

Research Paper

Caregiving Experience, Burden, Self Perceived Health and Self-Care in Family Caregivers of Patients Diagnosed with Schizophrenia

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ABSTRACT

Family caregivers of individuals diagnosed with schizophrenia frequently encounter significant emotional, physical and social challenges. This study investigates the caregiving experience, perceived burden, self-perceived health and self-care among such caregivers. Employing a cross-sectional mixed method approach, data were collected from 40 primary caregivers using standardized tools including Zarit Burden Interview, self-rated health scale, and self-care assessment questionnaire. Results indicated high levels of burden, often linked with poor health perception and inadequate self-care. These findings underscore the critical need for structured support systems and mental health policies that prioritize caregiver well-being, ensuring a more sustainable care environment for patients with schizophrenia.

Keywords: *Schizophrenia, Family Caregiving, Caregiving Burden, Self-Perceived Health, Self-Care, Mental Health Support*

Schizophrenia is a chronic and severe mental disorder that typically manifests in early adulthood, characterized by disorganized thinking, altered perception, and impaired emotional expression. The illness significantly impacts not only the individual diagnosed but also their immediate family members, who are often responsible for long term psychosocial and economic support. As patients with schizophrenia experience disruptions in cognition, perception, and emotion, they require continuous care, often beyond the capacity of healthcare institutions alone.

Historically, individuals with schizophrenia were primarily treated in institutional settings. However, the modern shift toward community-based mental health care has led to the increased involvement of family members as primary caregivers. Their family caregivers—typically parents, spouses, siblings, or children play a pivotal role in ensuring adherence to treatment regimens, managing daily functioning, and providing emotional support. Despite their crucial role, many caregivers receive minimal training and limited support, which adds to the complexity of their caregiving responsibilities.

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The persistent demands of caregiving often result in what is termed caregiver burden—a multidimensional strain that can negatively impact a caregiver’s emotional, physical, social, and financial wellbeing (Xiong et al., 2020). Studies have shown that prolonged caregiving, particularly in mental health contexts, is associated with increased rates of depression, anxiety, disturbed sleep, lowered immunity, and early onset of frailty. A critical but frequently underexplored aspect of caregiving is self-perceived health. This subjective assessment reflects how caregivers view their overall physical and mental health. Influenced by stress levels, coping resources and social context, self-perceived health offers valuable insight into caregivers’ well-being and their ability to continue providing care effectively. Equally important is the concept of self-care, defined as the routine practice of attending to one’s own physical and emotional needs to maintain personal health and functionality. Caregivers often compromise their own self-care due to overwhelming demands of caregiving, which can lead to deteriorating health outcomes and reduced caregiving capacity overtime.

Given these concerns, the present study aims to examine the caregiving experience, caregiving burden, self-perceived health, and self-care practices among family caregivers of individuals diagnosed with schizophrenia. By exploring these interrelated domains, this research seeks to highlight areas for intervention and inform policy aimed at supporting family caregivers in mental health care contexts.

Aim:

To explore aspects of care giving experience, burden, self-perceived health and self-care in family caregivers of patients with schizophrenia.

Objective:

A clinical diagnosis of schizophrenia can often lead to shock and the responsibilities that the caregiver has to deal with have a significant impact on the care givers life. The present study explores the dimensions of burden, depression anxiety and stress, subjective report of health as well as self-care in the lives of caregivers.

RESEARCH METHODOLOGY

Research Design

The descriptive cross-sectional research design was used in this study to evaluate a caregiving burden, self-perceived health, and psychological distress of family caregivers of schizophrenic individuals. The design enabled the gathering of data on a single-point of time on a naturally occurring in a real-world clinical sample.

Sampling Method

Participants were selected by a convenience sampling method. Patients, as well as the caregivers, in the outpatient department of the Psychiatry Ward at GRMC Hospital were identified randomly and invited to take part in the research. The method was convenient and allowed for finding caregivers who actively engaged in the process.

Participants

The participants of the study comprised of 40 family caregivers of patients with a formal diagnosis of schizophrenia with a history of illness being 2 years or above (fulfilling ICD-10 criteria of schizophrenia) were included. The participants were immediate family members to the patient – such as siblings, parent, spouse, grandparent, grandchild and other relatives

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were included. Only the primary caregivers of age 18 years and above and educated up to 5th grade were included. Caregivers with documented history of psychiatric illness or any physical disability were excluded.

Tools

The data for the present study were collected using standardized psychological assessment instruments. Prior to the commencement of data collection, formal institutional approval was obtained to ensure adherence to ethical research protocols. Participants were clearly informed about the objectives, procedures, and their rights related to participation in the study. Data were collected only after participants signed the consent form, for voluntary agreement to participate.

- The *Zarit Burden Interview (ZBI)*, developed by Zarit, Reever, and Bach-Peterson, was used to assess the subjective burden experienced by caregivers. This scale comprises 22 items designed to evaluate multiple dimensions of caregiver strain, including emotional, physical, social, and financial aspects associated with the caregiving role.
- To assess emotional distress, the *Depression Anxiety Stress Scales- 21 (DASS-21)*, an abbreviated version of the original instrument developed by Lovibond and Lovibond (1995), was used. This self-report measure consists of 21 items divided into three subscales that independently assess the severity of depression, anxiety and stress.
- The *Mindful Self-Care Scale (MSCS)*, developed by Catherine Cook-Cottone (2018), was included to measure the frequency of engagement in mindful self-care behaviours. This 33-item self-report instrument assesses various domains of self-care such as physical care, supportive relationships, mindful awareness, self-compassion, and balance.
- *Self-Rated Health (SRH)* was used as a general indicator of participants perceived health status. SRH is a widely validated, single-item measure that asks participants to evaluate their overall health with the question: “*In general, would you say your health is...*” with responses rated on a 5-point Likert scale ranging from “poor” to “excellent.” This measure is considered reliable and valid among populations without cognitive impairment and offers a succinct indicator of global health perception.

RESULT AND DISCUSSION

The correlational analysis conducted using Spearman’s rank-order correlation demonstrated significant relationships between caregiving burden and some psychological and health-related variables for family caregivers of individuals with schizophrenia.

Table 1: shows the gender frequency of the participants of the present study

Gender	Frequency	Percent	Valid Percent
Male	15	37.5	37.5
Female	25	62.5	62.5
Total	40	100.0	100.0

Table 2: shows the frequency of relationship with the patient.

Relationship	Parent	Spouse	Sibling	Relative	Total
Frequency	6	13	12	9	40

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A statistically significant negative correlation was identified between caregiving burden and self-reported health ($\rho = -0.351$, $p = .026$), which means that as caregivers report an increase in their caregiving burden, they also report a decrease in their health. This outcome substantiates the existing research that extended caregiving responsibilities can negatively impact the physical and psychological well-being of the caregiver (Schulz & Sherwood, 2008).

Caregiving burden also had positive significant correlations with depression ($\rho = 0.320$, $p = .045$) and stress ($\rho = 0.376$, $p = .017$). These results indicate that caregivers reporting higher levels of burden are more likely to experience depressive symptoms and increased stress. This finding is consistent with Awad and Voruganti's (2008) finding that emotional strain is a common finding of extended caregiving in psychiatric illness.

While the connection between the burden of caregiving and anxiety was positive ($\rho = 0.306$), it did not reach statistical significance ($p = .055$), suggesting a possible trend or association but not enough to say that a definitive conclusion can be drawn. This may suggest that anxiety for caregivers may depend on other variables that were not detected in this analysis.

Further, there was also a significant negative correlation between caregiving burden and self-care ($\rho = -0.351$, $p = .026$), pointing to the fact that as burden increases, caregivers are less likely to follow through and engage in regular self-care. This could indicate a potentially unhealthy cycle where the caregivers' personal health declines due to caregiving responsibilities and is further aggravated by psychological distress and health consequences (Cottone & Drucker, 2018).

Table 3: Spearman's Correlation between Caregiving Burden and Key Variables

Variable	Correlation Coefficient (ρ)	p-value	Significance
Self-Reported Health	-0.351	0.026	Significant
Depression	0.32	0.045	Significant
Anxiety	0.306	0.055	Not Significant
Stress	0.376	0.017	Significant
Self-Care	-0.351	0.026	Significant

CONCLUSION

This research was aimed at studying psychological and health-related consequences of caregiving burden among family caregivers of schizophrenic patients. The results provide valuable insights concerning the complexities of caregiving, as well as the associated issues, when dealing with a chronic psychiatric condition.

The gender split in its study demonstrated that more of the caregivers were female (62.5%), which is consistent with existing studies that argues that caregiving roles are usually unfairly concentrated in the hands of women within a family unit (Pinquart & Sorensen, 2006). Such gendered division can be regarded as an indicator of large-scale societal trends in which women are showed as more often inclined to adopt nurturing and supportive roles within the family structure.

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The burden of caregiving levels reported in the present study were striking, with a little over a half of the interlocutors (45%) reporting moderate to mild burden, whereas close to a quarter (22,68 %) experienced high burden. These results largely concur with those that have been previously documented of the extreme load on emotions, physically, and financially of having to take care of people with schizophrenia (Awad & Voruganti, 2008). Notably, caregiving burden was found to remain significantly and negatively related to self-reported health and, therefore, as perceived burden rose, the subjective health evaluation of caregivers declined. This supports the other claim by Schulz and Sherwood (2008) that long-term care provision is a serious social determinant of health, which in most cases has negative consequences on the care providers.

Moreover, the study found out that there were substantial positive relationships between caregiving burden and depression and stress and this cemented the fact that emotional distress is a common product when it comes to extended care giving (Zarit, Reever, & Bach-Peterson, 1980). Such psychological effects can, subsequently, influence the capacity of caregivers to offer proficient and responsive care and subsequently the patient outcomes. Although the connection between the caregiving burden and anxiety did not prove to be statistically significant ($p = .055$), the pattern indicated its potential relationship that is important to be examined further. This margin may be due to individual variations in coping or presence or lack of support support systems or actual care giving situation.

All of these findings taken in their entirety emphasize the necessity of effective interventions to caregiver stress, such as psychoeducation, stress management training, and the provision of mental health services based on the case. Further, to better establish how care giving burdens and its psychological effects change with time and how interventions can be developed to ensure that these effects are reduced it would be important to increase research on longitudinal methods of assessment.

Strengths and limitations:

This study's strength lies in its comprehensive assessment of caregiver burden using validated tools across psychological and health domains, offering a holistic view of the caregiving experience in schizophrenia. Including diverse caregiver relationships adds ecological validity. However, its limitation is the single-site outpatient setting, which may limit generalizability, and the inclusion of all schizophrenia subtypes, which restricts disorder-specific insights. Future studies should target specific subtypes, involve community-based supports like NGOs, and develop home-based and psychotherapeutic interventions tailored to caregivers' unique needs.

Future implications:

Future research should focus on specific subtypes of schizophrenia to better understand the distinct challenges faced by caregivers in each context. The role of community-based organizations, particularly NGOs, warrants further exploration, as their involvement could enhance caregiver support networks. Additionally, home-based intervention models should be developed to promote healthier and more stable family environments for both patients and caregivers. Finally, there is a need to formulate targeted psychotherapeutic interventions that directly address the emotional, psychological, and practical challenges encountered by caregivers.

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Conflict of Interest

The author(s) declared no conflict of interest.

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