

### Need for Financial Capability Assessment among family caregivers of Person with Severe Mental Illness

**Running Title:** Need for assessing financial capability in family caregivers.

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#### Abstract

This editorial discusses the significant impact on caregivers, emphasizing the chronic nature of severe mental illnesses like schizophrenia, bipolar disorder, and major depression and the challenges faced by individuals with limited income in India. The editorial underscores the importance of financial capability in family well-being and calls for more research to inform policy recommendations for economically disadvantaged individuals. It also addresses the practical and ethical importance of addressing financial capacity issues in people with severe mental illness, noting the vulnerability to financial exploitation. The editorial concludes by emphasizing the need for a more comprehensive understanding of the financial challenges faced by family caregivers supporting individuals with severe mental illness.

**Keywords:** Financial capability, Family caregivers, Person with severe mental illness, Mental Health.

#### Introduction

Mental illnesses are increasingly prevalent globally and represent a significant contributor to the global burden of disease. Severe mental illness (SMI) is considered a non-affective or affective disorder with psychotic features. Conditions such as schizophrenia, bipolar affective disorder, and major depression fall under the category of SMI. The impact of SMI on caregivers is substantial due to specific characteristics that distinguish these conditions. Firstly, they typically follow a chronic course with intermittent relapses. Research indicates that 30% to 50% of psychiatric patients, particularly those with SMI, may experience a recurrence of symptoms within the first six months and 50% to 70% within the first five years post-hospital discharge. Secondly, SMI has a profound effect on patients, leading to

significant impairment in one or more areas of functioning, contributing significantly to "years lived with disability" (YLD) as a measure. Thirdly, continuous, long-term care is often necessary for individuals with SMI, with approximately 10% requiring extended care. As a result of these SMI characteristics, caregivers bear a considerable burden.

Financial capability (FC) refers to individuals' capacity to make informed and beneficial financial decisions. Globally, those with lower incomes often face challenges in achieving sufficient FC. In India, individuals with limited income experience a lack of FC primarily due to restricted opportunities for earning, saving, borrowing, and investing. Additionally, their inadequate financial knowledge and skills contribute to this deficiency in FC. Research on the financial knowledge and skills of income-poor individuals in India is currently

insufficient. The ability to earn, save, borrow, and invest, coupled with the skillful understanding and management of one's finances, plays a crucial role in family well-being. Effective policy recommendations to improve the FC of economically disadvantaged individuals in India necessitate substantial research evidence.

Challenges related to financial capacity frequently arise in the context of PwSMI, and addressing these issues holds practical and ethical importance for the clients themselves, their families, and mental health professionals. Individuals with severe mental illness face a heightened vulnerability to having others directly take or misappropriate their disability payments. Severe mental disorders generally follow a chronic course marked by episodic exacerbations and remissions, accompanied by varying degrees of disability. In both exacerbations and remissions, family members are frequently involved in caring for individuals with severe mental illness. Unfortunately, the burden on these family members tends to be underestimated. Numerous studies explore the challenges of informal caregiving in the context of severe mental illness, depicting a complex scenario with various measurable adverse outcomes for the informal caregiver. These consequences include reduced productivity, financial burdens, and restrictions on personal activities'. There was little or minimal coverage of the surveys of family caregiver's attitudes, knowledge, or skills about money management.

### **Severe mental illness and financial management**

The term "severe mental illness" encompasses mental and emotional disorders that significantly disrupt the fundamental aspects of individuals' lives, such as self-care, employment, and interpersonal relations. It can also be defined diagnostically, encompassing a diverse range of psychiatric diagnoses within this population. This includes conditions like schizophrenia, affective disorders, personality disorders, and various others. The term "severe mental illness" denotes a mental health diagnosis, typically associated with psychosis, that

necessitates extensive inpatient and outpatient treatment and results in significant disability across one or more major life domains. Severe mental illnesses (SMI), such as schizophrenia and bipolar disorder, frequently lead to substantial impairments in the cognitive abilities and decision-making capacities of those affected. Financial capacity is frequently compromised in individuals with SMI. Many individuals with schizophrenia, although not universally, struggle to acquire basic financial skills and experiences. This challenge arises from the onset of their illness in early adulthood, the adverse developmental effects of both positive and negative symptoms, and the unfortunate impact on neurocognition associated with the disease. The consequences of these impairments in financial capacity can be profound, often resulting in devastating outcomes. Problems related to financial capacity in schizophrenia also extend to impact family members and relationships. Money mismanagement is a common issue among individuals with severe mental illnesses, whose conditions compromise their cognitive abilities, judgment (especially during episodes of mania or psychosis), and ability to resist financial exploitation. Money mismanagement by individuals with schizophrenia is a significant worry for family members, and the question of control over funds can frequently become a contentious issue involving clients, families, and government agencies. Consequently, financial capacity often takes center stage in the assessment, treatment, and rehabilitation of clients dealing with schizophrenia and severe mental illness.

### **The burden of the family caregiver of a Person with Severe Mental Illness**

Family carers find that providing long-term and difficult care for individuals with mental illness (PWMI) is especially difficult for severe disorders such as bipolar disorder, major depression, and schizophrenia. Family carers are defined as any member of the family who provides unpaid care for a PWMI, regardless of whether they are the primary or secondary carer".

Family members are the most crucial players

in patient care and readmission prevention. A significant proportion, ranging from 60% to 85%, of individuals with mental health issues receive care from their family members. This trend is observed not only in developed but also in developing countries, where family members often take on the responsibility of caring for their mentally ill relatives .

The dynamic process of caregiving involves both the patient and the carer for the patient's long-term needs. While cultural differences exist in caring for others, research indicates that carers often face significant psychological, physical, and financial strain. Giving care for a patient with a severe mental illness foreshadows a detrimental effect on the caregiver's quality of life since caring for people with chronic diseases often demands unceasing effort, energy, and empathy. First-degree relatives inside the family are more likely to provide care and may be more responsible than distant relatives. Family members' possessions, income, and savings are put at risk when they get a life-threatening diagnosis, such as SMI and cancer. Even for families covered by health insurance, medical procedures might be expensive. Families may face significant out-of-pocket costs in the case of a catastrophic or life-threatening disease. These costs may include large insurance co-pays or deductibles, as well as costs for items needed for care that are not covered by health insurance. In addition, patients and family carers frequently take unpaid leave or quit their jobs as a result of the effects of disease. Serious illnesses like SMI frequently put patients and their families in a difficult financial situation because of high out-of-pocket costs, additional medical and non-medical costs, income loss due to declining functional status, inability to keep job and health insurance for the patient, and, in a similar vein, loss of productivity at work and potential earnings for the primary family carer .

Family members undertake all the responsibilities of the work that the patient is unable to perform due to their acute illness. In addition, the family members take on the duty of overseeing the medicine, deciding on the course of treatment, including which doctor to contact and which medications to take, as

well as transporting the patient to the hospital and reintegrating them into society. Families attempt to accommodate the patient in conventional family occupations when daycare and rehabilitation facilities are unavailable. As a result, family members play a crucial role in helping people with mental diseases .

Among carers of people with mental and non-mental illnesses, there is a greater frequency of depression or anxiety and poorer quality of life (QoL) ratings associated with lower socioeconomic level, lower education, unemployment, or financial difficulties. The sickness of a family member causes close relatives a great deal of stress. Stress related to mental disorders and Financial Burden are influenced by both objective and subjective problems (e.g., the effect of an illness on the health of other family members, the ability to meet their needs, and the financial results for the family, or on the other hand, a feeling of burnout or anxiety from providing excessive care). A family's capacity to adjust to a challenging circumstance involving a member with a mental illness is contingent upon the resources available to that individual as well as the rate at which psychopathological symptoms emerge". Taking on more caregiving duties for a patient with SMI may put more strain on them, particularly if they are already struggling financially. In addition to being financially burdensome for the carer, carers with a history of financial hardship, particularly in the context of a weak social support system, may find it challenging to manage the financial consequences of a chronic SMI. This is because it often indicates that the patient will not take their medication as prescribed, which will inevitably result in subpar treatment outcomes and increase the caregiver's burden .

### **Need for Financial Capability Assessment among family caregivers of PwSMI.**

Reintegrating Person with Mental illness into society and their family carers requires several sophisticated factors to consider. For instance, to help families cope with challenging circumstances like unsettling, odd, or violent behaviours, professional

education is necessary. Given that Person with Mental illness's professional and vocational duties are compromised, financial or social help should be given". The unmet needs that carers of patients with mental illnesses most frequently expressed were those for food, transportation, personal connections, money, psychological distress alleviation, welfare benefits, and information about the condition and treatment. Carers of chronically ill patients, such as those with SMI, experience an immense psychological, financial, and social burden. Government and private organizations must adopt the proper strategies to mitigate the psychological, financial, and social strain on the carers of these children with chronic illnesses. The caregivers of persons with SMI suffer enormous emotional, physical, and financial burdens, and the need to increase the knowledge base in this regard, especially in India, is imperative to assess the burden of care and identify caregivers' needs as reported by them. This is an essential first step towards prompting appropriate intervention by relevant stakeholders in reducing caregivers' burden, enhancing support, and achieving the treatment goals for the patients. An assessment of the financial capability of the family caregivers of PwSMI can help to understand the flaws in their financial management in terms of giving care to the PwSMI. It can be used to develop a solution to enhance their financial capability, for example, a training package for enhancing the financial capability of the family caregivers of PwSMI. If successful, initiatives to enhance financial capability would benefit from reducing health inequality between rich and poor and improving the health of those targeted. Therefore, the need to assess the financial capability of the family caregivers of PwSMI is definite.

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