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Self Stigma and Burden Among Caregivers of Persons with Schizophrenia in Community: Cross Sectional Study

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ABSTRACT

Background: Caregivers of individuals with schizophrenia often experience significant psychological and emotional challenges, including self-stigma and caregiver burden. Understanding these phenomena is essential to develop supportive interventions.

Objective: This study aimed to examine the levels of self-stigma and caregiver burden among caregivers of persons with schizophrenia living in the community and to explore the relationship between these two variables.

Methods: A cross-sectional study design was employed involving 100 caregivers selected through purposive sampling. Data were collected using validated self-report questionnaires: the Self-Stigma of Family Members Scale (SSFS) and the Zarit Burden Interview (ZBI). Descriptive statistics and Pearson correlation analysis were conducted to assess the relationship between self-stigma and caregiver burden.

Results: The findings indicated that a majority of caregivers experienced moderate to high levels of both self-stigma and caregiver burden. A significant positive correlation was found between self-stigma and caregiver burden ($p < 0.01$), indicating that higher levels of self-stigma were associated with greater caregiver burden.

Conclusion: Self-stigma contributes to the burden experienced by caregivers of individuals with schizophrenia in the community. Interventions aimed at reducing stigma may help alleviate the psychological burden among caregivers and improve their well-being.

Keywords: self-stigma, caregiver burden, schizophrenia, community..

INTRODUCTION

Schizophrenia is a chronic and severe mental disorder characterized by disturbances in thought processes, perception, emotional responsiveness, and social interactions. Globally, schizophrenia affects approximately 24 million people, or 1 in 300 individuals (World Health Organization [WHO], 2022). In many low- and middle-income countries, including Indonesia, the care of individuals with schizophrenia often falls upon family members due to limited access to institutionalized mental health services and community-based psychiatric care (Suharsono, Marchira, Rahmat, 2020).

Family caregivers, such as parents, spouses, and siblings, play a pivotal role in supporting individuals with schizophrenia. Their responsibilities typically include monitoring medication adherence, managing behavioral symptoms, providing emotional support, and ensuring the individual's safety and social functioning. However, while caregiving can be rewarding, it often brings substantial psychological, emotional, and social burdens (Novak et al., 2021).

One of the most significant but often overlooked challenges faced by caregivers is self-stigma. Self-stigma, also referred to as affiliate stigma, occurs when caregivers internalize negative societal stereotypes and prejudices about mental illness (Corrigan & Miller, 2006). As a result, they may experience feelings of shame, guilt, embarrassment, and inferiority due to their association with a mentally ill relative (Moses, 2020). This internalized stigma can lead to social withdrawal, reluctance to seek help, and decreased psychological well-being.

Several studies have demonstrated that self-stigma negatively affects caregivers' mental health, increases stress, and reduces their overall quality of life (Chang et al., 2023; Ma et al., 2023). In some cultures, including those in Asia, mental illness is often attributed to supernatural causes, moral failure, or family disgrace, which further intensifies stigma (Suharsono et al., 2024). Caregivers may hide the illness, avoid social interactions, and suffer in silence due to fear of judgment, discrimination, or exclusion.

Caregiver burden encompasses the physical, emotional, financial, and social stress experienced as a result of caregiving duties (Zarit et al., 2022). High levels of caregiver burden are associated with adverse outcomes for both caregivers and care recipients, including lower adherence to treatment and higher relapse rates (Ma et al., 2023). Despite the critical importance of understanding these issues, studies exploring the relationship between self-stigma and caregiver burden, particularly in community settings in developing countries such as Indonesia , remain limited. Most studies have focused on the stigma and burden experienced by patients themselves, while the experiences of caregivers remain underexplored. Understanding the level and nature of self-stigma and burden among caregivers is crucial for developing culturally appropriate interventions aimed at reducing stigma, burden, and promoting caregiver well-being.

This study aims to examine the level of self-stigma and burden among caregivers of individuals with schizophrenia living in the community and to analyze the relationship between these two variables. By identifying the extent of self-stigma and caregiver burden, the findings can inform the development of psychoeducational programs and community-based support systems that address caregiver needs and contribute to reducing the broader societal stigma and burden surrounding mental illness.

METHODS

Study Design

This study employed a quantitative, descriptive-analytical design with a cross-sectional approach. The design was chosen to examine the relationship between self-stigma and caregiver burden at a single point in time among caregivers of individuals with schizophrenia living in the community.

Population and Sample

The population of this study consisted of family caregivers who provided primary care to persons diagnosed with schizophrenia residing in a community-based setting in Magelang, Central Java, Indonesia . Inclusion criteria included: (1) being a family member (parent, spouse, sibling, or child); (2) aged 18 years or older; (3) living in the same household or regularly providing care; and (4) having provided care for at least six months. Caregivers with a history of severe mental illness or cognitive impairment were excluded.

A total of 100 caregivers were selected using purposive sampling, based on their availability and willingness to participate, as well as their fulfillment of the inclusion criteria.

Data Collection Techniques

Before collecting data, the researcher gave informed consent, if the caregiver of schizophrenia agreed to participated in this research, the participants were given questionnaires. The Data were collected using a structured questionnaire consisting of three sections: Demographic Data Sheet, which captured the socio-demographic characteristics of the caregivers (age, gender, education, relationship to patient, duration of caregiving). Self-Stigma of Family Members Scale (SSFS), a validated instrument used to measure the internalized stigma experienced by caregivers. Zarit Burden Interview (ZBI), a widely used tool to assess caregiver burden, including emotional, physical, and social stress. The questionnaires were administered in person through self-report or assisted interview (depending on literacy level), ensuring clarity and comprehension for each participant.

Data Analysis Techniques

Data were analyzed using SPSS version 25.0. Descriptive statistics (frequencies, percentages, means, and standard deviations) were used to describe the characteristics of the participants and levels of self-stigma and burden. Inferential statistics were used to examine the relationship between self-stigma and caregiver burden. The spearman rank test was conducted to analize the relationship between self stigma and caregiver burden. A p-value of < 0.05 was considered statistically significant.

RESULT AND DISCUSSION

A total of 100 caregivers participated in the study. The majority were female (72%), with an average age of 46.3 ± 12.1 years. Most caregivers were parents (55%) or spouses (28%) of the person with schizophrenia, and 60% had been providing care for more than two years. It can be shown in tabel 1 bellow;

Table 1 : Characteristic respondents (n= 100)

Variable	Category	n	%
Age (Mean ± SD)	–	–	46.3 ± 12.1 years
Gender	Male	28	28.0%
	Female	72	72.0%
Education Level	No formal education	5	5.0%
	Primary school	18	18.0%
	Secondary school	39	39.0%
	Higher education	38	38.0%
Relationship to Patient	Parent	55	55.0%
	Spouse	28	28.0%
	Sibling	10	10.0%
	Child	5	5.0%
	Other	2	2.0%
Duration of Caregiving	< 1 year	15	15.0%
	1–2 years	25	25.0%
	> 2 years	60	60.0%

Source : Data Processed in 2025

This study examined the burden experienced by caregivers of persons with schizophrenia in the community, focusing on demographic characteristics and the levels of self-stigma and caregiver burden. The findings indicate that the majority of caregivers were female (72%) with an average age of 46.3 years, predominantly parents (55%) or spouses (28%) of the patients, and most had provided care for more than two years (60%). These results are consistent with previous research demonstrating that caregiving for individuals with schizophrenia is often assumed by middle-aged female family members, primarily parents and spouses, reflecting traditional family roles in many cultures (Chang et al., 2023; Novak et al., 2021).

The predominance of female caregivers aligns with global trends where women typically bear the caregiving responsibilities for mentally ill relatives (Pinquart & Sörensen, 2018). This gender disparity may be influenced by societal expectations and cultural norms that position women as primary caregivers. Moreover, the extended duration of caregiving (>2 years for 60% of respondents) underscores the chronic nature of schizophrenia and the long-term demands placed on family members, which has been linked to higher levels of physical and psychological burden (Perlick et al., 2016).

Analysis of the Self-Stigma of Family Members Scale (SSFS) revealed that 64% of participants experienced a moderate level of self-stigma, while 21% reported high self-stigma, and only 15% reported low levels of self-stigma.

Similarly, caregiver burden measured using the Zarit Burden Interview (ZBI) indicated that 58% of respondents experienced a moderate burden, 25% experienced a high burden, and only 17% reported a low burden. These results indicate that a significant proportion of caregivers endure moderate to high levels of both internalized stigma and caregiving burden. It can be shown in table 2 bellow:

Table 2 : self stigma and caregiver burden level (n= 100)

Variable	Category	n	%
Self-Stigma Level	Low	15	15.0%
	Moderate	64	64.0%
	High	21	21.0%
Caregiver Burden Level (ZBI)	Low	17	17.0%
	Moderate	58	58.0%
	High	25	25.0%

Source : Data Processed in 2025

Regarding self-stigma, 64% of caregivers reported moderate levels while 21% reported high levels of internalized stigma. This internalized stigma can significantly affect caregivers' mental health and willingness to seek external support (Corrigan & Rao, 2019). Caregivers may internalize societal negative stereotypes about mental illness, leading to feelings of shame, isolation, and reduced self-esteem, which exacerbate caregiver burden (Moses, 2020). Our findings corroborate those of Ma et al. (2023), who emphasized that self-stigma among caregivers is a critical but under-addressed factor contributing to their emotional distress (Suharsono & Noor Faidah, 2023).

The Zarit Burden Interview results showed that 58% of caregivers experienced a moderate burden and 25% a high burden. This is in line with previous studies indicating that caregivers of persons with schizophrenia face considerable emotional, social, and financial challenges (López et al., 2020; Zarit et al., 2022,; (Suharsono et al., 2024)). The chronic and often unpredictable course of schizophrenia, combined with stigma and social isolation, can intensify caregiver strain, negatively impacting their quality of life and health outcomes (Chang et al., 2023).

The positive correlation between self-stigma and caregiver burden ($\rho = 0.613$, $p < 0.001$) highlights the intertwined nature of these variables. As caregivers internalize stigma, their perceived burden increases, possibly due to diminished coping resources and social support (Chang et al., 2023; Corrigan & Rao, 2019). Interventions aimed at reducing stigma at both community and individual levels are therefore essential to alleviate caregiver burden (Suharsono, Marchira, Rahmat, 2020).

Tabel 3: the corelation between self stigma and cargiver burden

Variables	Spearman's rho (ρ)	p-value	Interpretation
Self-Stigma (SSFS) and Caregiver Burden (ZBI)	0.613	< 0.001	Positive and significant correlation

*spearman rank

Source : Data Processed in 2025

This study's findings have important implications for mental health services and policy. Psychosocial interventions such as psychoeducation, stigma reduction programs, and peer support groups could empower caregivers by improving knowledge, reducing self-stigma, and fostering resilience (Novak et al., 2021; Ma et al., 2023). Additionally, community-based mental health services should incorporate caregiver support as a core component to address their unique needs and challenges.

This study found that a substantial proportion of caregivers of individuals with schizophrenia in the community experienced moderate to high levels of both self-stigma and caregiver burden. These findings are consistent with previous research, which has highlighted the psychological toll caregiving can have, particularly in settings with limited mental health resources (Ma et al., 2023; Novak et al., 2021).

The significant positive correlation between self-stigma and caregiver burden suggests that internalized stigma may amplify the emotional and psychological stress experienced by caregivers. Caregivers who perceive negative societal attitudes toward mental illness may internalize these beliefs, leading to feelings of shame, isolation, and reduced self-worth, which in turn increases their burden (Corrigan & Watson, 2021; Chang et al., 2023).

Furthermore, the socio-cultural context likely contributes to the stigmatization of mental illness, particularly in communities where schizophrenia is misunderstood or associated with supernatural beliefs. This often leads to concealment and reduced help-seeking behavior among families, further intensifying the caregiver's load (Moses, 2020; WHO, 2022).

Given these findings, interventions should address not only the practical aspects of caregiving but also aim to reduce stigma through community education, support groups, and accessible psychosocial services. Empowering caregivers through mental health literacy and counseling could reduce self-stigma and alleviate their burden, ultimately benefiting both caregivers and care recipients.

Limitations include the cross-sectional design, which limits causal inference, and purposive sampling that may affect generalizability. Future longitudinal studies with larger, randomized samples could provide deeper insights into the dynamics of caregiver burden and stigma over time.

CONCLUSION

This study revealed that caregivers of individuals with schizophrenia in the community experience moderate to high levels of both self-stigma and caregiver burden. The significant positive correlation between self-stigma and caregiver burden suggests that internalized stigma plays a crucial role in increasing the psychological and emotional strain on caregivers. These findings highlight the urgent need for comprehensive interventions that not only support caregivers in managing daily care responsibilities but also address the stigma associated with mental illness. Efforts to improve mental health literacy, provide psychosocial support, and foster inclusive community environments may help reduce self-stigma and alleviate caregiver burden, ultimately improving the quality of life for both caregivers and individuals with schizophrenia.

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