

Understanding The Burden of Care Among Family Caregivers of Schizophrenia Patients in Malaysia: A Systematic Review

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Abstract. Family caregivers play a vital role in managing schizophrenia in Malaysia's family-centric society, but this often results in a significant and multifaceted burden. This systematic review, aims to systematically identify and synthesise existing research focused on the burden experienced by family caregivers of schizophrenia in Malaysia. This study using the PRISMA checklist to ensure compliance with the guidelines for systematic reviews and meta-analyses. A comprehensive literature search was conducted across four databases Scopus, ScienceDirect, Web of Science, and Google Scholar, covering publications from 2010 to 2025. Studies were included if they were original research, conducted in Malaysia, published in English or Bahasa Melayu, and focused on caregiver burden among family caregivers of schizophrenia patients. The search strategy employed Boolean operators combining keywords related to schizophrenia, caregivers, burden, and Malaysia. Quality assessment and data extraction were performed systematically. The result shows, out of 240 papers, only nine papers were selected based on inclusion and exclusion criteria. Overall, the collective findings provide a clear picture of caregiver burden as a complex and broad issue encompassing psychological, social, and financial dimensions based on previous study in Malaysia. The effects of schizophrenia make caregivers of patients need help and support to cope with the burden of caring for the patient with schizophrenia. Caring for a person with schizophrenia can have a significant impact on the mental, physical, emotional, and financial health of caregivers.

Keywords Burden; caregivers; schizophrenia; Malaysia; systematic review

Introduction

Schizophrenia is a mental illness faced by a small number of people, with a ratio of 1.5 million people in the world suffering from schizophrenia (Lefort et al., 2018). Schizophrenia is a serious mental illness of the type of psychotic disorder where patients will experience delusions, hallucinations, unclear speech, abnormal body movements, and behaviour, and have negative symptoms (American Psychiatric Association, 2024). Usually, this mental illness of schizophrenia occurs in adults and adolescents and rarely occurs in children and the elderly (Miller & Black, 2019). However, Schizophrenia can impact individuals and affect their lives if not treated properly. Among these impacts are suicide attempts, extreme anxiety, depression, inability to work, financial problems, and social isolation (Mayo Clinic, 2024). According to Seeman (2021), men and women have different tendencies to suffer from the symptoms of schizophrenia. In terms of age, men aged between 18 and 25 years have suffered from this mental illness. While women, between 25 and 40 years (Seeman, 2021).

Caring for a schizophrenic patient is not as easy as one might think. It requires close care and a long period of care. The burden of care has both negative and positive effects on caregivers of schizophrenia patients. The negative impacts include traumatic experiences, feelings of hopelessness regarding their own life and health, a lack of personal and social resources, uncertainty in their caregiving role, conflicts among family members, strained personal relationships, difficulties in understanding the patient, and the stigma

associated with mental illness. (Liu, Heffernan & Tan, 2020). On the other hand, some positive impacts of caregiving can include increased unity within the family, feelings of admiration and affirmation, love, compassion, the acquisition of knowledge and skills, enhanced self-confidence, personal growth, and a greater appreciation for life (Shiraishi & Reilly, 2019) schizophrenia patients, hopelessness in life and health, lack of personal and social resources, uncertainty, problems between family members, conflicts in personal relationships, difficulty understanding, and stigma. The positive impacts identified include unity within the family, admiration, affirmation, love, compassion, knowledge, learning skills, self-confidence, personal growth, and appreciation (Shiraishi & Reilly, 2019).

In Malaysia, it is estimated that 30 per cent of the population suffers from mental illness, including schizophrenia. Society often refers to schizophrenia as a disease of "orang gila," which translates to "mentally ill people" (Farhana Abd Hamid, 2023). Caregiver burden describes the multidimensional strain experienced by individuals caring for someone with a mental illness, encompassing physical, emotional, financial, and social challenges (Umair et al., 2022). It is crucial to study caregiver burden in Malaysia, particularly due to unique cultural norms, social structures, the stigma surrounding mental illness, and the evolving healthcare frameworks that impact caregivers' experiences and their access to support.

The importance of studying the burden of caregivers of schizophrenia patients, particularly in Malaysia, lies in the unique interplay of cultural, social and systemic factors that shape the caregiving experience. Culturally, Malaysia is a multi-ethnic Asian society where families have traditionally assumed primary responsibility for caring for ill family members, including those with chronic mental illnesses such as schizophrenia. This family obligation, rooted in societal and religious norms, often forces caregivers to provide extensive and long-term care at home with limited outside assistance, which can increase the burden experienced. Socially, the stigma associated with mental illness in Malaysia remains significant, leading to social isolation of both patients and caregivers. This stigma negatively impacts caregivers' psychological well-being, contributing to increased levels of anxiety, depression and feelings of shame, which exacerbates the overall burden. Furthermore, social support networks, while protective, can be variable and sometimes inadequate due to this stigma and the lack of formal community services. This systematic review, aims to systematically identify and synthesise existing research focused on the burden experienced by family caregivers of schizophrenia in Malaysia.

Methodology

Study Design

The present study employed a systematic review design based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 guidelines to ensure compliance with the reporting standards for systematic reviews and meta-analyses (Page et al., 2021). We took a methodological approach to ensure a comprehensive, transparent and replicable synthesis of existing evidence on caregiver burden among family caregivers of schizophrenia patients in Malaysia. The review aimed to reduce bias and improve the reliability of the findings in line with the PRISMA framework, thus providing solid evidence to guide practice and policy development in the Malaysian mental health context.

Search Strategy

Search strategy for this paper is using data identification. Data identification is the process of finding key keywords that are relevant to the study being conducted. Researchers search for and identify related terms and synonyms for the keywords. For example, the keywords used are burden, caregiver, and schizophrenia. In addition, the researchers searched for synonyms in the Thesaurus database for English and other databases.

The sources of information in this systematic review included primary databases, including Science Direct, Scopus, Web of Science, Google Scholar, and manual reference checks of included studies. The search strategy used a structured Boolean technique that combined keywords and vocabulary prefixes of core terms including "schizophrenia" OR "psychosis," "family caregiver" OR "caregiver" OR "relative," "burden" OR

"tension" OR "invisible" OR "stress" OR "stigma"*, and " Malaysia" with the full search string archived in the appendix.

Eligibility Criteria

The eligibility process was a process to determine all the keywords. In this process, each previous study was reviewed based on the title and abstract. Studies had to be original research articles which is primary studies rather than secondary sources like reviews or commentary, according to the inclusion criteria. In order to reflect the primary languages of academic and clinical discourse in Malaysia, publications had to be written in either English or Bahasa Melayu. The publication date was restricted to between 2010 and 2025 to ensure the currency and relevance of the evidence. All studies must be conducted in Malaysia.

Exclusion criteria were applied to filter out ineligible studies. Books, notes, letters, reviews, editorials, and conference papers were excluded as they do not present primary empirical data suitable for systematic review. Publications in languages other than English or Bahasa Melayu were excluded due to translation resource constraints. Studies published before 2010 were excluded to maintain the recency of evidence and research conducted outside Malaysia was excluded to preserve contextual specificity. Data eligibility criteria can be seen in the table 1 below.

Table 1. Data eligibility

Criteria	Eligibility	Exclusion
Type of previous studies	Research journals	Books, notes, letters, reviews, editorials and conference papers.
Language	English and Bahasa Melayu	Other than English and Bahasa Melayu
Year of publication	From 2010 to 2025	Before 2010
Place of study	Malaysia	Other country

Study Selection Proses

The study selection process followed the PRISMA flow diagram to document each stage of the review systematically and transparently. The eligibility process began by screening all identified records based on titles and abstracts to assess relevance to the review question. Following the initial screening, retrieve full texts of potentially eligible studies and assess them against the inclusion criteria to confirm suitability for inclusion. Exclude studies that do not meet all inclusion criteria, and document reasons for exclusion to maintain transparency. Subsequently, perform data extraction on all selected studies using a standardised data extraction form designed to capture key information systematically and consistently across studies.

Data Extraction

Data extraction was done on all selected past studies before conducting the analysis. Data extraction focused on primary and empirical data. The researcher will search for three important parts, abstracts, results and discussion before continuing to search for other information. Besides that, for the review, only primary studies were selected. This is because systematic reviews are secondary research and do not aim to analyse the studies.

The Findings

The literature search identified a total of 240 records across the four databases. After removing duplicates and screening, nine studies met the inclusion criteria. The detailed study selection process is illustrated in the PRISMA flow diagram. Based on Figure 1, the PRISMA flow diagram below shows that 1 paper was selected in Scopus, while 112 were found in ScienceDirect, there were no papers in Web of Science, and 127 were found in Google Scholar. A total of 240 papers were selected. However, 5 papers were duplicated and had to be discarded because they had the same title in two databases. Out of 240 papers, only nine papers were selected based on inclusion and exclusion criteria. The reason why 184 papers were excluded was that they did not meet the inclusion criteria, particularly in terms of the burden on caregivers of schizophrenia patients, did not conduct research in Malaysia, and used languages other than Malay and English.

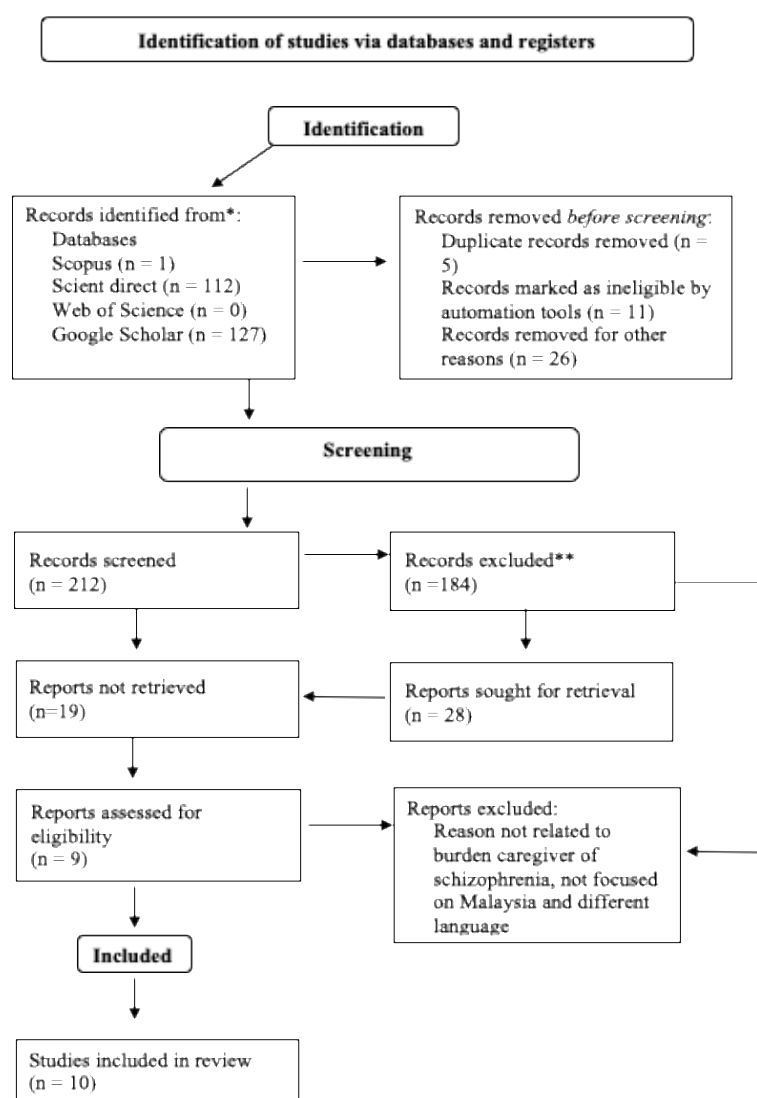


Figure 1. PRISMA flow diagram

The results of the systematic review of the literature revealed that previous studies on Table 2 above, employing various methodologies including cross-sectional, quantitative, and qualitative designs, had sample sizes ranging from 8 to 243 caregivers. This was to consistently identify a significant burden among caregivers of schizophrenia patients. This burden is of various types. The majority of previous studies in Malaysia experienced psychological burden, as evidenced by high levels of psychological distress, depressive disorders, anxiety, and stress (Alipah et al., 2010; Kai Shin et al., 2020; Ibrahim et al., 2022). At the same time, social burden was reported in various previous studies in Malaysia, characterized by experiences of stigma, disrupted family relationships, and lack of critical social support (Talwar & Matheiken, 2010; Tan et al., 2012; Fitriyasari et al., 2018; Wong et al.; Frizzell & Madon, 2020).

In addition, caregivers of schizophrenic patients also face significant economic burdens, with financial stress a direct concern and disparities observed between urban and rural settings (Talwar & Matheiken, 2010; Mohamad et al., 2013). These results also highlight gaps in support systems, as a low percentage of caregivers seek help from healthcare workers despite expressing an interest in receiving more help (Tan et al., 2012). Overall, the collective findings provide a clear picture of caregiver burden as a complex and broad issue encompassing psychological, social, and financial dimensions.

Table 2. Result of literature study

Study (Author, Year)	Study Design	Sample Size	Measurement Tools	Main Findings on Burden
Alipah et al. (2010)	Cross-Sectional Study	243 caregivers of schizophrenia	Socio-demographic questionnaire, the General Health Questionnaire (GHQ-30) and the McMaster Family Assessment Device. Mini International Neuropsychiatric Interview for diagnosing depressive disorders	Psychological distress was 14% (n = 33), and depressive disorders were 6% (n = 14).
Talwar & Matheiken (2010)	Questionnaire, Instrument-Rated, And Cross-Sectional.	50 schizophrenia patients and their caregivers in Malaysia and India	Burden Assessment Schedule (BAS)	Finance, family relationships, well-being and health.
Tan et al. (2012)	Descriptive And Quantitative Methods.	150 caregivers of schizophrenia	The Burden Assessment Scale and The Family Crisis-Oriented Personal Scales	31.3% distress, and 33.3% found stigma upsetting. 14.7% sought help from healthcare workers, and 49.3% were interested in knowing more. 24.7% verbalised sufficient social support.
Mohamad et al. (2013)	Questionnaire	154 family caregivers of schizophrenia	Experiences of Caregiving Inventory (ECI) and the Life Skills Profiles (LSP-39)	Economic burden between urban and rural areas
Fitryasari et al. (2018).	Qualitative	15 family members of patients with schizophrenia	Interpretive phenomenology approach, with in-depth interview	Care burden and stigma
Kai Shin et al. (2020)	Cross-Sectional Study	114 primary caregivers of a patient with schizophrenia	Sociodemographic and clinical characteristic questionnaire, Depression Anxiety Stress Scale – 21 and Multidimensional Scale of Perceived Social Support.	Psychological burden (depression, anxiety and stress)
Wong et al. (2020)	Qualitative Approach Using Caeli's Generic Principles	18 caregiver schizophrenia patients	Thematic analysis	Stigma
Ibrahim et al. (2022)	The Specific Methods Used For Assessment Are Not Mentioned In The Abstract	200 caregiver schizophrenia patients	The specific methods used for assessment are not mentioned in the abstract.	Higher psychological distress and burden.
Frizzell & Madon (2022).	Qualitative	8 caregivers of schizophrenia	Thematic analysis	Social burden (lacking social support)

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Discussion

This systematic review synthesizes recent evidence (2010–2025) showing that family caregivers of individuals with schizophrenia in Malaysia endure profound "unseen burdens." The nine studies consistently show that caregiving in this context is highly challenging. The burden spans psychological, social, and economic dimensions. The evidence highlights the significant toll on those who support family members with schizophrenia. The emotional and psychological well-being of caregivers is influenced by the symptoms and behaviors of the schizophrenic patients they care for. High levels of symptomatology in patients correlate with increased caregiver burden, leading to psychological distress and decreased caregiver quality of life (Gater et al., 2015; Stanley et al., 2017). Caregivers express a strong interest in learning more about schizophrenia and its treatment. They identify specific educational needs such as coping strategies, understanding symptoms, and information about new medications. This knowledge can empower caregivers to provide better support while effectively managing their own burden. Establishing a strong social support system is important for both caregivers and patients with schizophrenia so that caregivers should not hesitate to seek help from friends, family members, or professional services to ease some of the burdens associated with caring for a person with schizophrenia. Caregivers should also be prepared for potential crises by having a plan, being aware of early signs of the patient or distress experienced during the process of caring for a person with schizophrenia. This allows for timely interventions, and can provide effective management of the person with schizophrenia (Ranjan & Gupta et al., 2023).

In addition, according to Citrome et al. (2022) stated, caregivers may lack knowledge in obtaining important information to require them to care for schizophrenia patients but they show interest in learning more about schizophrenia. Psychoeducation can be used by caregivers of schizophrenia patients as an intervention to reduce the burden they face. Iswanti and Rumambo Pandi (2022) found that psychoeducation among family members showed a significant impact of therapy in reducing the symptoms faced by schizophrenia patients, improving social functioning, quality of life and behavior of schizophrenia patients in taking their medication. In addition, psychoeducation increases knowledge about the disease and reduces the stigma faced by caregivers and schizophrenia patients. Isawanti and Pandi (2022) also stated that components in helping caregivers manage stress include coping skills to adapt to stress among caregivers of schizophrenia patients (Iswanti & Rumambo Pandi, 2022). Psychoeducational programs among caregivers of schizophrenia patients can reduce stress and increase positive attitudes towards mental patients (Ahmed & Ghaith, 2018).

Meanwhile, based on the National Mental Health Policy 2012, communities should participate closely in identifying and implementing community-based activities. However, they tend to face problems, such as professional bodies in mental health service paying less attention to patients' families, accessibility to mental health service, and the quality of mental health services provided by mental health is poor for the community

(Mohamad et al., 2011). This has led to limited participation among the community, especially caregivers of schizophrenia in Malaysia to participate in activities provided by mental health services in hospitals. Therefore, services and policies can promote mental health services and awareness to the community. This is because most families still lack social support due to the effects of stigma from the local community. Furthermore, intervention programs and social services related to the management and care of mental patients in the community are very limited. Based on the Mental Health Act (2001) which encourages families to take care of family members with mental illnesses themselves after they are discharged from the hospital, caregivers are still found to be less prepared to take care of their family members, especially those with schizophrenia because they require special care and observation to care for them (American Psychiatric Association, 2024).

In addition, to provides evidence-based recommendations to improve the caregiver support system at the institutional and government levels, National Mental Health Policy need to highlight gaps in the existing support system, such as the lack of hospital care, social work services or tailored financial assistance programs for caregivers of schizophrenia patients through the needs identified in this study. The Malaysian government can improve the overall mental health care framework by addressing these needs through policy changes or new service offerings to avoid criticism from various quarters due to the increasing mental health problems in the country (Hamzah & Othman, 2024).

Conclusion

In conclusion, Schizophrenia has placed a burden on caregivers to care for the patient. Caregivers have to deal with the patient's symptoms, send the patient to the hospital for treatment and help the patient in carrying out their daily activities. The effects of schizophrenia make caregivers of patients need help and support to cope with the burden of caring for the patient with schizophrenia. Caring for a person with schizophrenia can have a significant impact on the mental, physical, emotional, and financial health of caregivers. The responsibilities of providing care, monitoring the patient's behaviour, and managing finances can be overwhelming and lead to poor outcomes. Caregivers need support, counselling, and respite care to promote their well-being and quality of life. Healthcare providers need to reduce the burden faced by caregivers and provide them with adequate support, education, and resources to manage the challenges of caring for a loved one with schizophrenia.

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Conflicts of Interest: The authors declare no conflict of interest.

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