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“Unseen Burden, Silent Strain: A Comprehensive Review on the Assessment of Perceived Stress Levels Among Primary Caregivers of Individuals with Mental Illness”

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Date of Publication: 14/05/2026

DOI [10.5281/zenodo.20178688](https://doi.org/10.5281/zenodo.20178688)

Abstract: Mental illness affects not only individuals diagnosed with psychiatric disorders but also their families and caregivers, who often experience significant psychological, emotional, social, and financial burdens. Primary caregivers play a pivotal role in ensuring treatment adherence, emotional support, rehabilitation, and daily functioning of individuals with mental illness. Continuous caregiving responsibilities expose caregivers to elevated levels of perceived stress, adversely affecting their physical and mental health. This review article explores the concept of perceived stress among primary caregivers of individuals with mental illness, the contributing factors, assessment methods, theoretical perspectives, consequences, coping mechanisms, and nursing implications. The review synthesizes findings from various national and international studies regarding caregiver stress associated with psychiatric disorders such as schizophrenia, bipolar disorder, depression, dementia, autism spectrum disorders, and substance use disorders. Standardized assessment tools commonly employed in caregiver stress evaluation are also discussed. The article highlights the importance of early identification, psychosocial interventions, caregiver education, and supportive mental health services to reduce stress burden and improve caregiver well-being. Strengthening caregiver support systems is essential for enhancing patient outcomes and ensuring holistic psychiatric care.

Keywords: Perceived stress, primary caregivers, mental illness, caregiver burden, psychiatric nursing, mental health, stress assessment, caregiver coping, family caregivers, psychosocial support

Introduction

Mental illness represents one of the major public health challenges worldwide. Psychiatric disorders such as schizophrenia, bipolar disorder, major depressive disorder, dementia, obsessive-compulsive disorder, autism spectrum disorders, and substance use disorders significantly impair an individual's cognitive, emotional, social, and occupational functioning. While much attention is often directed toward patients, the burden borne by primary caregivers frequently remains unnoticed. Family members, particularly parents, spouses, siblings, or children, often assume the role of informal caregivers, providing long-term support and supervision for individuals with mental illness. This caregiving responsibility may persist for years and may eventually influence the caregiver's physical, emotional, social, and economic well-being.¹

Perceived stress refers to the extent to which individuals evaluate situations in their lives as stressful or overwhelming. Caregivers of

persons with mental illness frequently experience uncertainty regarding disease prognosis, stigma, financial instability, social isolation, emotional exhaustion, and disturbances in family relationships. Such persistent stress may lead to depression, anxiety, burnout, sleep disturbances, impaired immunity, hypertension, and reduced quality of life.² The chronic nature of many psychiatric disorders further intensifies caregiver strain because caregivers are required to manage unpredictable behaviors, medication adherence, frequent relapses, aggressive episodes, and social dysfunction.

The transition from institutionalized psychiatric care to community-based mental health care has increased the responsibilities placed upon families. In many developing countries, including India, family caregivers constitute the backbone of psychiatric rehabilitation services due to limited mental health resources and inadequate institutional support.³ Cultural expectations and family obligations further compel relatives to continue caregiving despite substantial



emotional strain. Consequently, assessing perceived stress among caregivers has become a critical area of psychiatric nursing and mental health research.

Understanding caregiver stress is essential because caregiver well-being directly affects patient outcomes. High stress levels among caregivers may compromise caregiving quality, increase expressed emotions within families, and contribute to patient relapse or rehospitalization. Therefore, early identification and management of caregiver stress are necessary to ensure comprehensive psychiatric care.⁴

Concept of Perceived Stress

Perceived stress refers to an individual's subjective appraisal of life situations as unpredictable, uncontrollable, or overwhelming. It is not merely the presence of stressful events but rather the interpretation of those events that determines stress perception. Lazarus and Folkman's transactional model emphasizes that stress results from interactions between individuals and their environment, mediated by cognitive appraisal and coping abilities.⁵

Among caregivers of mentally ill individuals, perceived stress arises when caregiving demands exceed available coping resources. The stress experienced may vary according to disease severity, duration of caregiving, social support, economic status, coping style, and caregiver resilience. The emotional burden often becomes intensified because psychiatric illnesses frequently involve behavioral disturbances, social stigma, and long-term dependency.

Table 1: Caregiver stress is multidimensional and may include:

Dimension of Stress	Description
Emotional Stress	Anxiety, sadness, frustration, hopelessness
Physical Stress	Fatigue, insomnia, headaches, hypertension
Financial Stress	Treatment expenses, loss of income
Social Stress	Isolation, reduced leisure activities
Psychological Stress	Burnout, depression, emotional exhaustion
Occupational Stress	Reduced work productivity or unemployment

The persistent exposure to caregiving responsibilities may eventually impair coping mechanisms and reduce psychological resilience. Therefore, evaluating perceived stress is essential for identifying vulnerable caregivers and planning supportive interventions.⁶

Primary Caregivers in Mental Illness

A primary caregiver is an individual who assumes major responsibility for providing physical, emotional, social, and financial support to a person with illness or disability. In mental health settings, caregivers are usually family members who spend significant time caring for the patient without financial compensation.⁷

Primary caregivers perform several essential functions, including:

- Supervising medication adherence
- Managing behavioral disturbances
- Accompanying patients to healthcare facilities
- Assisting with activities of daily living
- Providing emotional reassurance
- Monitoring symptoms and relapse signs
- Facilitating social interaction and rehabilitation

Caregivers of psychiatric patients frequently encounter challenges unique to mental illness, including hallucinations, delusions, aggression, suicidal behavior, impaired judgment, social withdrawal, and unpredictable emotional reactions. Unlike many physical illnesses, psychiatric disorders often carry substantial stigma, leading to discrimination and social alienation for both patients and caregivers.⁸

Women, especially mothers and spouses, are often the primary caregivers in many societies. Female caregivers may experience higher stress levels because of multiple responsibilities related to household management, childcare, and caregiving simultaneously. Elderly caregivers also face additional physical and emotional strain while caring for mentally ill family members.

Epidemiology of Caregiver Stress

Research evidence indicates that caregivers of individuals with mental illness experience significantly higher stress levels than the general population. Studies across different countries have consistently demonstrated elevated rates of depression, anxiety, sleep disturbances, and caregiver burden among family caregivers.⁹

Table 2: Prevalence of Stress Among Caregivers in Different Mental Illnesses

Mental Illness	Common Caregiver Experiences
Schizophrenia	Emotional burden, social stigma, burnout
Bipolar Disorder	Anxiety regarding relapse episodes
Dementia	Chronic exhaustion, sleep disturbances
Depression	Emotional fatigue and helplessness
Autism Spectrum Disorder	Financial strain and parental stress
Substance Use Disorders	Family conflict and psychological distress

Caregivers of individuals with schizophrenia often report severe emotional and social burden because of chronic symptoms, impaired social functioning, and recurrent relapses. Dementia caregivers experience progressive stress due to increasing dependency and cognitive deterioration in patients. Similarly, caregivers of individuals with substance use disorders frequently face violence, financial instability, and social stigma.¹⁰

Factors Influencing Perceived Stress Among Caregivers



Perceived stress among caregivers is influenced by multiple interrelated factors. These factors may be categorized as patient-related, caregiver-related, social, and environmental factors.

Patient-Related Factors

Severity and duration of mental illness significantly influence caregiver stress. Chronic psychiatric disorders requiring prolonged supervision increase emotional exhaustion among caregivers. Aggressive behavior, poor treatment adherence, suicidal tendencies, and cognitive impairment further elevate stress levels. Frequent hospitalizations and relapse episodes also contribute to caregiver anxiety and uncertainty.¹¹

Caregiver-Related Factors

Age, gender, educational status, physical health, coping ability, and relationship with the patient affect stress perception. Female caregivers often report greater stress than males due to societal expectations and emotional involvement. Elderly caregivers may experience physical fatigue and health deterioration. Poor coping skills and lack of resilience can intensify perceived stress.¹²

Social and Environmental Factors

Stigma associated with mental illness remains a major contributor to caregiver stress. Families often experience social rejection, criticism, and isolation. Financial burden resulting from treatment costs, unemployment, and caregiving responsibilities further aggravates stress. Inadequate mental health services and poor social support systems may worsen caregiver experiences.¹³

Table 3: Factors Affecting Caregiver Stress

Category	Contributing Factors
Patient Factors	Severity, relapse, aggression
Caregiver Factors	Gender, age, coping style
Social Factors	Stigma, isolation
Economic Factors	Financial burden, unemployment
Healthcare Factors	Limited support services

Assessment of Perceived Stress

Assessment of perceived stress among caregivers is essential for identifying psychological distress and planning interventions. Various standardized tools are used in clinical practice and research to measure stress levels and caregiver burden.

Perceived Stress Scale (PSS)

The Perceived Stress Scale developed by Cohen is one of the most widely used tools for assessing perceived stress. It evaluates how

unpredictable, uncontrollable, and overloaded respondents perceive their lives during the past month. The scale is simple, reliable, and widely applicable across different populations.¹⁴

Zarit Burden Interview (ZBI)

The Zarit Burden Interview measures caregiver burden associated with functional impairment and dependency of patients. It evaluates emotional, physical, social, and financial aspects of caregiving burden. Higher scores indicate greater caregiver strain.¹⁵

General Health Questionnaire (GHQ)

The GHQ assesses psychological well-being and identifies symptoms of anxiety, depression, social dysfunction, and stress-related disorders among caregivers. It is commonly used in mental health research settings.¹⁶

Depression Anxiety Stress Scale (DASS)

The DASS is used to evaluate depression, anxiety, and stress symptoms simultaneously. It provides valuable insights into caregivers' emotional health and psychological functioning.¹⁷

Table 4: Common Tools Used for Stress Assessment

Tool	Purpose	Components
PSS	Measures perceived stress	Stress perception
ZBI	Assesses caregiver burden	Emotional and social burden
GHQ	Screens mental health status	Anxiety, depression
DASS	Evaluates emotional distress	Depression, anxiety, stress

Assessment should also include qualitative evaluation of coping mechanisms, family relationships, financial burden, and support systems. Comprehensive assessment facilitates individualized caregiver interventions.

Theoretical Perspectives Related to Caregiver Stress

Several theories explain caregiver stress and adaptation processes.

Transactional Model of Stress and Coping

Lazarus and Folkman proposed that stress results from cognitive appraisal of stressful events and the individual's coping resources. When caregivers perceive caregiving demands as exceeding their coping abilities, stress occurs. Coping strategies determine adaptation outcomes.¹⁸

Caregiver Stress Process Model

Pearlin's stress process model explains how primary stressors such as caregiving demands interact with secondary stressors like financial



problems and social isolation to influence caregiver outcomes. Social support and coping skills act as mediators.¹⁹

Family Systems Theory

This theory emphasizes the interconnectedness of family members. Mental illness in one member affects the emotional and functional stability of the entire family system. Therefore, caregiver stress should be understood within the broader family context.²⁰

Impact of Perceived Stress on Caregivers

Persistent caregiver stress has profound consequences on physical, psychological, social, and occupational health.

Physical Impact

Chronic stress can impair immune functioning and increase susceptibility to hypertension, diabetes, cardiovascular disease, headaches, fatigue, and sleep disturbances. Caregivers often neglect self-care and medical needs due to caregiving responsibilities.²¹

Psychological Impact

High perceived stress is associated with depression, anxiety disorders, emotional exhaustion, hopelessness, and burnout. Some caregivers may develop suicidal ideation or substance abuse problems due to prolonged emotional strain.²²

Social Impact

Caregivers frequently experience social withdrawal, reduced leisure participation, and strained interpersonal relationships. Stigma related to mental illness may lead to discrimination and social isolation.²³

Economic Impact

Long-term caregiving may result in job loss, reduced productivity, and financial hardship. Treatment expenses, transportation costs, and reduced employment opportunities further contribute to economic burden.²⁴

Coping Strategies Among Caregivers

Coping strategies play a crucial role in reducing stress and improving caregiver adaptation.

Problem-focused coping involves seeking information, organizing care routines, and accessing support services. Emotion-focused coping includes emotional expression, spirituality, relaxation techniques, and acceptance. Social support from family, peers, healthcare professionals, and support groups significantly enhances caregiver resilience.²⁵

Positive coping strategies include:

- Seeking professional counseling

- Participating in support groups
- Practicing yoga and meditation
- Developing stress management skills
- Sharing caregiving responsibilities
- Maintaining social interaction
- Engaging in recreational activities

Maladaptive coping mechanisms such as denial, social withdrawal, aggression, and substance abuse may worsen psychological distress. Therefore, healthcare professionals should encourage adaptive coping methods and provide psychoeducation.²⁶

Role of Psychiatric Nurses in Caregiver Stress Management

Psychiatric nurses play a central role in identifying and managing caregiver stress. They function as educators, counselors, advocates, and coordinators of mental health services.

Nurses can assess caregiver burden using standardized tools, identify psychological distress, and provide emotional support. Psychoeducation regarding illness nature, medication management, relapse prevention, communication techniques, and coping strategies can empower caregivers and reduce uncertainty.²⁷

Counseling interventions help caregivers express emotions and develop adaptive coping mechanisms. Nurses can also facilitate family therapy, support groups, and community-based rehabilitation programs. Home visits and telepsychiatric support services may enhance continuity of care and reduce caregiver strain.

Table 5: Nursing Interventions for Caregiver Stress

Nursing Intervention	Expected Outcome
Psychoeducation	Improved illness understanding
Counseling	Emotional support
Stress management training	Reduced anxiety
Support groups	Enhanced coping
Family therapy	Better communication
Referral services	Improved access to care

Psychiatric nurses should advocate for caregiver-centered policies and integrate caregiver assessment into routine mental health services.

Interventions to Reduce Caregiver Stress

Multiple interventions have demonstrated effectiveness in reducing perceived stress among caregivers.

Psychoeducational Interventions

Structured psychoeducation programs improve caregiver knowledge regarding mental illness, medication adherence, symptom



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YEAR: 2026

VOLUME: 4

ISSUE: 1

ISSN: 3107-4162

management, and coping skills. Such interventions reduce anxiety and increase confidence in caregiving roles.²⁸

Cognitive Behavioral Therapy

Cognitive behavioral interventions help caregivers identify negative thought patterns and develop adaptive coping strategies. CBT has shown effectiveness in reducing depression, stress, and emotional exhaustion.²⁹

Mindfulness and Relaxation Therapy

Mindfulness meditation, breathing exercises, yoga, and progressive muscle relaxation improve emotional regulation and reduce stress symptoms among caregivers.³⁰

Support Groups

Peer support groups provide emotional sharing, encouragement, and practical guidance. Caregivers benefit from interaction with individuals facing similar experiences.³¹

Community-Based Rehabilitation

Community mental health services offering respite care, home visits, vocational support, and rehabilitation programs can significantly reduce caregiver burden.³²

Challenges in Assessing Caregiver Stress

Despite growing awareness, several challenges hinder effective assessment of caregiver stress. Many caregivers fail to seek help because they prioritize patient needs over their own health. Cultural beliefs and stigma may discourage emotional expression or mental health consultations.³³

Limited mental health resources, inadequate caregiver support programs, shortage of trained professionals, and poor integration of caregiver assessment into routine psychiatric care further complicate stress identification. Subjective variations in stress perception also make assessment challenging.

Researchers face methodological limitations such as small sample sizes, cross-sectional designs, and cultural variations in caregiver experiences. Longitudinal studies are needed to understand stress trajectories over time.³⁴

Implications for Nursing Practice, Education, and Research

Assessment of caregiver stress has important implications for psychiatric nursing practice. Routine caregiver screening should become an integral component of mental health assessment. Nurses should provide individualized interventions addressing emotional, educational, and social needs of caregivers.³⁵

In nursing education, greater emphasis should be placed on caregiver-centered care, family therapy, stress assessment, and communication skills. Training programs should equip nurses with competencies required for caregiver counseling and psychosocial support.

Future research should explore culturally sensitive interventions, technology-based support systems, resilience-building programs, and long-term outcomes of caregiver stress management interventions. Comparative studies across different psychiatric disorders may further enhance understanding of caregiver experiences.³⁶

Conclusion

Primary caregivers of individuals with mental illness experience significant perceived stress due to prolonged caregiving responsibilities, emotional strain, financial burden, stigma, and social isolation. Caregiver stress adversely affects psychological well-being, physical health, social functioning, and caregiving quality. Assessing perceived stress using standardized tools such as the Perceived Stress Scale, Zarit Burden Interview, GHQ, and DASS is essential for early identification of vulnerable caregivers.

Psychiatric nurses play a vital role in caregiver assessment, psychoeducation, counseling, stress management training, and support facilitation. Comprehensive interventions including psychoeducation, cognitive behavioral therapy, mindfulness techniques, and community-based support services can effectively reduce caregiver stress and improve quality of life.

Mental health services must adopt a family-centered approach recognizing caregivers as essential partners in psychiatric care. Strengthening caregiver support systems and integrating caregiver-focused interventions into routine psychiatric practice are crucial for promoting holistic mental health care and improving patient outcomes.

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YEAR: 2026

VOLUME: 4

ISSUE: 1

ISSN: 3107-4162

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