

## UNDERSTANDING CAREGIVER PSYCHOLOGICAL DISTRESS THROUGH PATIENT'S LACK OF INSIGHT AND PERCEIVED STIGMA IN PSYCHOTIC DISORDERS: A SYSTEMATIC REVIEW

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DOI: <http://doi.org/10.5281/zenodo.20795781>

Received	Revised	Accepted	Published
14 May, 2026	03 June, 2026	15 June, 2026	18 June, 2026

### ABSTRACT

Family caregivers of individuals with psychotic disorders are disproportionately affected by psychological distress, including anxiety, depression, and caregiver burden. A range of clinical and psychosocial factors including patient's lack of insight, perceived stigma, treatment non-adherence, social isolation, and insufficient social support are known to exacerbate this distress. The present systematic review examined the individual and combined contributions of patient's lack of insight and perceived (affiliate) stigma to caregiver psychological distress. A systematic search of Google Scholar, PubMed, and Elsevier databases was conducted for studies published between 2018 and 2026. Fourteen studies meeting the inclusion criteria were identified, encompassing quantitative, qualitative, and mixed-method designs (including correlational, cross-sectional, longitudinal, and meta-synthesis studies). Findings consistently indicated that both patient's lack of insight and caregivers' perceived stigma significantly and interactively contribute to elevated psychological distress among family caregivers of individuals with psychotic disorders. Clinical implications and directions for future research are discussed.

**Keywords:** Psychotic disorders, caregiver distress, lack of insight, perceived stigma, affiliate stigma, caregiver burden, schizophrenia

## Introduction

In recent years, mental health has emerged as a critical global concern, with a growing number of individuals experiencing clinically significant mental health difficulties. Family caregivers of persons with psychotic disorders constitute a particularly vulnerable group, with the majority reporting elevated rates of anxiety, depression, and psychological burden (Tay et al., 2025; Villena Jimena et al., 2024). Two broad categories of factors are identified as primary contributors to caregiver psychological distress: patient-related clinical factors and psychosocial factors. The present systematic review focuses specifically on two variables: patient's lack of insight as the central patient-related factor, and perceived stigma as the key psychosocial factor. Lack of insight refers to a patient's limited awareness of their mental illness, its symptoms, and the corresponding need for treatment (Lincoln et al., 2007). Estimates indicate that between 50% and 80% of individuals with psychotic disorders present with clinically significant insight deficits (Gerretsen et al., 2014). When patients lack insight, they may refuse treatment, discontinue medication, or fail to acknowledge the necessity of clinical intervention placing considerable demands on family caregivers who must manage crises, ensure patient safety, and often enforce treatment adherence. Evidence suggests that caregivers of patients with poor insight experience significantly greater burden, anxiety, and depression compared to caregivers of patients with adequate insight (Grover et al., 2012; Novak & Guest, 1989).

Perceived stigma, also termed courtesy stigma or affiliate stigma, refers to caregivers' subjective experience of being devalued, rejected, or discriminated against by others as a consequence of their association with a person with mental illness (Goffman, 1963). Caregivers of individuals with schizophrenia frequently report social rejection, marginalization, and erosion of social support

networks factors that exert a substantial negative impact on their psychological health (Mukherjee & Shukla, 2024). Emerging evidence further links perceived stigma to increased caregiving hours, reduced access to illness-related information, and elevated caregiver distress (Masmoudi et al., 2024). Internalized negative societal attitudes may manifest as shame, embarrassment, and social withdrawal, with many caregivers concealing the patient's diagnosis from family and community members to avoid judgment (Batool et al., 2024; Tajudeen, 2024).

The relationship between lack of insight, perceived stigma, and caregiver distress is multifaceted. Recent research has demonstrated that caregiver burden serves as a partial mediator between affiliate stigma and caregiver quality of life (Cheng et al., 2025). Caregivers of individuals with schizophrenia report moderate-to-severe burden and significant stigma, both of which negatively affect their overall wellbeing (Mukherjee & Shukla, 2024). Emotional disruptions—including sadness, fear, hopelessness, and uncertainty are commonly reported, alongside interference with daily functioning (Villena Jimena et al., 2024). The objective of the present systematic review is to synthesize available evidence on the individual and combined impact of patient's lack of insight and perceived stigma on psychological distress in family caregivers of individuals with psychotic disorders.

## Method

### *Search Strategy and Eligibility Criteria*

A systematic literature search was conducted across three electronic databases: Google Scholar, PubMed, and Elsevier (ScienceDirect). The search was restricted to studies published between January 2018 and March 2026. Search terms included combinations of the following: "caregiver psychological distress," "lack of insight," "perceived stigma," "affiliate stigma," "psychotic disorders,"

"schizophrenia," "caregiver burden," and "family caregiver."

Studies were included if they: (a) examined caregiver psychological distress (operationalized as anxiety, depression, burden, or quality of life) among family caregivers of individuals with psychotic disorders (schizophrenia, schizoaffective disorder, bipolar disorder with psychotic features, or first-episode psychosis); (b) assessed patient's lack of insight and/or caregiver-perceived stigma as predictor or associated variables; (c) employed quantitative, qualitative, or mixed-method designs; and (d) were published in English between 2018 and 2026. Foundational theoretical or methodological works cited within the included studies (e.g., Goffman,

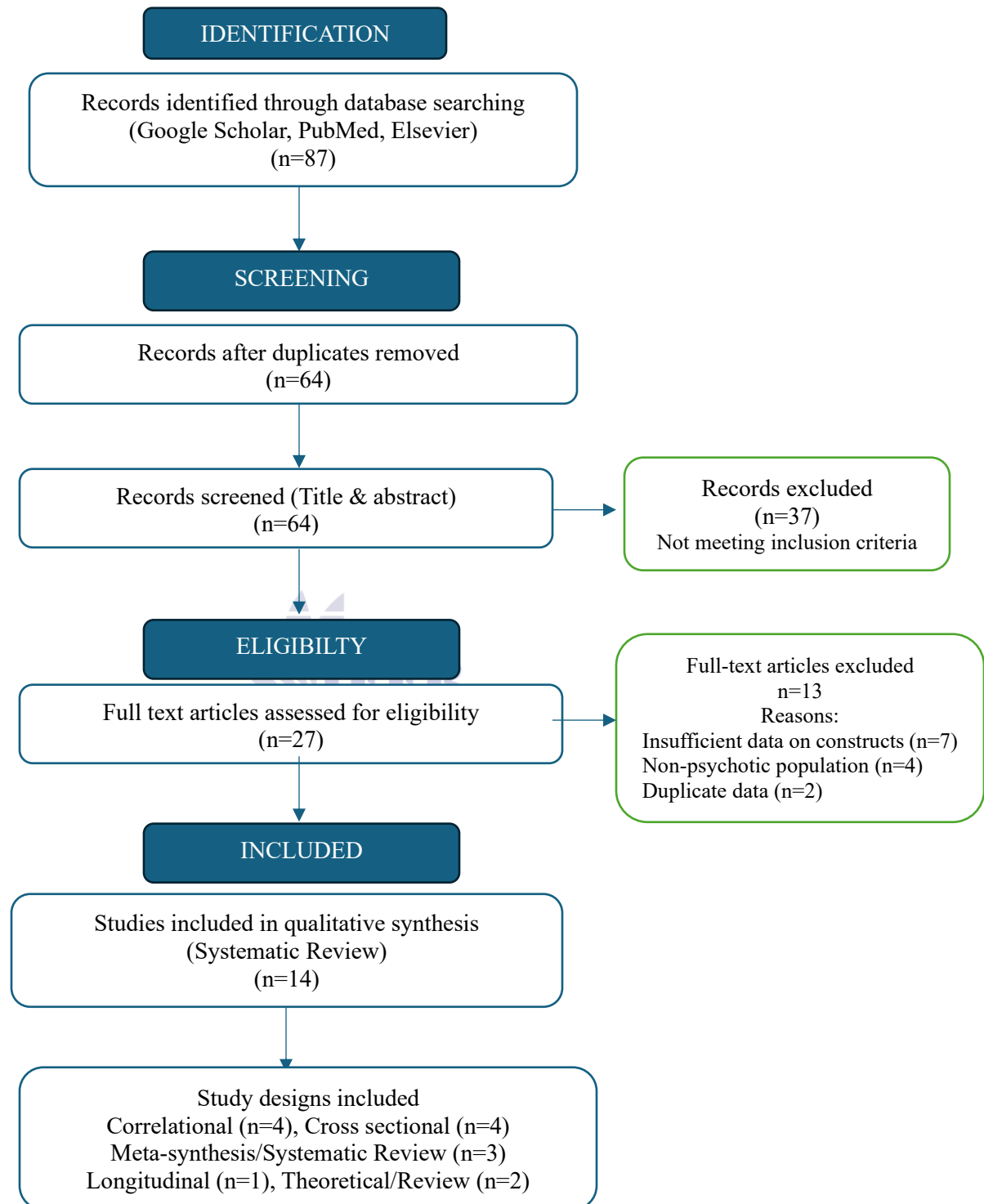
1963; Novak & Guest, 1989) were retained to provide conceptual grounding. Studies focusing exclusively on non-psychotic populations, and those lacking sufficient data on the constructs of interest, were excluded.

### **Results**

The database search yielded an initial pool of articles, from which 14 studies met the full inclusion criteria following title, abstract, and full-text screening. The PRISMA flow diagram illustrating the selection process is presented in Figure 1. Table 1 provides a summary of the included studies, including author(s) and year, study focus, sample size, population, and key findings.



PRISMA FLOW DIAGRAM



**Table 1:** *Summary of Included Studies*

S.No.	Author(s) Year	& Focus	Sample Size	Population	Findings
1	Tay et al. (2025)	Experiences of informal caregivers caring for individuals with chronic schizophrenia	1,345 caregivers (57 studies meta-synthesis)	Caregivers of individuals with chronic schizophrenia in Asia	Caregivers face significant stigma and compassion fatigue; cultural and traditional factors amplify distress; lack of support and challenges in caregiving are primary themes.
2	Abdelkader et al. (2025)	Perceived stigma and associated factors among family caregivers of patients with severe mental disorders	633 relatives	Caregivers of patients with psychiatric disorders (37% schizophrenia), Egypt	Patient-focused stigma reported by 64%, family-focused stigma by 37.4%; stigma significantly associated with longer illness duration, treatment non-adherence, and frequent hospitalizations.
3	Wang et al. (2023)	Affiliate stigma and caregiving burden among family caregivers of persons with schizophrenia	320 caregivers	Family caregivers of persons with schizophrenia in rural China	Majority of caregivers experienced severe affiliate stigma and caregiving burden; culture-specific anti-stigma interventions are crucial.
4	Znaidi et al. (2021)	Affiliate stigma among natural caregivers of patients with schizophrenia	150 caregivers	Natural caregivers of patients with schizophrenia, Tunisia	Caregivers subjected to affiliate stigma leading to community rejection, isolation, and negative impact on psychological wellbeing.
5	Megersa et al. (2025)	Perceived stigma and associated	375 caregivers	Caregivers of patients with	54.9% experienced perceived stigma; 89%

S.No.	Author(s) Year	& Focus	Sample Size	Population	Findings
		factors among caregivers of patients with severe mental illness		SMI (37.3% schizophrenia), Ethiopia	had moderate-to-severe burden; schizophrenia diagnosis (AOR: 1.91) and lack of social support (AOR: 0.5) were significant predictors.
6	So & Chan (2021)	Stigma and help-seeking behavior among Chinese caregivers of elderly with psychiatric issues	28 studies (systematic review)	Caregivers of elderly patients with psychiatric issues in Chinese communities	Over 50% of Chinese individuals with mental disorders fail to obtain help; stigma leads to isolation, discrimination, and reduced healthcare access.
7	Jang et al. (2017)	Affiliate stigma and associated factors among family caregivers of patients with schizophrenia, bipolar disorder, and major depressive disorder	215 caregivers	Caregivers of patients with schizophrenia (n=86), bipolar disorder (n=65), and MDD (n=64), Taiwan	Caregivers of schizophrenia patients had significantly higher affiliate stigma than those of bipolar disorder ( $\beta = -0.109$ , $p < 0.05$ ) and MDD ( $\beta = -0.230$ , $p < 0.001$ ); self-esteem and burden were significant factors.
8	Mak & Cheung (2008)	Development of Affiliate Stigma Scale for caregivers of people with intellectual disability or mental illness	262 caregivers	Caregivers of people with intellectual disability or mental illness, Hong Kong	Developed Affiliate Stigma Scale with three subscales (cognitive, affective, behavioral); showed good predictive validity on subjective burden after controlling for caregiving involvement and stress.



S.No.	Author(s) Year	& Focus	Sample Size	Population	Findings
9	Grover et al. (2012)	Relationship between insight and caregiver burden in schizophrenia and bipolar disorder	100 caregivers	Caregivers of patients with schizophrenia (n=50) and bipolar disorder (n=50), India	Caregivers of patients with poor insight reported higher levels of burden, anxiety, and depression compared to those caring for patients with good insight.
10	Gerretsen et al. (2014)	Effects of aging on insight into illness in schizophrenia	47 studies (review)	Patients with schizophrenia (mean age 18-65 years)	50-80% of individuals with psychotic disorders demonstrate clinically significant lack of insight; aging associated with progressive insight deterioration.
11	Lincoln et al. (2007)	Correlates and long-term consequences of poor insight in patients with schizophrenia	40 studies (systematic review)	Patients with schizophrenia	Lack of insight is associated with treatment non-adherence, poorer functioning, and increased caregiver burden.
12	Novak & Guest (1989)	Multidimensional caregiver burden inventory	125 caregivers	Family caregivers of elderly patients (Alzheimer's, dementia, heart cancer, heart disease)	Developed 24-item multidimensional caregiver burden inventory with five subscales: time-dependence, developmental, physical, social, and emotional burden.
13	Goffman (1963)	Courtesy stigma experienced by family members	Theoretical work (no sample)	Family members of individuals	Defined 'courtesy stigma' which family caregivers experience

S.No.	Author(s) Year	& Focus	Sample Size	Population	Findings
		of stigmatized individuals		with mental illness, disabilities, and other stigmatized conditions	due to affiliation with a mentally ill patient; introduced foundational framework for understanding stigma transfer.
14	Healthcare Communications Network (2025)	Mental health literacy and caregiver experiences of people with psychosis	159 caregivers + 48 first-person accounts + 18 experts	Family members and carers of people with psychosis, United Kingdom	82.8% of caregivers described inadequate mental health literacy; caregivers experience shock, isolation, grief cycles, and communication barriers with healthcare systems.

Note. SMI = Severe Mental Illness; MDD = Major Depressive Disorder; AOR = Adjusted Odds Ratio.

### Discussion

The present systematic review synthesized evidence from 14 studies examining the role of patient's lack of insight and perceived stigma in the psychological distress of family caregivers of individuals with psychotic disorders. Findings across studies consistently demonstrated that both variables are significant contributors to elevated caregiver distress, and that their effects may be interactive and mutually reinforcing.

#### *Patient's Lack of Insight and Caregiver Distress*

Lack of insight is a pervasive clinical feature of psychotic disorders, affecting an estimated 50–80% of individuals with these conditions (Gerretsen et al., 2014). When patients are unable to recognize their illness, they frequently resist treatment, discontinue medication, and fail to appreciate the severity of their condition (Lincoln et al., 2007).

These behaviors place considerable burden on family caregivers, who must assume responsibility for managing crisis situations, ensuring physical safety, and facilitating treatment adherence. Grover et al. (2012) found that caregivers of patients with poor insight reported significantly higher levels of burden, anxiety, and depression relative to those caring for patients with adequate insight. Cumulatively, the evidence indicates that insight deficits contribute to treatment non-adherence, diminished functional outcomes, and heightened caregiver psychological distress (Lincoln et al., 2007; Gerretsen et al., 2014).

#### *Perceived Stigma and Caregiver Distress*

Perceived stigma encompassing both courtesy stigma and affiliate stigma was identified across multiple studies as a potent determinant of caregiver psychological distress. Abdelkader et al. (2025) reported that patient-focused stigma was experienced by 64% and family-focused stigma by

37.4% of caregivers, with stigma scores significantly associated with longer illness duration, treatment non-adherence, and frequent hospitalizations. Similarly, Megersa et al. (2025) found that 54.9% of caregivers experienced perceived stigma and 89% reported moderate-to-severe burden, with schizophrenia diagnosis and low social support as significant predictors. Tay et al. (2025) highlighted that cultural and traditional beliefs further amplify stigma-related distress among Asian caregivers, while Wang et al. (2023) underscored the need for culturally adapted anti-stigma interventions in Chinese caregiving contexts.

The consequences of stigma extend beyond psychological distress. Znaidi et al. (2021) documented community rejection and social isolation as outcomes of affiliate stigma. So and Chan (2021) reported that stigma discourages help-seeking behavior, with over half of Chinese individuals with mental disorders failing to access services. Mak and Cheung (2008) provided a validated psychometric tool the Affiliate Stigma Scale enabling standardized measurement of the cognitive, affective, and behavioral dimensions of stigma among caregivers. Healthcare Communications Network (2025) further documented that 82.8% of caregivers of individuals with psychosis reported insufficient mental health literacy, compounding their distress through communication barriers with healthcare systems.

### ***Interaction Between Lack of Insight and Perceived Stigma***

The mechanisms through which lack of insight and perceived stigma jointly elevate caregiver distress include: treatment refusal precipitating public psychotic episodes; concealment of diagnosis driven by fear of social judgment; reduced access to social support; and social withdrawal from community networks. These mechanisms collectively contribute to sleep disturbances, appetite disruption, irritability, reduced occupational productivity, and

emotional exhaustion, all of which increase caregiver anxiety, depression, and diminish quality of life. Recent research by Cheng et al. (2025) confirmed that caregiver burden functions as a partial mediator between affiliate stigma and caregiver quality of life, providing preliminary evidence for a causal pathway from stigma to distress via burden.

### **Implications**

#### ***Early Identification and Screening***

Routine psychological assessment of family caregivers should be integrated into psychiatric clinical settings. Standardized screening for anxiety, depression, and caregiver burden should be conducted at the time of patient diagnosis and at regular intervals during treatment. Additionally, clinicians should assess both patient insight levels and caregiver-perceived stigma as part of comprehensive psychosocial evaluations.

#### ***Psychoeducational Interventions***

Given that lack of insight is a neurobiologically determined symptom rather than volitional denial, psychoeducation programs targeting family caregivers should reframe insight deficits as a clinical feature of the illness. Such reframing can reduce caregiver frustration, self-blame, and expressed emotion, thereby mitigating psychological distress. Structured family psychoeducation programs have demonstrated efficacy in improving caregiver coping and reducing burden in psychotic disorders.

#### ***Stigma Reduction Programs***

Community-level and institutional anti-stigma interventions should address both public stigma (societal stereotypes and discrimination) and affiliate stigma (internalized negative attitudes among caregivers). Caregiver support groups can provide a safe environment for sharing experiences, reducing isolation, and alleviating shame. Culturally sensitive programs are particularly indicated for

populations in which traditional beliefs compound stigma-related distress.

### ***Clinical and Diagnostic Implications***

Psychiatric assessment should incorporate comprehensive tools that evaluate patient-related factors (insight, symptom severity, treatment adherence) alongside caregiver-related factors (perceived stigma, burden, social support, coping strategies). Family-centered interventions should be embedded within standard psychiatric treatment protocols, recognizing that caregiver psychological health is inextricably linked to patient outcomes.

### ***Research and Policy Implications***

Longitudinal research designs are needed to elucidate causal pathways among insight deficits, perceived stigma, caregiver burden, and psychological distress. Culturally adapted interventions require validation across diverse populations, particularly in low- and middle-income countries with limited mental health resources. Policy initiatives should mandate the provision of respite care, financial assistance, and accessible mental health services for family caregivers. Healthcare systems should institutionalize family participation in treatment planning and monitoring.

### **Conclusion**

The present systematic review provides evidence that patient-related factors particularly lack of insight and psychosocial factors particularly perceived stigma interact to produce elevated psychological distress in family caregivers of individuals with psychotic disorders. Across the 14 studies reviewed, both variables demonstrated significant and consistent associations with caregiver anxiety, depression, and burden. These findings underscore the importance of addressing caregiver wellbeing as an integral component of psychiatric care. Sustained monitoring of caregiver distress, psychoeducation regarding insight as a clinical symptom, stigma reduction initiatives,

family-centered clinical management, and supportive policy frameworks are all essential to safeguarding the psychological health of caregivers of individuals with psychotic disorders.

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