

The Shadows of Stigma and Social Isolation among Caregivers of Patients with Mental Illness

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Abstract

Mental illness affects not only the individuals diagnosed but also profoundly impacts their caregivers, who often face stigma and social isolation. Caregivers play a crucial role in providing emotional, physical, and financial support, yet their own well-being is frequently overlooked. Stigma, arising from societal misconceptions and prejudices, can lead to feelings of shame, guilt, and discrimination, further isolating caregivers from their communities. This isolation can strain their mental health, reduce social interactions, and limit access to support systems. Understanding the stigma and social isolation caregivers face is essential for fostering a more compassionate, informed society and improving mental health care outcomes.

Objectives: The main objectives were to assess the level of stigma and social isolation among caregivers of mentally ill patients, correlations between these variables, and examine their associations with selected sociodemographic factors.

Materials and Methods: Conducted at the Institute of Mental Health, Chennai, the research employed a quantitative, non-experimental descriptive design with a sample of 60 schizophrenia patients selected through non-probability consecutive sampling. Data were collected using Socio-Demographic Data and validated tools, including the Affiliate Stigma Scale and BRI Isolation Scale Tool, and analysed with IBM SPSS software.

Results: The study revealed that Among 100 caregivers of patients with mental illness, stigma levels revealed that 30% experienced mild stigma, 35% moderate stigma, and 25% severe stigma. Social isolation levels indicated that 24% had low isolation, 55% had moderate, and 21% had high isolation. A strong correlation ($r=0.98$) was found, suggesting that increased stigma relates to higher social isolation. Employment status, caregiving duration, healthcare access, and income showed higher stigma scores, while gender correlated with increased social isolation. Statistical significance was assessed using the

chi-square test, highlighting critical demographic influences on stigma and isolation levels.

Conclusion: In conclusion, caregivers of individuals with mental illness often experience significant stigma and social isolation, impacting their emotional well-being and quality of life. Addressing these challenges through increased awareness, social support, and inclusive mental health policies is vital. Empowering caregivers with resources and reducing societal prejudices can enhance both their lives and the overall care for Patients.

Keywords: Stigma, Social Isolation, caregivers of Patients with mental illness.

INTRODUCTION:

“Caregivers of mentally ill patients are often invisible, unseen, and unheard. It’s time to break the silence.

Mental illness affects millions globally, ranging from depression and anxiety to more severe conditions like schizophrenia and bipolar disorder. While Patients struggle with the symptoms of their conditions, caregivers—often family members—face immense challenges in providing continuous support. Their role encompasses emotional, physical, and financial responsibilities, often without formal training. Despite the crucial part they play, caregivers’ needs and struggles are frequently overlooked in both clinical settings and broader societal discussions. The burden they bear can be overwhelming, especially when compounded by the stigma and isolation they may face due to their association with mental illness.

The stigma associated with mental illness stems from deep-rooted societal misconceptions, prejudices, and fears. Many people perceive mental health conditions as personal failings or signs of instability, leading to discrimination and marginalization. This stigma not only affects Patients but extends to their caregivers, who may be unfairly judged or blamed for their loved one's illness. In some cultures, mental illness is shrouded in shame, and families go to great lengths to conceal it, further isolating both Patients and caregivers.

The stigma faced by caregivers can lead to social isolation, as they may withdraw from social interactions to avoid judgment or discrimination. The demands of caregiving often leave them with limited time or energy to engage in social activities, further increasing their isolation. Friends, family members, and colleagues may also distance themselves, unsure of how to provide support or lacking understanding of the caregiver’s situation. This isolation can take a heavy toll on caregivers' mental and emotional health, contributing to feelings of loneliness, frustration, and helplessness, while also diminishing their ability to seek help or form support network.

NEED FOR THE STUDY:

The escalating prevalence of mental illnesses globally necessitates a deeper understanding of the challenges faced by caregivers, who play a pivotal role in the management and support of affected individuals. Despite their crucial contribution, caregivers often encounter substantial stigma and social isolation, factors that can significantly impair their well-being and effectiveness. A study by Smith et al. (2022) highlighted that a staggering 70% of caregivers experience social stigma, underscoring the urgency to address this issue. This study aims to fill a critical gap in existing research by comprehensively exploring the nature and extent of stigma and social isolation among these caregivers. By identifying the specific challenges they face, the study seeks to inform the development of targeted

interventions and support mechanisms. Moreover, understanding these dynamics is vital for shaping public health policies and societal attitudes towards mental health caregiving. Ultimately, this research aspires to enhance the quality of life for both caregivers and patients, fostering a more inclusive and supportive environment for mental health care.

Finally, focusing on the challenges faced by caregivers is crucial for developing a comprehensive approach to mental health care. Caregivers play a vital role in the recovery and support of individuals with mental health conditions, and their well-being is directly linked to the quality of care they can provide. By exploring the issues of stigma and social isolation, this study aims to contribute to the establishment of support systems that empower caregivers. Ultimately, enhancing caregivers' well-being will lead to better outcomes for both Patients and families, fostering a more supportive and healthy society overall.

MATERIALS AND METHODS:

The study would be conducted after approval of the Institutional Ethical Committee. In this study, using a non-probability Consecutive sampling technique, the researcher adopted a non-experimental descriptive research design with 100 samples. The duration of the study was 4 weeks. The study was conducted on caregivers of Patients with mental illness in IMH, Chennai-10. The researchers collected data using three main instruments: Socio-Demographic Data, Affiliate Stigma Scale and BRI Isolation. Participants' socio-demographic information, such as Age, Gender, marital status, educational status, Employment status, type of family, religion, Rural or urban residence, health care access, duration of caregiving, relationship and income level, was collected to provide a context for the study and identify any potential demographic factors that may influence the results. The reliability of the tool was assessed by using the Cronbach alpha method. These correlation coefficients were 0.82 very high and it is a good tool for assessing caregivers of patients with mental illness disorders.

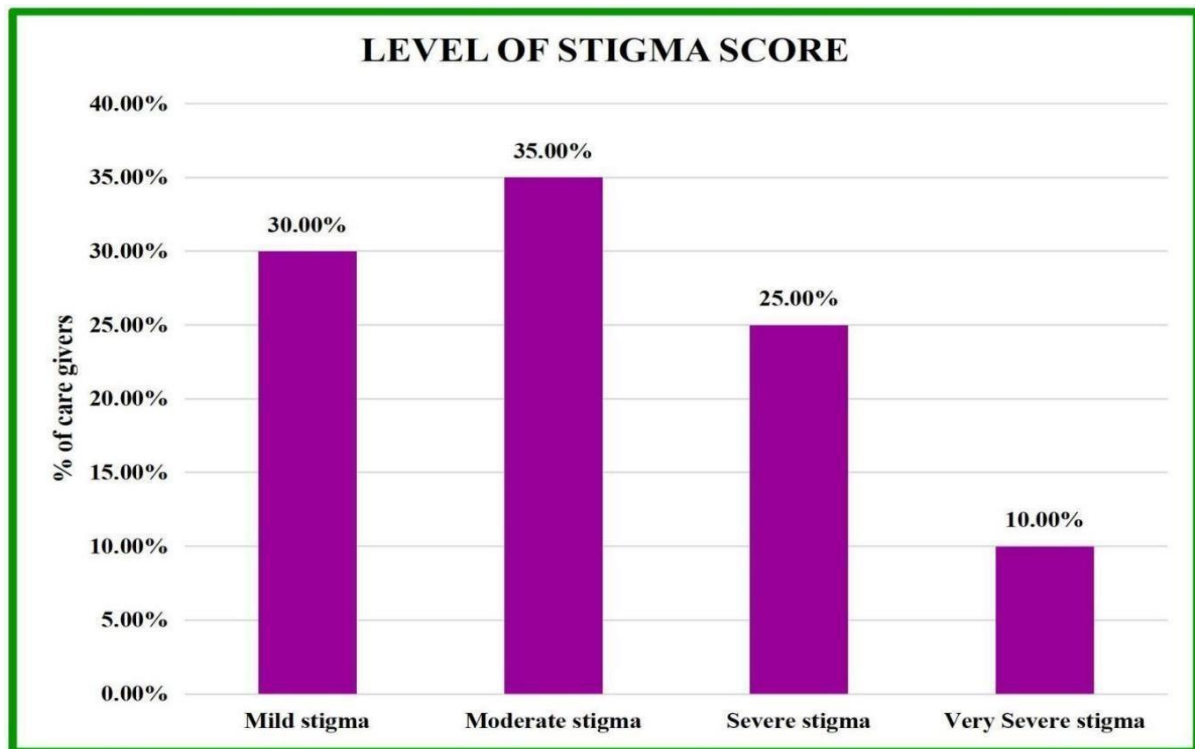
RESULTS:

MAJOR FINDINGS OF DEMOGRAPHIC VARIABLES OF CAREGIVERS OF PATIENTS WITH MENTAL ILLNESS.

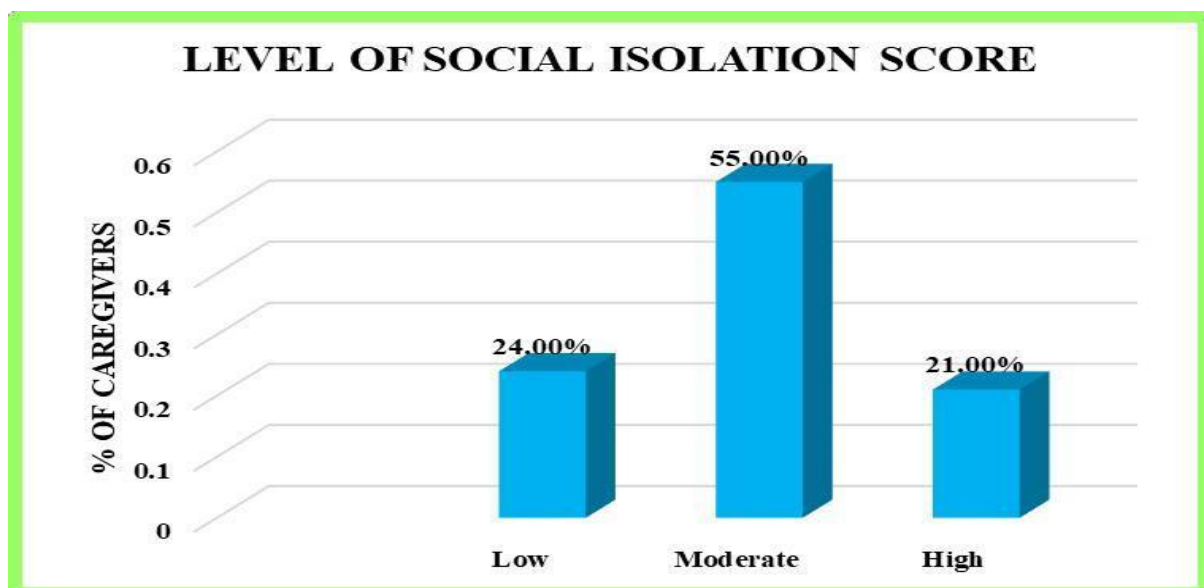
- ❖ A significant representation of age groups 26-35 years and 36-45 years (25.00% each).
- ❖ Female caregivers predominated at 55.00%.
- ❖ Married respondents made up 50.00% of the sample.
- ❖ Secondary education (25.00%) and higher secondary education (20.00%) were most common among caregivers.
- ❖ 30.00% of caregivers were employed in the private sector.
- ❖ Joint and nuclear families were equally represented (40.00% each).
- ❖ 50.00% identified as Hindu.
- ❖ 50.00% of respondents resided in urban areas.
- ❖ 40.00% reported easy access to healthcare; 25.00% indicated poor access.
- ❖ 40.00% had been caregiving for 1-3 years.
- ❖ Spouses (35.00%) and parents (30.00%) were the most common relationships to the care recipient.
- ❖ Income levels varied, with 30.00% earning between ₹10,001 to ₹25,000.

LEVEL OF STIGMA SCORE

The graph showed the level of stigma among caregivers of patients with mental illness. In general, the table shows the Stigma levels among 100 participants based on Affiliate Stigma scores. 30.00% had a mild stigma, 35.00% had a moderate stigma, 25.00% had a severe stigma and 10.00% had a very severe stigma.



LEVEL OF SOCIAL ISOLATION SCORE

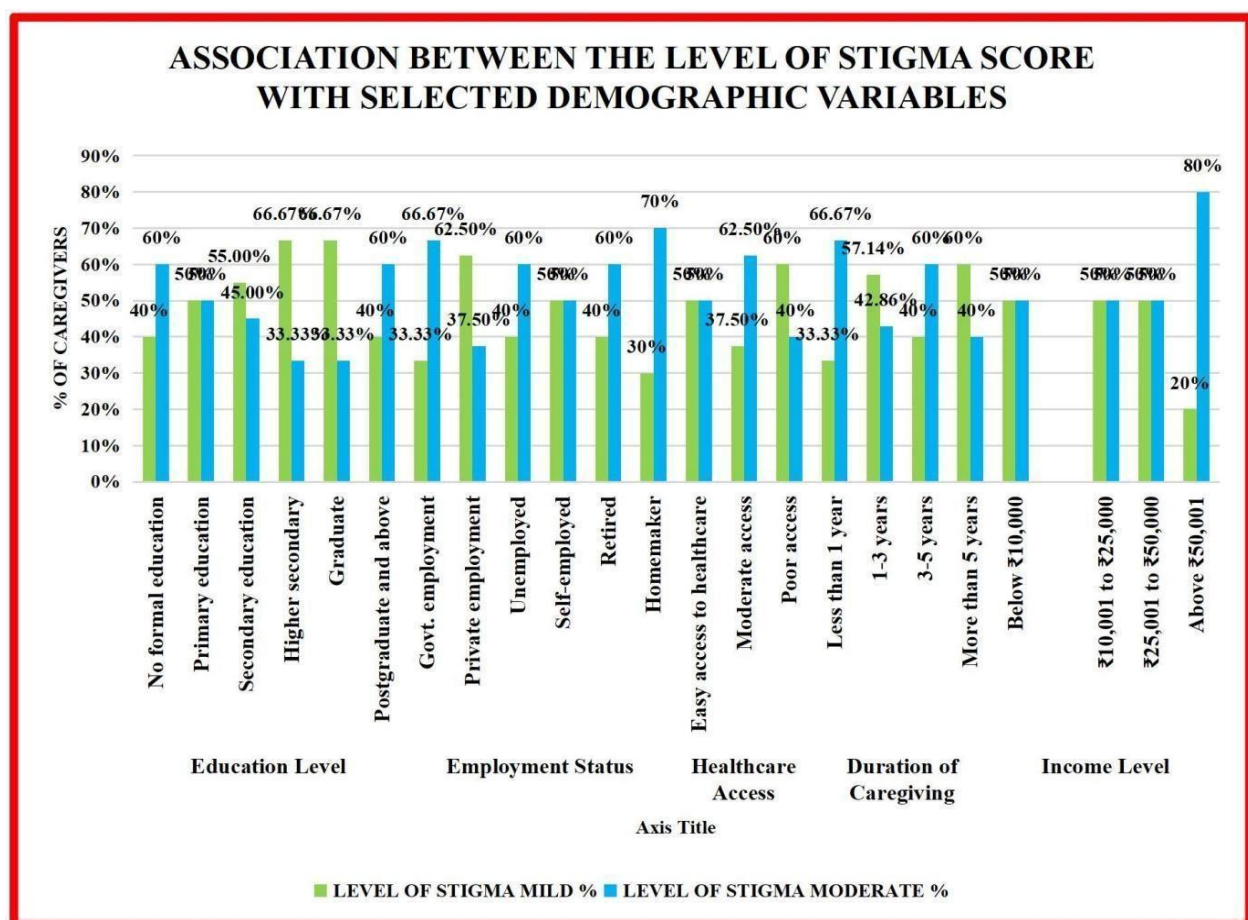


The graph shows the level of Social Isolation among 100 participants. 24.00% had a low level of isolation, 55.00% had moderate isolation, and 21.00% had a high level of isolation scores.

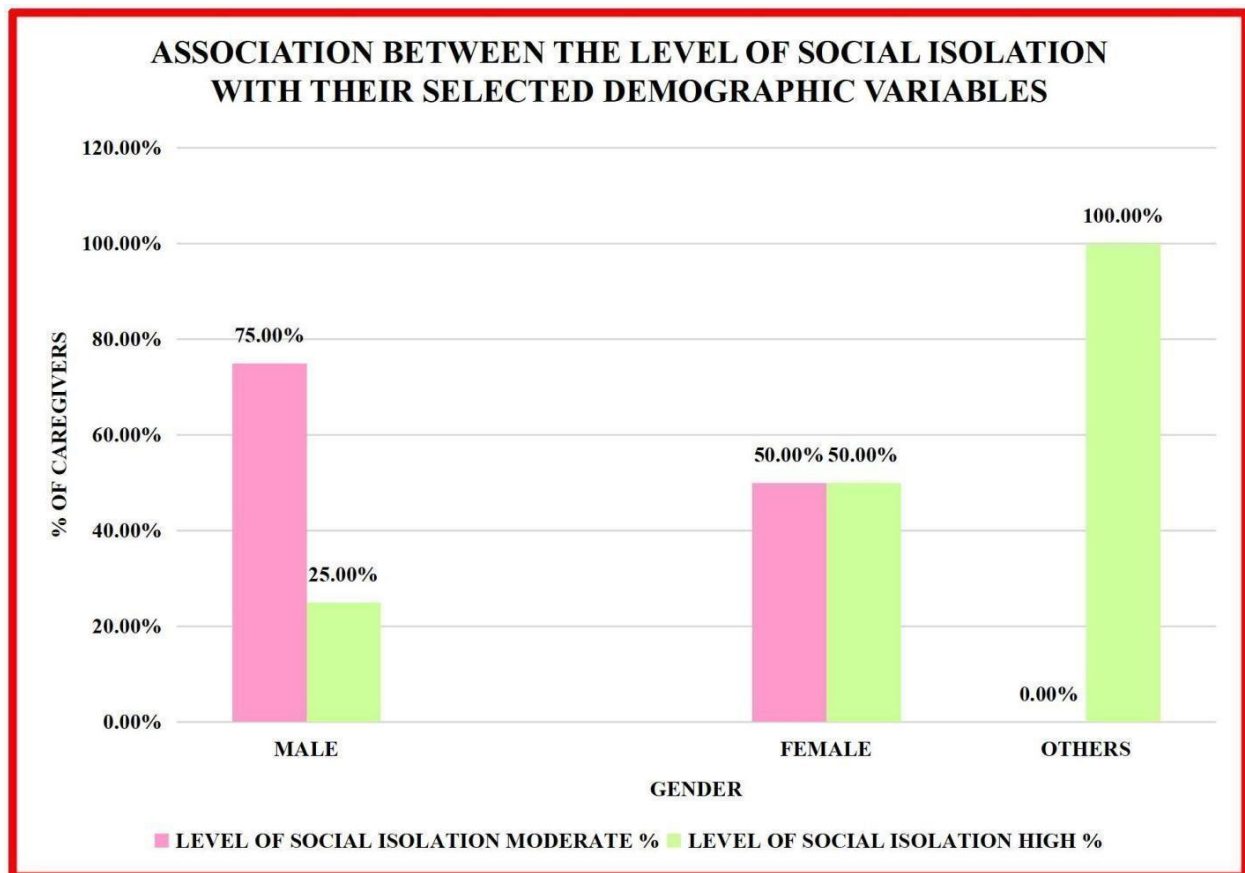
CORRELATION BETWEEN THE LEVEL OF STIGMA AND SOCIAL ISOLATION AMONG CAREGIVERS OF PATIENTS WITH MENTAL ILLNESS.

The correlation between the level of stigma and Social Isolation among caregivers of Patients with mental illness. The stigma scores increase, and the social isolation score scores also tend to increase($r=0.98$). This significant correlation suggests that higher levels of stigma are associated with high Social Isolation among the participants.

ASSOCIATION BETWEEN THE LEVEL OF STIGMA AND THE LEVEL OF SOCIAL ISOLATION AMONG CAREGIVERS OF PATIENTS WITH MENTAL ILLNESS WITH THEIR SELECTED SOCIO-DEMOGRAPHIC VARIABLES



The above table shows the association between the levels of Stigma among caregivers of Patients with mental illness with their selected demographic variables. Employment status, duration of caregiving, health care access, and income levels had more stigma scores than others. Statistical significance was analyzed using the chi-square test



The above table showed the association between the levels of Social Isolation among caregivers of Patients with mental illness with their selected demographic variables. Gender had more Social Isolation scores than others. Statistical significance was analyzed using the chi-square test.

DISCUSSION:

STIGMA AND SOCIAL ISOLATION:

Umesh G. et al. (2021) carried out a cross-sectional study to evaluate stigma among 100 caregivers of Patients with mental illness in Kanchipuram District, Tamil Nadu. Using the Family Interview Schedule stigma scale, they found a mean stigma score of 12.27 ± 9.43 , with 44% of caregivers reporting high stigma, 36% low stigma, and 20% zero stigma. Caregivers of psychosis Patients experienced significantly higher stigma compared to those caring for neurosis Patients. Significant associations were identified between perceived stigma and factors such as the Patients' duration of illness, diagnosis, and caregiver burden, highlighting the need for early interventions and routine mental health assessments for caregivers.

Guan, Poon, and Zwi (2023) implemented a scoping review to investigate social isolation and loneliness (SI/L) among family caregivers of individuals with severe mental illness (SMI). Analyzing 51 studies published between 2011 and 2021 across 18 countries, the review found consensus on the definition of loneliness, while definitions of social isolation varied. Risk factors for SI/L included sociodemographic elements, illness-related factors, health and well-being, and stigma. The review highlighted a lack of comprehensive measurement tools, few longitudinal studies, and limited knowledge of effective interventions. The authors recommend future research to fill these gaps and

develop targeted interventions for caregivers experiencing SI/L.

CORRELATION BETWEEN STIGMA AND SOCIAL ISOLATION

Kaggwa et al. (2023) conducted a cross-sectional study on the involvement and burden of informal caregivers of patients with mental illness, focusing on the mediating role of affiliated stigma among 428 caregivers in Uganda. Results indicated that affiliated stigma fully mediates the relationship between caregiver roles and involvement ($\beta=15.97$, $p<0.001$). Additionally, female caregivers experienced a greater burden ($\beta= -0.23$, $p<0.001$). The study concludes that addressing affiliated stigma in mental health care is essential to alleviating caregiver burden.

Above the discussion, the studies highlight the significant impact of stigma on caregivers of patients with mental illness, affecting their burden and social isolation, particularly influenced by demographic factors like employment, gender, and caregiving duration. Hence, Hypothesis 2 was accepted.

The study revealed that Among 100 caregivers of patients with mental illness, stigma levels revealed that 30% experienced mild stigma, 35% moderate stigma, and 25% severe stigma. Social isolation levels indicated that 24% had low isolation, 55% had moderate, and 21% had high isolation. A strong correlation ($r=0.98$) was found, suggesting that increased stigma relates to higher social isolation. Employment status, caregiving duration, healthcare access, and income showed higher stigma scores, while gender correlated with increased social isolation. Statistical significance was assessed using the chi-square test, highlighting critical demographic influences on stigma and isolation levels.

RECOMMENDATIONS:

- ❖ Employ diverse research methodologies (qualitative, quantitative, mixed methods) for comprehensive understanding.
- ❖ Ensure an adequate sample size for reliable findings.
- ❖ Formulate specific, measurable research questions or hypotheses.
- ❖ Consider longitudinal studies for insights on changes over time.
- ❖ Collaborate with professionals from various disciplines for enriched perspectives.
- ❖ Involve community stakeholders for relevant and applicable findings.
- ❖ Conduct pilot studies to identify potential design issues.
- ❖ Prioritize ethical considerations, including informed consent and participant safety.
- ❖ Leverage technology for efficient data collection and analysis.
- ❖ Use validated instruments to ensure quality measurements.
- ❖ Investigate factors influencing the implementation of evidence-based practices.
- ❖ Establish mechanisms for ongoing feedback to adapt and improve the research process.

CONCLUSION:

In conclusion, this study underscores the critical impact of stigma and social isolation on caregivers of mentally ill patients. These challenges not only hinder caregivers' mental health and well-being but also affect their ability to provide optimal care. The findings highlight the necessity for increased awareness and education about mental health to reduce stigma and promote support systems. Establishing support networks and resources for caregivers can alleviate feelings of isolation and empower them in their roles. By addressing these social dynamics, we can enhance caregivers' experiences and, consequently, improve the overall care of mentally ill patients.

Conflict of Interest – None

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