8%)
Functional ability in activities of daily living	Independent	21 (41.2%)
	Perform under supervision	22 (43.1%)
	Need assistance	8 (15.7%)

Description of stress and well being of primary caregivers of elderly with psychosis:

The result highlighted that the minimum stress score of the primary caregivers was 10 and maximum was 39, mean and standard deviation of stress of among primary caregivers of elderly with psychosis was found to be 22.49±7.77. Most of the primary caregivers i.e. 45.1% (f=23) of the primary caregivers had severe stress, 9% (f=17.6) of the primary caregivers had mild stress and 37.3% (f=19) of the primary caregivers had moderate stress.

The findings revealed that the minimum well being score was 32 and maximum well being score was 70, mean and standard deviation of caregiver well being score of primary caregivers of elderly with psychosis was 53.40±13.63. 50% (f=5) of the primary caregivers scored above the mean score and 50% (f=5) scored below the mean score.

Table-3: Frequency and percentage distribution of stress and well being of primary caregivers of elderly with psychosis.

n=51

VARIABLE	FREQUENCY (f) and PERCENTAGE (%)
Interpretation of Primary caregiver's stress	
Mild stress	9 (17.6%)
Moderate stress	19 (37.3%)
Severe stress	23 (45.1%)
Primary caregiver well being score	51.80±8.93 (32-70)
Interpretation of primary caregiver's well being	
Above the mean score	27 (52.9%)
Below the mean score of well being.	24 (47.1%)

Association of stress and well being with selected socio demographic variables and clinical variables:

The result showed that there was a statistically significant association found between stress and family income of the primary caregivers of elderly with psychosis at the level of <0.05 (***p*** =0.01) and functional ability in activities of daily living of the elderly with psychosis as well at the level of <0.05 (***p***=0.04).

Table-4: Association of primary caregiver's stress with sociodemographic variables of primary caregivers and elderly with psychosis
n=51

Socio-demographic variables of primary caregivers & elderly with psychosis		**Kingston caregiver stress**			**χ2 (Chi square)**	**df**	***p* value**	**S/NS**
		Mild	**Moderate**	**Severe**				
Socio-demographic variables of primary caregivers								
Age	18-36 years	7	9	12	2.40	2	0.30 (fisher's exact ***p*** value)	NS
	37-59 years	2	10	11				
Sex	Male	7	15	13	2.85	2	0.27 (fisher's exact ***p*** value)	NS
	Female	2	4	10				
Occupation	Unemployed	3	8	10	0.28	2	0.93 (fisher's exact ***p*** value)	NS
	Other than unemployed	6	11	13				
Marital status	Married	5	14	17	1.19	2	0.60 (fisher's exact ***p*** value)	NS
	Other than married	4	5	6				
Family income per month (in rupees)	More than or equal to 19333	7	11	6	8.36	2	0.01 (fisher's exact ***p*** value)	***S**
	Less than 19333	2	8	17				
Socio-demographic variables and clinical variables of elderly with psychosis								
Functional ability in activities of daily living	Independent	8	6	7	10.27	2	<0.01 (fisher's exact ***p*** value)	***S**
	Perform under supervision and need assistance	1	13	16				

*** S= Significant, NS= not significant Significant at the level of <0.05 level**

The study revealed that, there was a statistically significant association found between primary caregiver's well being and functional ability in activities of daily living of the elderly with psychosis at the level of <0.05 (***p***=0.02).

Table-5: Association of primary caregiver's well being with Socio-demographic variables and clinical variables of elderly with psychosis

n=51

Socio-demographic variables and clinical variables of elderly with psychosis		**Primary caregiver well-being Mean= 51.80**		**χ2 (Chi square)**	**df**	***p* value**	**S/NS**
		Higher well being	**Lower well being**				
Diagnosis	F20	16	11	0.91	1	0.33	NS
	Other than F20	11	13				
Gender	Male	12	9	0.25	1	0.61	NS
	Female	15	15				
Functional ability in activities of daily living	Independent	15	6	4.89	1	0.02	***S**
	Perform under supervision and need assistance	12	18				

*** S= Significant, NS= not significant Significant at the level of <0.05 level**

Corelation between stress and well being among the primary caregivers of elderly with psychosis:
The result uncovered that there was negative corelation found between stress and well being among primary caregivers of elderly with psychosis (r=-0.58, ***p*** < 0.01) at significant level of 0.05.

DISCUSSION

Less studies exist on stress and well-being of caregivers for the elderly with psychosis in North East India. This research was conducted to address that gap, and the findings will help guide future studies.

In the present study, the primary caregivers of elderly with psychosis were between the age group 18 years & 59 years. The mean age was 36.84 years and standard deviation was 10.63 among the primary caregivers of elderly with psychosis. Similar age group of primary caregivers of elderly with psychosis was seen in a study conducted by Sinha V. et al. [21].

This study highlighted that majority of primary caregivers, i.e. 68.4% (f=35) were male, 31.4% (f=16) were female. In a study by Romdhane FF et al. [9] found that 78.8% of caregivers for older adults with mental illness were female while 21.1% were male, which contradicts this finding of the study. This discrepancy might be due to the purposive sampling technique which was adopted in this study.

The current study result revealed that, 70.6% (f=36) of the primary caregivers were married, 27.5% (f=14) were unmarried and 2% (f=1) of the primary caregivers were widow. In a research study by Romdhane FF et al. [22] showed similar result where 78% of caregivers of older patient with schizophrenia spectrum disorder were married, 14% were single, 6% were divorced and 2% were widower.

This study highlighted, most of the primary caregivers of elderly with psychosis i.e. 45.1% (f=23) had severe stress, 37.3% (f=19) had moderate stress and 9% (f=17.6) had mild stress. Romdhane FF et al. [9] found 36.5% of caregivers of older patients with schizophrenia spectrum experienced moderate to severe stress, which is similar to this study result.

The study revealed, mean and standard deviation of well being of primary caregivers of elderly with psychosis was found to be 51.80±8.93, where 52.9%(f=27) of the primary caregivers were above the mean score and 47.1% (f=24) were below the mean score. In studies conducted by Perrig-Chiello P et al. [17] and Zegwaard MI et al. [18] found that caregiving of elderly with psychosis was most evident in the declining quality of the caregiver's psychosocial well-being, which contradict the current study result.

It was found that there was a statistically significant association found between stress and family income of the primary caregivers of elderly with psychosis at the level of <0.05 level (***p*** =0.01). This might be a reason that financial strain can cause limits access to healthcare, support services and coping resources which increases caregiver stress.[23]

The study highlighted, there was a statistically significant association found between primary caregiver's stress and functional ability in activities of daily living of the elderly with psychosis at the level of <0.05 level (***p***=0.04). In studies conducted by Romdhane FF et al. [9] & Samanta A et al. [24] found similar result to this study result.

The study result revealed that there was a statistically significant association found between primary caregiver's well being and functional ability in activities of daily living of the elderly with psychosis at the level of <0.05 level (***p***=0.02). In a study done by Martens I et al.[25] found that dependency of the adult and elderly individuals with schizophrenia and schizoaffective disorder is negatively associated with psychological well-being of the caregiver.

The present study result showed there was negative corelation found between stress and well being among primary caregivers of elderly with psychosis (r=-0.58, $p < 0.01$) at significant level of <0.01. In studies, conducted by Romdhane FF et al. [9], Gupta A et al. [26] and Das et al.[27] showed that increased caregiving demands elevate stress levels and there is a strong negative correlation present between burden and psychological well being (r=-0.81) among the caregivers of adult patients with schizophrenia.

LIMITATIONS

- The study is a cross-sectional, single-centered study. The sample may not represent an entire population.
- The sample group was not homogeneous. The sample group consists of many extraneous variables like different age group, religion, educational, occupation, family income per month, duration of illness and duration of treatment of the elderly with psychosis etc.

RECOMMENDATION:

- The study can be replicate in same or different setting with a large sample size.
- Comparative study can be done among primary caregivers of elderly with psychosis and other type of mental disorders.
- Experimental study can be conducted to find out effectiveness of interventional module to reduce stress and to improve wellbeing among the primary caregivers of elderly with psychosis.

CONCLUSION

After conducting the study, the researcher found that most of the primary caregivers i.e. 45.1% (f=23) experienced severe stress, 9% (f=17.6) had mild stress and 37.3% (f=19) of the primary caregivers had moderate stress. Additionally, 47.1% (f=24) of primary caregivers scored below the average on well-being. This finding suggests that taking care of elderly individual with psychosis can be very stressful, which can negatively affect the well-being of primary caregivers.

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