A CROSS-SECTIONAL STUDY OF DEPRESSION, ANXIETY, STRESS AND RESILIENCE AMONG THE PRIMARY CAREGIVERS OF PERSONS WITH SCHIZOPHRENIA FROM TERTIARY CARE RURAL HOSPITAL IN CENTRAL INDIA

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ABSTRACT:

Background: Schizophrenia is characterized by disordered thoughts, emotions, perceptions, language, sense of self and behavior. Primary caregivers of individuals with Schizophrenia encounter comprehensive care giving challenges that causes physical as well as mental stress and can deteriorate the family functioning. However, if primary caregivers are resilient enough with strong and positive mindset, they can overcome burden associated with patient care and preserve own health and health of family as well.

Aim: To assess the relationship between depression, anxiety, stress and resilience perceived by primary caregivers of persons with Schizophrenia

Materials and Methods: Primary caregivers of person diagnosed with Schizophrenia disease reporting to OPD and IPD of Department of Psychiatry of Medical College as per DSM-5 diagnostic criteria will be assessed for depression, anxiety, stress and resilience after taking informed consent for the study by applying inclusion and exclusion criteria. Then psychological scales will be applied on these primary caregivers. The Depression Anxiety and Stress (DASS-21) and Brief Resilience Scale (BRS) scales will be applied and accordingly the points will be given.

Conclusion: We expect to find significant relationship between depression, anxiety, stress and resilience perceived by caregivers of persons with Schizophrenia.

Key words: depression, anxiety, stress, resilience, caregivers, Schizophrenia

Introduction:

Schizophrenia continues to be defined and diagnosed as a psychiatric disorder solely based on its clinical phenomenology^[1]. One of the major community mental health problem faced by psychiatry is the group of disorders that account for the diagnostic category of Schizophrenia. They usually leave the person with varying degrees of psychological, affective and cognitive impairment^[2]. It is a chronic disease with relapsing and remitting course. Schizophrenia is characterized by disordered thoughts, emotions, perception, language, sense of self and behavior. Common experiences faced are psychosis, delusions (false beliefs) and hallucinations. Schizophrenia involves a range of emotional, behavioral and cognitive symptoms. According to the most comprehensive and current Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5), the prevalence of Schizophrenia was found to be approx. 1.25% [3]. Studies have shown that psychic disorders have a higher prevalence in early to mid-life. Despite the fact that Schizophrenia can occur at any age, the average age of onset typically appears earlier between 15-20 years in young adult men and between 20-30 years in women^[4]. Interpersonal relationships among the individuals with Schizophrenia gets impaired enough to prevent courtship, following marriage and later procreation. Individuals with Schizophrenia usually denied to personal and social adulthood benefits to a considerable degree.

Primary caregivers often encounter increasing psychological and social demands of mentally ill patients. Such caregivers feel low, stressed, anxious, as the illness sustains to be persistent and quite challenging. Sometimes it may result in caregiver burnout. Psychological stress is a unique, discomforting, emotional state, response to a specific stressor. Primary caregivers who have unremitting stress are more prone to having low quality of life and greater physical health risks in comparison with general population. According to a study, the prevalence of stress among the primary caregivers of persons with Schizophrenia is 5.39% [5]. Depression causes a persistent feeling of sadness, lack of interest in activities, and decreases person's ability to do work. Studies have found that depression rate among the primary caregivers of patient with mental illness is more than double than that of common citizens^[6, 7]. The burden (anxiety, stress, depression) among the primary caregivers of individuals with Schizophrenia comprises disturbed daily routine activities, reduction in intimacy, feeling of hopelessness, disorientation observed in their own lives. Mental illness is often affiliated with raised physical morbidity as well^[8, 9]. According to the study by P Kumar et al., the prevalence of depression among the primary caregivers of individuals with Schizophrenia is 13.7% [10]. The difficulties experienced during caregiving period (especially in coping with challenging behavior) and negative symptoms tend to increase an anxiety among the primary caregivers

of persons with Schizophrenia^[11]. According to the study of P Kumar et al., the prevalence of anxiety among the primary caregivers of persons with Schizophrenia is 3.49%^[5].

Resilience is the ability to withstand and rebound from disruptive life challenges by reducing the tendency to blame, shame and pathologies by viewing their situations as being normal^[12]. It includes willpower, capability, flexibility, optimism and the ability to deal positively and easily recovered when confronted with any adversity and challenges or any setbacks. It is a part of normal healthy development that can be improved with different phases of life. It is influenced by various risk factors and protective factors (such as problem-solving skills, seeking social support etc.) in the self and surrounding and also plays a vital role in the maintenance and improvement of health. A study has suggested, a strong positive correlation between the score of caregiving burden and depression scores thus reflecting the idea of more caregiver burden with higher level of depression. Likewise, there is a direct correlation between the score of caregiving burden and score of anxiety. The higher the score caregiving burden, the higher the anxiety score^[13]. One of the studies conducted in North India suggest that the resilience levels were high in caregivers who were above 35 years of age, males, educated, employed and were parents of their patient^[14]. Some studies do suggest existing link having correlation of caregiving burden with stress, anxiety, depression among the caregivers of individuals with Schizophrenia^[7, 13, 15, 16, 17]. Others have studied Resilience and its associated factors among the caregivers of persons with Schizophrenia [14, 18, 19]. In addition, this present study is the first study in rural setting of Central India assessing the ^{17]}, we hypothesized that depression, anxiety, and stress acts as predictors towards the resilience in the primary caregivers of individuals with Schizophrenia. "Will there be association between depression, anxiety, stress and resilience perceived by primary caregivers of individuals with Schizophrenia?" reflects the research question of the present study. The null hypothesis [H0] will be that there will be no such association between Depression, Anxiety, Stress and Resilience in the primary caregivers of individuals with Schizophrenia.

Need for the study – Primary caregivers of individuals with Schizophrenia often encounter comprehensive care giving challenges that causes physical as well as mental stress and can deteriorate the family functioning^[20]. However, if family members are resilient enough with the strong and positive mindset, they can overcome the burden associated with patient care and can preserve their own health and family health as well. Resilience of primary caregivers of persons with schizophrenia brings a positive change in recovery and adaptation of the family. It reduces caregiver burnout, improves quality of life and optimizes family function. Hence, we are conducting this study with the aim to determine the relationship between depression, anxiety, stress and resilience perceived by the primary caregivers of individual with Schizophrenia attending department of Psychiatry.

Objective: - The primary objective of the present study will be to study the relationship between the depression, anxiety, stress and resilience among the primary caregivers of persons with Schizophrenia.

Methodology:

Study type – The present cross-sectional study will be conducted in psychiatry inpatient as well as outpatient department of Psychiatry from tertiary care rural hospital in central India.

Study Duration- The present study will be of 6 months duration.

Sample size – The Sample size has been calculated using the formula for cross-sectional study ($n=4pq/l^2$), where p is the prevalence of stress among caregivers of schizophrenia patients, q=100-p, l is the allowable error. Considering the prevalence of stress amongst the primary caregivers of persons with Schizophrenia as 5.39%, 95% confidence interval with absolute precision of 5%, the minimum sample size comes out to be 80 primary caregivers of individual with Schizophrenia.

Source of data: - Primary caregivers of individual with diagnosis of Schizophrenia as per DSM-5 diagnostic criteria attending OPD and IPD (both new and follow up patients of Department of Psychiatry) of medical college.

Method/ Sampling procedure: -

Primary caregivers of Patient diagnosed with Schizophrenia disease reporting to OPD and IPD (both new and follow up patients) of Department of Psychiatry of medical college as per the DSM-5 diagnostic criteria will be assessed for depression, anxiety, stress and resilience after taking informed consent for the study by applying inclusion and exclusion criteria. Prior to beginning of the study, the nature of the study will be explained to study participants in their vernacular language and then written informed consent will be taken from the study participants. Confidentiality regarding each and every participant's personal identity and privacy will be strictly maintained. Then psychological scales will be applied on these primary caregivers. The Depression Anxiety and Stress Scale (DASS-21) and Brief Resilience Scale (BRS) scales will be applied and accordingly the points will be given. The observations obtained will be analyzed.

Tools for study: -

1. **Depression Anxiety and Stress Scale 21**: DASS-21 is a significant collection of three self-report scale in order to estimate subjective emotional state of Stress, Anxiety, Depression. The reliability of DASS-21 showed that it has excellent Cronbach's alpha value of depression, anxiety and stress respectively. It is reliable, valid & easy to administer^[21]. Table 1 below shows the various cut off scores of DASS-21 for depression, anxiety and stress.

Table 1. Cut off scores of DASS-21 subscales of depression, anxiety and stress

Grading	Depression	Anxiety	Stress
Normal	0-9	0-7	0-14
Mild	10-13	8-9	15-18
Moderate	14-20	10-14	19-25
Severe	21-27	15-19	26-33
Extremely severe	28+	20+	34+

2. **Brief Resilience Scale**: Brief Resilience Scale provides unique essential information about people coping with health-related disorders. It is a reliable means of analyzing the resilience as the potential to recover or retrieve from emotional imbalance ^[22]. Table 2 below presents the various cut off scores of BRS scale for interpretation of the level of resilience.

Table 2. Cut off scores of BRS scale for interpretation of the resilience

BRS scale	Inference
1.00-2.99	Low resilience
3.00-4.30	Normal resilience
4.31-5.00	High resilience

Inclusion criteria: -

- 1. Those primary caregivers giving consent
- 2. Primary caregivers of patients whose patients fulfill DSM 5 diagnostic criteria for schizophrenia
- 3. Primary caregivers from age group 18 to 60 years

Exclusion criteria: -

- 1. Primary caregivers not giving consent
- 2. Primary caregivers below 18 and above 60 years of age
- 3. Primary caregivers having history of psychosis, dementia, terminal illnesses, head / brain injuries and substance use disorder except for nicotine.

Statistical methods used: -

Data from the questionnaire will be entered with the help of Microsoft Excel version 2007. The final data will be analyzed with the help of SPSS statistical software version 15(IBM, Chicago, Illinois, United States of America). Continuous data will be presented as Mean and Standard Deviation (MSD), categorical data will be presented as frequency and percentage. Chi-square test and Fisher exact test will be used to determine the level of significance.

Ethical clearance -The synopsis copy has been submitted to the institution for ethical approval.

Results/ Expected Outcomes: We expect to find that the primary caregivers with higher resilience level will have lower rates of depression, anxiety and stress.

Discussion: The present study will assess the relationship of Depression, Anxiety and Stress with resilience among the primary caregivers of individuals suffering from Schizophrenia. One of the bunches of challenges in the present time is that the primary caregivers of persons with Schizophrenia faces daily life difficulties in coping with aggressive behavior, social isolation, withdrawal and the lack of motivation which are the characteristics of Schizophrenia. To deal with this, the concept of resilience was introduced. While searching literature, we found out that there is paucity of Indian studies assessing the link between depression, anxiety, stress and resilience among the primary caregivers of individual with Schizophrenia^[23, 24, 25]. Glanville et al., inferred that the complex nature and multidimensionality of caregiver burden were neglected and treatment approach was being paid less attention to caregiver appraisals^[23]. Knock J et al., inferred that additional studies are needed to learn more about the challenges faced by caregivers of individuals with Schizophrenia^[24]. Seeman MV inferred more counselling and special attention is needed as women (spouse) suffers a lot of burden^[25]. In our study we have excluded the primary caregivers having history of psychosis, dementia, terminal illnesses, head / brain injuries and substance use disorder keeping in mind patients already having psychiatric disorders may

experience recurrence due to stress diathesis interaction. Exclusion of primary caregivers reporting medical illness is done in the view of impaired physical health can affect their psychological well-being and increase the risk of incorrect assessment^[26, 27,28]. Young age group of primary caregivers were excluded as they are not well aware of concept of caregiving, nature of illness, medication issues and thus may report more stress and less resilience. A number of related studies reflect evidences of mental health problems around the globe^[29-32]. Few studies on schizophrenia and related issues were reviewed ^[33,34].

Implication: We will assess the caregiver burden in the form of depression, anxiety, stress and resilience as Schizophrenia is a lifelong illness demanding mental, physical and financial support of caregivers for their family members (persons) suffering from illness. Patient's illness can increase mental, physical and financial burden on the primary caregivers which tend to develop emotional burden of depression, anxiety and stress. Integration of mutual support, education, coping strategies conveyed within community awareness programs can bring down the primary caregiver burden and boost their mental health. So, we will assess relationship of depression, anxiety, stress with resilience among the primary caregivers of individuals suffering from Schizophrenia. It will further help to assess and improve resilience among the primary caregivers.

Strengths of the study: The use of standard scales, DASS-21 and BRS scale adds the significance in the findings of the present study. The knowledge of primary caregivers' resilience level will help psychiatric professionals in planning counselling. Identifying the cut off scores of burdens and managing appropriately help in coping with depression, anxiety and stress in follow ups. This will help in reduction of negative impacts (uncertainty, family disruption, etc.) among the primary caregivers of individuals with Schizophrenia. Also, by developing mutual support and educating, mental health of primary caregivers can be improved.

Limitations of the study: As the present study is a type of cross-sectional study, a causal relationship couldn't get established. It doesn't help to determine cause and effect in depth. Further study needs to focus on covering in depth domains that are missed in our study. In present times there is strong need for developing stress coping techniques and counselling intervention for promoting resilience among the primary caregivers of individuals with Schizophrenia.

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