

## Editorial

### **Caring For Older Caregivers: Managing Depressive Symptoms and Stress among Family Caregivers of Persons with Severe Mental Illnesses (PwSMI)**

**Running title:** Caring for Older Family Caregivers

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**Abstract:** The global rise in mental health issues, with approximately 970 million people affected, has contributed to a significant burden on caregivers, particularly those supporting Persons with serious mental illnesses (PwSMIs) such as depression, anxiety, and schizophrenia. In India alone, 197.3 million people suffer from mental disorders, with depression being the leading contributor to the disease burden. Caregivers, often family members, provide essential emotional and practical support, but this responsibility is accompanied by considerable stress and depressive symptoms. The emotional, physical, and financial toll of caregiving leads to a phenomenon known as caregiver burden, which can severely impact the well-being and quality of life of those involved, particularly older caregivers. Cultural factors, particularly in South and Southeast Asia, influence caregiving roles and can either alleviate or intensify stress. Coping strategies play a pivotal role in mitigating this burden, with maladaptive coping linked to negative outcomes for both caregivers and patients. Effective interventions, such as psycho-education, community support, and healthcare system resources are essential to reduce caregiver burden and improve the care provided to individuals with SMIs. Addressing caregiver needs is crucial for enhancing both caregiver health and patient recovery outcome.

**Keywords:** Caregiver Burden, Depression, Mental Health, Older family caregivers, Person with severe mental illness.

## Introduction

The incidence of mental illness is rising at an alarming rate globally, with a corresponding proportional rise in the burden of care among caregivers of those who are mentally ill. Mental health issues affect 1 in every 8 people, making them one of the leading contributors to the overall disease burden<sup>[1]</sup>. In fact, about 970 million people worldwide are living with mental or behavioral disorders[1]. Depression, in particular, accounts for the largest share of the global disease burden, making up 4.3% of it, and is one of the primary causes of mental illness around the world. On top of that, nearly 30% of people across the globe experience mental health challenges each year. In India 197.3 million (95% CI 178.4–216.4) people had mental disorders as of 2017[1]. Among Severe Mental illnesses, the overall prevalence of both depression and anxiety disorders was 3.3%. Specifically, depressive disorders had a prevalence range of 3.1% to 3.6%, and anxiety disorders ranged from 3.0% to 3.5%. In comparison, bipolar disorder had a prevalence of 0.6% (ranging from 0.5% to 0.7%), while schizophrenia was less common, with a prevalence of 0.3% (ranging from 0.2% to 0.3%)[2].

Serious mental illness (SMI) are categorised as a mental, emotional, or

behavioural condition that results in significant difficulty in functioning, making it hard to carry out everyday activities. People with SMI often face major challenges in their daily lives due to the impact of their condition. Around 90% of people with serious mental health conditions receive daily practical and emotional support from family caregivers [3]. However, many of these caregivers endure considerable psychological stress and are overwhelmed by the demands of caregiving, often due to their lack of preparation for the role as informal caregivers. A study on the prevalence of mental distress in caregivers of people with mental illnesses in Ethiopia found that 56.7% of caregivers experienced depression, indicating a high rate of mental distress among people who care for individuals with severe mental illness[4]. The need and obligation of caregiving significantly impact the caregiver's health, work, social life, and relationships, often resulting in feelings of unhappiness and dissatisfaction[5,6]. Experiencing mental distress and taking on the responsibilities of caring for a family member with a mental illness not only negatively impacts the caregiver's well-being and quality of life, but it also lowers their productivity and capacity to provide effective care, which can worsen the person's health and reduce

the likelihood of recovery or improvement[1].

### **Depression Symptoms and Stress among Older Family Caregivers**

In cultures like India and other South and Southeast Asian societies, informal caregiving is common, with family members, especially the elderly, taking on caregiving roles (An informal caregiver normally is a person who provides some type of unpaid, ongoing assistance with activities of daily living (ADLs) or instrumental activities of daily living (IADLs) to a person with a chronic illness or disability[7]. The concept of filial piety[8], which emphasizes family duty and respect for elders, deeply influences the caregiving experience in these regions. This cultural backdrop may both alleviate and intensify caregiver stress and the emergence of depressive symptoms, depending on individual circumstances and social expectations.

Family caregivers, are relatives who provide unpaid care and support to individuals with severe mental illness, regardless of whether they are the primary or secondary caregivers and are often older adults, typically aged 45 years and above. In many cases, these caregivers are between 45 to 60 years of age, with an average age

around 40 years[7,8]. Caregiving responsibilities can take a significant toll on their mental health and overall well-being.

In India, where mental health services and support systems may be limited, the burden on older family members as caregivers is even more pronounced. When older adults, often with their own health issues and aging-related challenges, are tasked with the responsibility of providing long-term care to individuals with serious mental health conditions, it can lead to a deterioration in their own mental health. This can manifest in depression, stress, anxiety, and burnout.

The mental and emotional toll on these caregivers is compounded by social, financial, and physical strain[9], as they often lack formal support systems or respite care. As the caregiving role progresses, it can severely impact the caregiver's quality of life.

Hoenig and Hamilton were the first to introduce the concept of burden, suggesting that it can be categorized into 'subjective' and 'objective burden'. Where, subjective burden mainly refers to the emotional experiences of caregivers while fulfilling their caregiving duties, whereas objective burden is characterized by events or activities associated with negative aspects

of caregiving[10]. Zarit, Reeve, and Bach-Peterson defined burden as "the degree to which caregivers perceive their emotional and physical health, social life, and financial situation to be affected by caring for a family member". Additionally, they viewed burden as resulting from a specific, subjective, explanatory process[11]. Collins et al.[12] described caregiver burden as encompassing mental distress, physical health problems, financial and social challenges, strained family relationships, feelings of hopelessness, and other adverse consequences of caregiving. Nijboer et al.[13] suggested that caregiver burden is a multifaceted concept that includes both positive and negative aspects of caregiving.

### **Causes, Coping Mechanisms and Outcomes**

Caregiver stress is significantly influenced by the self-perception of caregiving burden, which can vary widely among caregivers. Bhattacharjee et al.[14] define caregiver burden as the positive or negative feelings and perceptions that caregivers have related to their caregiving responsibilities. A study by De Korte-Verhoef et al[15] using a mixed approach found that although over 50% of the caregivers experienced high levels of burden, only a quarter of them

reported that this burden adversely affected their daily lives. This indicates that while caregivers may experience high levels of stress, they do not always perceive it as detrimental to their quality of life.

The relationship quality between the caregiver and the care receiver also plays an important role in determining the caregiver's burden. Positive, supportive relationships can reduce stress, while conflicts and overburdening caregiving responsibilities may increase stress. Caregiver role overload, where caregiving duties extend beyond reasonable limits, can lead to emotional strain and burnout.

Another critical determinant is the duration of illness and caregiving. Chronic caregiving, particularly when the care recipient's condition does not improve, increases stress over time. As caregiving becomes more prolonged, caregivers may experience social isolation, withdrawing from social activities, and developing higher levels of anxiety and depression. The constant responsibility of caregiving, along with the worry about the patient's well-being, negatively affects the caregiver's quality of life[16], leading to greater vulnerability to mental health issues.

Family members, as the primary caregivers for individuals with mental illness, often

encounter societal stigma, shame, and prejudice. These negative perceptions of the behaviours associated with mental illness contribute to the social isolation of caregivers, diminishing their social interactions and support networks. This social exclusion has a detrimental impact on the caregivers' mental health, exacerbating their stress.

Stress is also significantly influenced by the sociodemographic characteristics of carers, including age, gender, socioeconomic level, and education. Although there is still no clear correlation between age and quality of life (QoL), female carers typically report worse QoL because of their conventional family responsibilities. Similarly, caregivers of individuals with schizophrenia often report a lower QoL compared to those caring for people with other conditions. Financial struggles, lower education, and unemployment contribute to elevated stress and poorer well-being. [9]

The patient's condition also impacts caregiver stress. More severe disease symptoms, such as psychosis, mood instability, or aggressive behaviour, increase the caregiving burden. Caregivers must manage these challenging behaviours, including suicidal attempts, which can lead to a heavier emotional and physical load,

exacerbating the caregiver's distress. In sum, caregiver stress is multifactorial, influenced by personal, relational, and contextual factors, with both caregiver- and patient-dependent determinants shaping the caregiving experience.

Caring for persons with severe mental disorders, such as schizophrenia or bipolar disorder, presents significant challenges for caregivers. As the demands and responsibilities associated with caregiving continue to rise, there is growing concern about caregivers' ability to effectively manage or cope. Coping can be understood as the continuous cognitive and behavioural effort individuals exercise to handle external or internal demands that are believed to be overwhelming or beyond their available capacities.

Lazarus and Folkman[17] describe 'coping' as the process by which an individual responds and takes action in response to stress, especially when the intensity of stress increases. Their theory classifies coping strategies into emotion-focused and problem-focused types[18]. While problem-focused coping tries to directly address and resolve the stressful situation by addressing or removing the source of stress, emotion-focused coping incorporates techniques meant to lessen the negative emotional impact of stress.[19].

Additionally, people may adopt either adaptive or maladaptive coping strategies to manage stress. It was discovered that techniques like active coping, acceptance, positive reframing, religion or spirituality, social support, positive life growth, and reinterpretation were positively correlated with less discomfort. On the other hand, strategies such as self-blame, avoidance, and mental disengagement were positively correlated with higher levels of distress[20]. For instance, Rammohan et al<sup>[21]</sup> found that caregivers' denial of the circumstances was a significant predictor of caregiver burden, leading to total exclusion of their family members with mental illness and their eventual referral to psychiatric services. Grover and Pradyumna[22] emphasize that caregivers' coping strategies may have an influence on patient outcomes, including relapses, hospital readmissions, and overall reduced quality of life. Thus, developing effective and adaptive are not only crucial for the health outcomes of the caregiver but also dictate the quality of care that will be received by the Persons with severe mental illness (PwSMI).

All these stressors experienced by carers along with using maladaptive and emotion-focused coping may lead to poor psychological health outcomes for the caregivers. Reports show that carers are

twice as likely to have depressive symptoms compared to non-carers[23]. When caregivers have significantly depressed moods, it can negatively impact their ability to maintain their own health and care for themselves. Research indicates that family caregivers often face more physical and emotional distress than those in the same age group who aren't caregivers. Many studies suggest that caregivers are at a higher risk of developing clinical depression, with some showing that nearly half of caregivers meet the criteria for depression when assessed through structured clinical interviews. There's also evidence that the caregiving role itself can contribute to depression. For example, a study by Dura et al[24] found that nearly a quarter of caregivers developed depression while taking on caregiving responsibilities, even though they had never been diagnosed with depression before. It's clear that when the person being cared for exhibits more challenging behaviours or greater functional impairments, the caregiver experiences higher levels of strain, which in turn increases the likelihood of depression.

### **Caring for Caregivers- Some Recommendations**

To address the burden on caregivers (especially the older ones) and improve

outcomes for both patients and caregivers, several recommendations can be made, from personal, community level and health system based changes.

The caregivers need to be trained in better coping mechanisms with focus on problem focused coping. In addition, the implementation of psycho-education and counselling services within mental health settings is essential. These programs help caregivers understand the nature of mental illnesses like schizophrenia, its prognosis, and how to cope with relapses. Studies have shown that psycho-educational programs significantly improve caregivers' knowledge, coping skills, and the patients' overall functioning. Such programs are particularly important in regions with limited awareness or high levels of illiteracy, where caregivers may struggle to understand the mental health issues at hand. Providing caregivers with access to social supportive networks, including peer support groups, can significantly mitigate their burden. Research indicates that participation in peer support groups allows caregivers to share their experiences, learn coping strategies, and feel less isolated in their caregiving roles. These groups not only benefit caregivers' emotional well-being but also positively affect the mental

health and functioning of the patients they care for[25].

There is a pressing need for public education to reduce stigma and fear toward people with mental illnesses, particularly those with schizophrenia. Raising public awareness of mental illness, its signs, and the difficulties that sufferers and carers encounter can promote acceptance and lessen rejection. This will not only alleviate the pressure on caregivers but also improve the social integration of patients.

Strengthening community-based mental health services is crucial. These services can support both caregivers and patients by offering accessible resources and guidance within the community. Research by Roick and colleagues[26] has shown that the use of community health services reduces caregivers' burden while improving patient health outcomes.

Clinical interventions should not only focus on the patient but also address the needs of the caregivers. The healthcare system must expand its support to caregivers, offering resources, training, and counselling to aid them in managing the demands as well as the challenges of caregiving. This approach would help reduce the incidence of caregiver burnout and improve the overall

quality of care provided to individuals with serious mental illness.

Caregivers should be considered an essential cog of the care team. They are essential in helping their loved ones with mental illness maintain their independence while negotiating the difficulties presented by the healthcare system. Ensuring that caregivers are supported and communicated with by healthcare providers can significantly reduce the strain they experience.

### **Conclusion**

For elder family members who frequently assume this taxing task, caring for a loved one with a severe mental illness is both a noble and difficult duty. There is an urgent need to provide them with genuine support because of the tremendous emotional, physical, and social hardship they endure. We can lessen the strain on carers by assisting them in creating strong peer and community support networks, lowering the stigma associated with mental illness, and assisting them in developing efficient coping mechanisms. It is more crucial than ever to acknowledge carers as essential collaborators in the healing process. We can guarantee that carers enjoy better, more satisfying lives in addition to improving the quality of care for individuals with mental

illness by putting their well-being first and giving them the tools they require.

### **Conflict of Interest**

Nil.

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