

## **A Review of The Literature on The Psychological Distress Experienced by Carers of Schizophrenia Patients and Their Perception of Their Burden**

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### **Abstract**

Schizophrenia is a psychiatric mental disorder that effect on thought, emotion, perception and behaviour of the person. Caregiver literally played an important role in caregiving of schizophrenia patients. This review was defined on anxiety, depression and perceived burden of care of caregiver of schizophrenia patients. All the article were collected from google scholar, PubMed, Ncert, Sudhganga, Web of Science, EBSCOhost, in the years of 2010-2022. Most of the studies outcome were higher level of perceived burden of care in caregiver of schizophrenia patients. Severity of anxiety and depression also were higher level on caregiver of schizophrenia patents. Anxiety and depression were positively correlated with perceived burden of caregiver of schizophrenia patients. Female caregivers were higher level of depression than male caregivers. This review suggested that caregiver should be needs knowledge of care and patients should be needs intervention.

**Keywords-** Schizophrenia, Anxiety, Depression, Perceived burden of caregiver

### **Introduction**

It takes a lot of work and energy to care for someone who has a mental condition. It normally requires a lot of time, effort, and money over potentially lengthy periods. That could be unpleasant or uncomfortable, as well as physically or emotionally stressful. Particularly in traditional societies like India, this might be challenging. The responsibility for care falls on the family, which is seen as the "natural" carer because of the close-knit family structure and the lack of suitable state resources to support people with mental illness.

As chlorpromazine (medication process) was discovered in 1950 and antipsychotic use for the treatment of schizophrenia increased as a result, the phrase "burden of care" came into use by Gulseren et al., (2010). In developing nations, more than 50% of people with schizophrenia do not receive the right care; one of the causes of this problem is the inaccessibility to healthcare facilities. Schizophrenia is a complex psychiatric mental disorder that affects many aspects of the person such as behaviour, self-experience, emotion, thinking, cognitive, perception by Vadher et al., (2022). It has positive and negative symptoms. Positive symptoms included hallucination, delusions, confused thoughts and disorganised, trouble concentrating, movement disorders. Negative symptoms included lack of pleasure, trouble with speech, flattening withdrawal, struggling with the basics of daily life by Zhou et al., (2021). Symptoms of the schizophrenia diagnosed by DSM-V and ICD-10. The causes of schizophrenia unknown yet but some research indicated that some factors such as psychological, physical, genetic and environmental. National Institute of Mental Health was assessed on prevalence of schizophrenia rate is between 0.25% and 0.64 %. Prevalence of schizophrenia in non-institutional rate between 0.33% to 0.75% It is also a serious, chronic psychological illness that causes long-term incapacity. In a previous study conducted in India, 53.7% of people with schizophrenia had certifiable deficits by Ranjan et al., (2010). Consequently, both the sufferer and their family are affected Yilmoz et al., (2014).

### Research Questions

1. What is the caregiver's responsibility for schizophrenia patients?
2. Does stress have an impact on the amount of work required to care for schizophrenia patients?
3. How does anxiety impact the amount of work required to care for schizophrenia patients?
4. What impact does depression have on the amount of work that carers for people with schizophrenia must do?

### Literature review

An extensive literature analysis covering the years 2010 to 2022 was carried out to examine the perceived load and psychological suffering on carers of schizophrenia patients. the results of this study and examine both the broad data analysis of the publications that were included

(for example, factors, groups, pertinent papers, keywords) and the specialised data assessment relating to some research concerns. These results offer an overview of the current research as well as a list of topics that still require investigation and a list of potential directions for future study by suggesting an agenda. Future research on carers for people with schizophrenia and related challenges can build on the findings of this review. Schizophrenia is characterised by a lack of contact with reality, a distortion or disorganisation of mental capability, and a person's ability to understand people and establish connections. Schizophrenia symptoms frequently include chronic impairment and those of psychotic episodes, which may have an effect not only on the patient but also on those around them, especially those closest to them. These closest friends and family members frequently assist patients as carers. Although their involvement in the early phases of the illness is very crucial, family involvement in schizophrenia patients will become highly obvious in those who experience long-term damage. Early family intervention is crucial to helping both the patient and the carer understand the sickness, treat disordered thought and emotion, lower negative evaluation, and prevent the patient from expressing themselves emotionally intensely. The foundation of this research study is secondary data that was acquired from journals, other research papers, web sources, and google searches. The objective of the current review is to investigate and assemble exact data concerning the psychological discomfort and perceived load of carers of schizophrenia patients.

### **The role of caregiver of schizophrenia patients**

Caregiver literally played an important role in caregiving of schizophrenia patients. Caregiver gives valuable time to patients with schizophrenia from her/his life span. May mentally, physically and emotionally burden to caregiver because per day 24 hours needed for caregiving. Caregiver takes care of all the part of schizophrenia patients such as brushing, bathing, dressing, eating food, health check-up, taking medicine, observing behaviour, socialize with society and other daily activity work. Caregiver faced many types of challenges, difficulties, responsibility. It is not an easy work for all people to become caregiver of schizophrenia patients. According to research conducted in India, the load and psychological anguish experienced by carers of people with schizophrenia are very high. Caregiver of schizophrenia patients experienced by psychological burden like anxiety, depression, and stress

during caregiving. Due to their long-term participation in caregiving and psychological distress, carers often have a low quality of life by Nasir et al., (2022).

Family carers now play a bigger part in the rehabilitation of schizophrenia patients when treatment is moved from hospitals to the community. Family carers are accountable for giving financial and emotional support, monitoring medicine intake, upholding treatment adherence, and encouraging social engagement. Schizophrenia symptoms are frequently linked to persistent impairment and the traits of psychotic episodes that may affect not only the sufferer but also those nearby, especially those closest to them. These family members frequently assist patients and act as caretakers by Suaryanaik et al., (2022). When it comes to helping family members who are afflicted with psychiatric disorders, carers are crucial. Caregiver burden is defined as a psychological state that results from a combination of physical work, emotional, and social pressure, such as the financial constraints that emerge from caring for patients by Vadher et al., (2020) Yu et al., (2020), Yadav et al (2021). While subjective burden refers to one's own feelings of load, feeling of loss, embarrassment and sadness objective burden refers to interruptions that can be seen and verified as a result of delivering care by Karambelas et al., (2022), Gupta et al., (2015), Raj et al., (2016). A prior study found that 42.31% of carers in India who had schizophrenia patients experienced a severe level of care load. Psychiatric problems have grown to be a significant concern and public health issue. When the caregiver burden increased level of anxiety and depression also increase Yadav et al., (2021).

A carer is a member of the patient's family who stays with them, spends a lot of time providing various forms of care, such as bathing, toileting, bedding, clothing, and grooming, and supports the patient in social interactions. Giving care is a job that must be done continuously with no compensation, sick days, or benefits Behera et al., (2020). A caregiver's quality of life may suffer as a result of the demanding and challenging nature of caregiving. It is said that extended caregiving strains the carer, leading to psychosocial problems like anxiety and depression that decreased quality of life of caregiver of schizophrenia patients by Don et al., (2020), Stanley et al., (2017). These factors are discussed below.

### **Anxiety**

Anxiety is a type of mental disorders defined by extreme dread or concern about actual or imagined threats, which frequently results in altered behaviour as well as physical signs such a

raised heart beats or tense muscles, feelings of fear, irritability, fatigue, feeling agitated, excessive worry, restlessness, trouble concentrating, difficulty falling asleep, sweating, trembling. It's normal to sometimes feel anxiety but in case of caregiver of schizophrenia patients the level of anxiety develops gradually. An emotional condition known as psychological discomfort is characterised by anxiety symptoms in caregiver of schizophrenia patients by Ranjan et al., 2022. Anxiety disorder can feel debilitating for caregiver of schizophrenia patients but a mental health professional can help. These symptoms may differently experience from person to person. As caregiver of schizophrenia patients' chance of acquiring anxiety disorders may be increased by a combination of genetic and environmental variables. The family care load factors that affect the anxiety, and levels of carers of chronic schizophrenia patients are not described in any Indian studies. In order to better understand how family care burden affects carers of chronic schizophrenia patients' anxiety levels, symptoms, we want to examine this topic. Previous study reported that chronic patients of schizophrenia prevalence of anxiety score was 56.2%. Extremely severe score was 28% of caregiver of schizophrenia patients.

### **Relationship between caregiver burden of schizophrenic patients and anxiety**

As these patients receive years of ongoing care and support from their caretakers, the carers run the danger of experiencing psychological anxiety. The caregiver often faced burden on day to day during caring patients with schizophrenia and gained different level of anxiety. Main burden is economic burden experienced by the caregiver of schizophrenia patients. The caregiver gained a negative experience from caregiving. If increased caregiver burden of schizophrenia patients, then increased anxiety. Between 32% and 100% of carers of schizophrenia patients reported experiencing anxiety in some earlier research Ranjan et al., 2022. Result of the last study was showing that a positive relationship between caregiver burden and anxiety. According to the study's findings, 70.8 percent of carers of schizophrenia patients reported being overburdened with care. The majority of carers (56.2%) reported having extremely high levels of anxiety by Ranjan et al., 2022. The correlation coefficient between the caring load and anxiety ratings was 0.694, with a p-value of 0.001 indicating a significant positive link by Suryana IK et al., 2022.

## **Depression**

A collection of illnesses like depression in caregiver of schizophrenia patients developed gradually. Because when increased the level of severity of schizophrenia patients then increased depression of caregiver of schizophrenia patients. That otherwise known as bipolar disorder that can cause one's mood to rise or fall. These are the symptoms of depression in caregiver of schizophrenia patients' sadness, loss of interest, hopeless, worried, being easily frustrated, irritated, eating too little and too much that may be weight loss and weight gain, insomnia, hypersomnia, having fatigue or low energy, difficulties in concentrating, problems remembering things and making decision. It affects how you feel, think, and behave and can cause a number of mental and physical issues. It is also known as major depressive disorder or clinical depression.

The prevalence of depression in the current study rate was 80.7%. Younger carers had a higher prevalence of depression, with 91.7% of those under the age of Twenty-five years had depression. Compared to male carers, who experienced depression at a rate of 78.9%, female carers had it at a rate of 82.3%. Compared to carers living in urban regions, where the incidence of depression was 76.4%, carers in rural areas had a greater prevalence of depression, or 83.2%. Divorced or widowed carers had a 100% prevalence of depression. Nuclear family carers had a high frequency of depression (94.5%), whereas those from joint families had a low prevalence (67.5%). Caregiver depression was present in 89.7% of uneducated carers and 73.2% of educated carers.

## **Caregiver burden effect on depression of schizophrenia patients**

Caregiver of schizophrenia patients always caregiving by caregiver, without caregiver caregiving can't possible. There are 24 hours duty no sick leave, pay checks and rewards in caregiving. The caregiver played an important role in caregiving to schizophrenia patients. The caregiver of schizophrenia patients often faced depression during caregiving. That is very critical condition for caregiver of schizophrenia patients. Depression is a psychological burden that is very harmful to caregiver of schizophrenia patients. Most of the time depression effect on day-to-day life of caregiver of schizophrenia patient because other burden like financial, physical, social, educational, effect on depression.



### **Relationship between caregiver burden of schizophrenia patients and depression**

Lokesh Kumar Ranjan et al., in (2022) Psychological state like depression that comes from a combination of emotional, physical work, financial, social pressure that increased from caring schizophrenia patients. Caregiver of schizophrenia patients they have deducted their important time to caregiving with schizophrenia patients. Therefore, restricted from personal space, social activities, and freedom of family members therefore increased burden. Caregiver may lead depression through suffering from physical, emotional, and financial difficulties. Depression is a sign of an emotionally suffering condition that refers from psychological distress. These signs can include feelings of sadness, tearfulness, emptiness, hopeless, for caregiver of schizophrenia patients, angry outbursts, irritability, frustration on small matters of the caregiver of schizophrenia patients, loss of interest, pleasure on all small things, sleeping too much, sleep disturbances, including insomnia, tiredness, lack of energy, on small activity takes extra effort, reduced appetite, and weight loss and increased craving for food and weight gain of caregiver of schizophrenia patients. Some previous study was conducted on depression that prevalence of depression ranged was 29.4% to 100% of caregiver of schizophrenia patient. Some of Indian study was found that higher level of psychological distress in caregiver of schizophrenia patients. Result of the recent study depression was showing a positive relationship between caregiver of chronic schizophrenia patient by Ranjan et al., 2022.

### **Research Gap**

The literature reviews also have indicated that many authors have conducted research among caregiver of schizophrenia patients in India and other countries but have not done so in Odisha yet. Heavy burden of care was shown in maximum reviews that affected day to day life of caregiver in schizophrenia patients. It is a big challenge for caregiver of schizophrenia patients to care every day, that leads objective and subjective burden. Objective burden like disturbing patient behaviour, Economics problem and subjective burden like Anxiety, Depression, and caregiver burden. Burden of care of caregiver of schizophrenia patients are hampering in their duties like office work, family's responsibility, entertainment, time spend with friends and exempted to live a quality of life.

## Objectives

1. To analyse the anxiety of the caregiver of schizophrenia patients
2. To assess the depression of the caregiver of schizophrenia patients
3. To assess the perceived burden of caregiver of schizophrenia patients

## Methodology

The review was done using the databases and search methods from Scopus, Web of Science, EBSCOhost, PubMed, Ncert, Sudhganga and ERIC, Google Scholar searches were also conducted. A few of the search terms and phrases used when looking for carers of schizophrenia patients were anxiety, depression, perceived load, and quality of life. Before being included in the evaluation, the collected articles were checked for substance and clarity. Using the "snowball" approach, which entailed looking for relevant articles that were cited in the most recent works, additional papers were discovered. The main objectives, methodological framework, significant variables, sample data, and measurement tools of the included investigations are also displayed in this study.

## Discussion and Conclusion

This study has discussed a lot of reviews on anxiety, depression, and burden among caregiver of patients with schizophrenia. Result of the study showed that caregiver of schizophrenia patients was correlated with psychological and sociodemographic burden. We found that in previous study Inadequate social support, economic hardship, the presence of a chronic physical disorder in the carers, patient violence towards the carers, total illness duration, the number of hospitalisations, Positive and Negative Symptoms (PANNS) total and subscale scores, Social Functioning Scale (SFS), Back Depression Inventory (BDI), and Back Anxiety Inventory (BAI) scores were all associated with carer Perceived Family Burden Scale (PFBS) scores. Male patients and female carers were also associated with carer Perceived Family Burden Scale (PFBS) scores. The severity of the patients' positive symptoms, the scores on the Social Functioning Scale (SFS) subscales measuring independence/competence and interpersonal functioning, and the carers' levels of anxiety and sadness were all found to be predictive of perceived burden of care by (Leyla Gulseren et al., 2010). According to the study's findings, carers of schizophrenia patients experienced a significant level of care strain (70.8%).



The majority of the carers (59.2%), reported experiencing extreme levels of stress, anxiety, and despair (48.5%). According to the study's findings, stress, anxiety, and depression among those who care for chronic schizophrenia patients are significantly positively correlated with the burden of family care by (Lokesh Kumar Ranjan et al., 2022). Strong positive and significant relationships between the burden of caregiving and issues including stress, anxiety, and depression have been found by (I Kadek Suaryana et al., 2020). It was estimated that 37.7% of carers had depressed symptoms. Having more social support was inversely correlated with having fewer depression symptoms. The carer load had a role in mediating this association, with higher levels of carer burden having a negative correlation with depressed symptoms. A significant increase in depressed symptoms was also observed by carers who were female, provided care for a long period of time, and had poor health by (Yaqin Zhong et al., 2020). 80.7% of primary carers of individuals with schizophrenia reported having depression overall. A high rate of depression was seen among carers who were younger, female, from rural areas, widowed or divorced, residing in nuclear households, lacking education, performing domestic or agricultural tasks, and who were parents of the patient by (Rameshwar S Manhas et al., 2017). As a result, the findings of the present systematic review may help to define and further define the family carer burden, anxiety and depression in schizophrenia patients as well as its many characteristics.

We have considered in this review on psychological functions and care burden how experienced in carers of schizophrenia patients. Result of some studies were shows that, carers of schizophrenia patients experienced high level burden of care. Anxiety and depression were positively correlated with burden of care of schizophrenia patients. Result of fewer studies were shows that, higher burden of care of caregiver of schizophrenia. female caregivers were significantly higher level of psychological distress than male. Maximum number of studies were suggested that intervention may help to reduced psychological distress and burden of care of caregiver of schizophrenia patients.

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