

Determinants of Burden in Family Caregivers of Individuals With Schizophrenia

A Systematic Review

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ABSTRACT

The current systematic review was performed to determine the specific burdens placed on families of individuals with schizophrenia. Scopus, PubMed, and CINAHL databases were searched, resulting in 21 articles that met inclusion criteria. Results showed that treatment of individuals with schizophrenia poses a burden on families. Most caregivers experienced emotional and financial problems that affected their quality of life. Influencing factors in caregivers were age, sex, educational level, family status, income, time spent with the individual per day, knowledge regarding schizophrenia, attitude, and psychological stress. Influencing factors in individuals with schizophrenia were age, sex, severity of illness, social function, and treatment adherence. Environmental factors were stigma, social support, and professional support from health care providers. Family caregivers of individuals with schizophrenia need to be empowered to improve resilience and acceptance in caring for these individuals. [*Journal of Psychosocial Nursing and Mental Health Services*, xx(x), xx-xx.]

Schizophrenia is characterized by psychotic thought processes; emotional, perceptual, and affection disorders; and autism (Zahnia & Wulan Sumekar, 2016). The complexity of resulting disturbances decreases individuals' with schizophrenia lifetime productivity, making them highly dependent on family members or others (Bahari et al., 2017). According to Nurhidayah et al. (2020), family caregivers must accompany individuals with schizophrenia 24 hours per day. The World Health Organization (WHO) states that approximately 21 million individuals have schizophrenia and mental health problems, accounting for 13% of total disease worldwide. This percentage is predicted to increase to 25% by 2030 (Warner & de Girolamo, 2015). According to Indonesia's Basic Health Research Data in 2018, the prevalence of schizophrenia in Indonesia is seven individuals per mile, and in East Java Province, the number of individuals with schizophrenia has increased from 2.2 per mile to 5 per mile (Ministry of Health of the Republic of Indonesia, 2018). Globally, there are only 0.61 outpatient mental health facilities per 100,000

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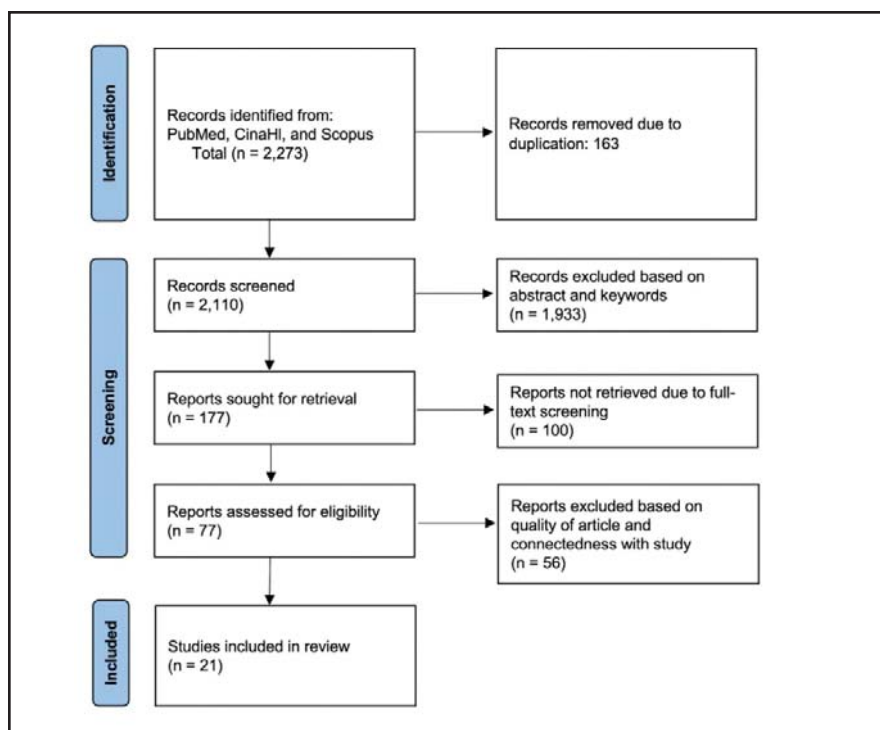


Figure 1. Flow chart of study selection.

people and 17.5 hospital beds available per 100,000 people (Warner & de Girolamo, 2015).

The family management framework developed by Knafl and Deadrick (1990) states that if a family member has health problems, the family should engage in effective and sensitive interventions to encourage all members to be in good health (Knafl et al., 2008). For this reason, the role of family in achieving health is important. However, family also has the responsibility to care for the ill individual, but in practice, this care creates burdens on the family (Nuraenah et al., 2012). Many individuals with schizophrenia require optimal treatment to improve their quality of life (Fitri et al., 2020). According to Jannah (2019), individuals with schizophrenia need family members who are able to provide holistic care. Family members also help these individuals with daily activities, such as bathing, dressing, eating, taking medication, and toileting (Jannah, 2019). The burden felt by family members also includes subjective elements, such as worry about the individual's health status, poor financial

conditions, and trouble meeting daily needs. Meanwhile, objective burdens are experienced in the form of poorer health of family caregivers, higher family stress, and ineffective family coping, all of which result in the failure of the family to care for the individual with schizophrenia (Wardani & Dewi, 2018).

According to research, 80% of schizophrenia recurrences are caused by a patient's family's failure to regulate their own emotions, and frequent criticism from family members results in a patient's recurrence (Amaresha & Venkatasubramanian, 2012; Fadli & Mitra, 2013). In addition, 90% of families are burdened in terms of medical costs, time spent caring for the individual with schizophrenia, stigma related to having a family member with a mental disorder, disruption at work, and reduced productivity (Sulastri, 2018). Various factors influence family burden in caring for individuals with schizophrenia, such as knowledge regarding schizophrenia, education, and attitude (Syafwani, 2012). Research has been performed on factors that influence family burden of care for

individuals with schizophrenia. From this information, it is possible to provide a model that reduces caregiver burden.

METHOD

Search Strategy

The current study used the Preferred Reporting Items for Systematic Reviews and Meta-Analyses method (Page et al., 2021). A comprehensive search for articles was performed in three databases (Scopus, PubMed, and CINAHL). The search was limited to full-text articles in English published between 2016 and 2020. Keywords used in the literature search were "Determinant" AND "family" AND "empowerment" AND "(care OR caregiver)" AND "schizophrenia" AND "burden."

Study Selection

Articles were screened and evaluated to meet inclusion criteria. We selected articles written in English, including case studies, cohort studies, randomized controlled trials, and qualitative studies. From these articles, we observed factors that could affect burden in families with an individual with schizophrenia. Researchers considered positive and negative impacts on families. These findings may help provide a more accurate representation of factors that contribute to the burden placed on such families.

The search obtained 2,273 articles. Of these articles, 163 were duplicates. Researchers performed a screening based on article titles, abstracts, and keywords. Researchers then filtered the articles and analyzed the entire text. Finally, 21 articles were deemed eligible for the study (Figure 1). Table A (available in the online version of this article) provides a summary of the selected articles.

RESULTS

Most of the 21 articles were cross-sectional and performed in several countries, including China (Chen et al., 2019; Liu & Zhang, 2020; Yu et al., 2020; Yu et al., 2018), Egypt (Ebrahim et al., 2020), India (Alka et al., 2018), Indonesia (Nuralita et al., 2019), Iran (Hajebi et

al., 2019), Japan (Shiraishi et al., 2019; Sruamsiri et al., 2018), Korea (Park & Lee, 2017), Nepal (Shrestha & Dwa, 2018), Pakistan (Ehsan et al., 2018), Romania (Strunoiu et al., 2019), Spain (Blanthorn-Hazell et al., 2018; Ribé et al., 2018), Taiwan (Chang et al., 2018), and the United States (Brain et al., 2018; Rhee & Rosenheck, 2019; Velligan et al., 2019; Villalobos et al., 2017).

Many studies have been performed and developed to measure the burden felt by family caregivers of individuals with schizophrenia. From the current systematic review, we conclude that family caregivers experience moderate to heavy burden in caring for family members with schizophrenia. We found several factors that influence overall family burden: caregiver, patient, and supporting factors. Caregiver factors include age, sex, educational level, family status, income, time spent with the individual with schizophrenia per day, knowledge, attitude, and psychological stress. Patient factors include age and clinical symptoms. Supporting factors were social and professional support.

From the 21 articles reviewed, apart from family burden factors, we also found that most caregivers experienced emotional and financial problems in caring for individuals with schizophrenia. Emotional problems, which included depression and anxiety, affected caregivers' personal life and relationships with the community (Ehsan et al., 2018; Hajebi et al., 2019; Liu & Zhang, 2020; Shrestha & Dwa, 2018; Yu et al., 2018). From a financial perspective, caregivers experienced decreased productivity, job loss, and decreased income, which resulted in decreased quality of life (Chen et al., 2019; Nuralita et al., 2019; Ribé et al., 2018; Sruamsiri et al., 2018). In addition, caregivers also experienced stigma from the community because of their family members' diagnosis (Ebrahim et al., 2020).

Schizophrenia carries a high stigma, causing caregivers to feel ashamed and burdened (Blanthorn-Hazell et al., 2018; Park & Lee, 2017). However, caregivers

who accept the condition of their family members with schizophrenia and know their roles in caring for these individuals tend to have lower levels of burden (Chang et al., 2018; Velligan et al., 2019). In addition, caregivers who have experience in caring tend to have low levels of stress and accept the condition more readily (Rhee & Rosenheck, 2019). Therefore, it is necessary to raise caregivers' acceptance and awareness regarding their duties in caring for family members with schizophrenia, as this can be a way to overcome burden. In addition, a culture-based approach to overcome the burden experienced by caregivers is needed, as well as policies from the government to help caregivers, especially in increasing knowledge and care for individuals with schizophrenia (Alka et al., 2018; Brain et al., 2018; Shiraishi et al., 2019; Yu et al., 2020).

DISCUSSION

In the current context, *burden* is defined as the negative impact of caring for a person who has a disorder, which is experienced by caregivers in their activities (objective burden) or feelings (subjective burden). Burden involves family members' emotional and physical health, social life, and financial status (Nihayati et al., 2021; Nuralita et al., 2019). Hoenig and Hamilton (1996) defined *objective burden* as an event or activity related to a caregiver's negative experience, whereas *subjective burden* is the feeling that arises in a caregiver due to their role. From the current review, it can be concluded that most family caregivers feel burdened in caring for family members with mental illnesses, such as schizophrenia. The impact can be felt in caregivers' lives (objective burdens) or emotions (subjective burdens).

Age is positively correlated with burden of care. As a caregiver ages, they worry about who will care for their family member in the future (Nuralita et al., 2019). Older individuals also tend to have more experience in coping with problems than younger individuals. According to a study on gender differences in parenting among the schizophrenic

population in China, female caregivers are more likely to experience depression and anxiety than their male counterparts (Yu et al., 2018). Female caregivers also report more adverse effects on physical and mental health, such as depression and anxiety (Yu et al., 2018).

Furthermore, uneducated caregivers experience a significantly heavier burden in caring for individuals with schizophrenia than educated caregivers (Ebrahim et al., 2020). Level of education is a variable that can moderate level of burden experienced by a family. This moderation is explained by the fact that people who have more knowledge about schizophrenia and more social resources provide better care. Family members who play dominant roles will determine function when they realize that one family member is sick, namely by making efforts to rearrange roles within the family. One study showed that critical comments and emotional over-involvement expressed by family members increased burden on primary caregivers (Hajebi et al., 2019). A Japanese study showed that the loss of productive care for individuals with schizophrenia was large and placed a significant burden on society (Sruamsiri et al., 2018). One study reported that 19% of caregivers used to work but had to quit their job (Sruamsiri et al., 2018). In addition to caring for family members with schizophrenia, caregivers also experience financial difficulties.

Caregivers' role in caring for individuals with schizophrenia includes facilitating basic activities, such as eating, bathing, and maintaining personal hygiene (Janardhana et al., 2015). Caregivers must also constantly monitor these individuals. Research has revealed that caregivers' role on average lasts for 11 years, and that they provide care for approximately 36.8 hours per week (Janardhana et al., 2015). Immediate care hours involve a variety of activities, including medical care. Family caregivers who care for individuals with schizophrenia for long periods of time experience heavy burdens and feelings of hopelessness (Brain et al., 2018).

The attitude shown by the family in caring for the individual with schizophrenia is related to the level of knowledge that the family has about the illness. This finding is supported by a study that claims the family's attitude toward caring for persons with schizophrenia is correlated with knowledge (Alka et al., 2018). Chen et al. (2019) identified three main types of loads in family caregivers of individuals with schizophrenia: financial and daily work burdens, limited social communication, and psychological pressure. Family caregivers experience severe psychological pressure because of prejudice and discrimination from others (Monnapula-Mazabane & Petersen, 2021), which can increase social isolation and insecurity.

Based on several studies, it is known that the burden experienced by families can be reduced through psychoeducation and group psychotherapy programs conducted by health professionals. Professional support also has an impact on the quality of life for families with members who have schizophrenia (Chien, 2008; Navidian et al., 2012; Ribé et al., 2018; Sin et al., 2017). Family members are likely to provide care for an extended period of time for individuals with schizophrenia after they are discharged from the hospital (Haselden et al., 2018). This care can be a burden and puts pressure on the family (Amaresha & Venkatasubramanian, 2012). The burden experienced by caregivers is increased by a perception of difficulty in caring for individuals with schizophrenia (Nuralita et al., 2019). Families who have cared for such individuals said that there was an increase in the burdens they bear, psychological and social. Psychological burdens include feelings of guilt, sadness, anger, fear, anxiety, and anxiety about the individual's condition (Velligan et al., 2019). Social burdens include stigma and angry reactions from neighbors and communities (Wahyuni et al., 2019).

Support from people around them makes caregivers stronger, enabling them to better perform their role. This support helps caregivers by minimizing potential

stress that arises during caregiving. Most caregivers without family support experience a heavier burden. Family support makes caregivers more optimistic in facing challenges (Nurmalisyah, 2018).

CONCLUSION

Burdens are difficulties faced by family caregivers in caring for individuals with schizophrenia. These burdens include caregiver, patient, and environmental factors. Most caregivers experience emotional and financial problems that affect their quality of life. Mental health nurses should consider these factors as a basis for developing a model of family empowerment. Interventions to reduce burden and increase resilience and acceptance of caregivers' roles in caring for individuals with schizophrenia are needed.

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Table A. Description of Selected Articles ($N = 21$)

Title and Authors	Years of Publication	Places of Research	Research Methodology	Sample Size	Measures	Results	Conclusion
Productivity loss of caregivers of schizophrenia patients: a cross-sectional survey in Japan (Sruamsiri et al., 2018)	2018	Japan	A cross-sectional study design	171 respondents	Work Productivity and Activity Impairment Questionnaire" (WPAI)	Among the selected caregivers, a relative majority (47 percent) provided care for their spouse, 18 percent provided care for their sibling or sister, and 16 percent provided care for their children. Work engagement was responsible for 97 percent of the overall presenteeism expenses, which came to a total of JPY 2.42 million in per capita productivity costs.	The decrease in the productivity of the caregiver of schizophrenic patients is quite large. Most of the caregivers who quit their jobs had relatively low incomes at their jobs.
Quality of life in family caregivers of schizophrenia patients in Spain: caregiver characteristics, caregiving burden, family functioning, and social and professional support (Ribé et al., 2018)	2017	Spain	A cross-sectional study design	100 caregivers	WHOQOL-BREF Questionnaire, Zarit Scale, Social Network Questionnaire, APGAR Family and professional support scale (Escala de Apoyo Profesional.	There is a statistically significant relationship between the caregiver's burden and their quality of life. Caregiving load, social support, and professional assistance were found to be the greatest predictors of quality of life.	The quality of life of a schizophrenia patient's family caregiver that most influences the burden of care, social support and professional support.
The chronic sorrow experiences of caregivers of clients with schizophrenia in Taiwan: A phenomenological study (Chang et al., 2018)	2017	Taiwan	A phenomenology study design	12 participants	Unstructured interview guidelines	Three themes and eight subthemes emerged, including encountering sorrow, talking with sorrow, and living with sorrow.	Emotional management such as dealing with sadness, talking with sadness, living with sadness and living with responsibilities has an effect in dealing with schizophrenia patients.
Burden in Caregivers of Schizophrenic Patient of Psychiatry O.P.D & Ward of Manipal Teaching Hospital, Pokhara, Nepal (Shrestha & Dwa, 2018)	2018	Nepal	A descriptive study design	72 respondents	Demographic Performance and schedule of family interviews by Pai and Kapoor	Majority 54. 2% of the caregivers was from age 41-65 years but Majority 63. 9 % of the schizophrenic patient were from age group 21-40 years. More than half 52. 8% Caregivers were female and Majority 59. 7 % of the schizophrenic patient were Male. Majority 86% were getting treatment from more than 1 year. Majority 52. 6% of the female Caregiver was having Moderate to severe burden. Financial burden (3. 54±1. 45) was high	The health effects for caregivers are depression and anxiety. Female Caregiver were having Moderate to severe burden. High burden was found in financial burden of caregivers. The caregiver burden is reduced by formal support programs to improve caregiver stress management and coping skills and informal sources of social support.

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A Study to Assess Knowledge and Attitude of Caregivers Regarding Homecare of Family Member with Schizophrenia at Selected Hospital of Dehradun, Uttarakhand (Alka et al., 2018)	2018	Uttarakhand	A cross-sectional study design	100 caregivers	Socio-demographic performance, structured knowledge questionnaires and structured attitude scales.	burden in Caregivers of patients with schizophrenia. A statistically significant correlation between monthly income, residence, age, educational status, relationship with patient and knowledge.	The caregiver has knowledge about the homecare of family members with Schizophrenia which shows the need for an intervention program to increase the knowledge of caregivers.
Gender differences in caregiving among a schizophrenia population (Yu et al., 2019)	2019	China	A cross-sectional study design	327 caregivers	Demographic questionnaire, The Global Assessment of Function (GAF) scale, 24-item Family Burden Interview Schedule (FBIS), nine-item Patient Health Questionnaire (PHQ-9), seven-item Generalized Anxiety Disorder Scale (GAD-7)	Family burden was significantly higher for male patients on the domains of effect on physical and mental health of others, and significantly higher for female caregivers on the domains of financial burden and effect on physical and mental health of others. Caregivers of male patients were more likely to suffer from anxiety than caregivers of female patients (52.7% vs 38.1%, p=0.012); female caregivers were more likely to suffer from depression (51.2% vs 38.6%, p=0.031) and anxiety (51.6% vs 38.1%, p=0.020) than male caregivers.	The family burden is higher for male patients on the anxiety, and female more likely on depression and anxiety.
Negative repercussions of caregiving burden: Poor psychological well-being and depression (Ehsan et al., 2018)	2018	Pakistan	A cross-sectional study design	100 respondents	Zarit Burden Interview (ZBI), The Beck Depression Inventory (BDI), Warwick-Edinburgh Mental Well-Being Scale (WEMWBS).	Findings indicated that informal caregivers of schizophrenia have greater depression and poor psychological well-being in comparison to the non-caregiver controls	Family members who care for people with schizophrenia have greater depression than family members who do not.
Relationship between Caregiver Burden and Expressed Emotion in Families of Schizophrenic Patients (Nuralita et al., 2019)	2019	Indonesia	A cross-sectional study design	100 respondents	Family Questionnaire (FQ), Zarit Burden Interview (ZBI)	The burden of care for the families of the most schizophrenic patients was mid load as many as 36 people, namely 36%, the light burden of 34 people, 34%, no burden of 18 people, 18%, and the heavy burden of 12 people, 12%. There is a significant relationship	The family burden of a schizophrenic has an impact on emotional, physical health, social life, and financial status.

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Does Improvement in Symptoms and Quality of Life in Chronic Schizophrenia Reduce Family Caregiver Burden? (Rhee & Rosenheck, 2019)	2019	United States of America	A cross-sectional study design	446 caregivers	Family Experience Interview Schedule (FEIS), Positive and Negative Syndrome Scale (PANSS), Calgary Depression Rating Scale, self-reported SF-12 mental health summary score	between the burden of treatment with expressed emotion. we examined the association of changes in patient symptoms and quality of life with changes in measures of family caregiver burden. Clinical changes in patient symptoms and quality of life were not significantly associated with changes in family caregiver burden. The weak association likely reflects those small clinical changes in chronically ill adults are insufficient to affect long established experiences of burden.	Changes in the patient's clinical symptoms and quality of life were not associated with changes in the caregiver's family burden. Minor clinical changes in chronically ill adults do not affect long-standing stress experiences.
Korean Sibling Caregivers of Individuals Diagnosed with Schizophrenia (Park & Lee, 2017)	2017	Korea	A phenomenology study design	Eight participants	Semi-structured interview guidelines	We discerned six key themes: sorrow, burnout, shame, different perspectives in life, acceptance, and responsibility. We categorized these themes into three groups: suffering, hope, and responsibility and obligation. Path analyses showed partial support for the attribution model of help-giving. Specifically, attributions of responsibility negatively predicted caregiver's warmth, which in turn predicted more administered support. Contrary to hypotheses, attributions were not associated with caregiver criticism, and criticism was positively related to administered support. In addition, caregiver support was not related to burden at either baseline or a year later. Criticism was a significant predictor of burden at follow-up through burden at baseline.	Families who care for schizophrenics, they love their families, but they sometimes feel ashamed and afraid. Even though families lack understanding about schizophrenia, they have a desire to learn more about the disease. In particular, attributions of responsibility negatively predict caregiver warmth, which in turn predicts more support provided. In addition, caregiver support was not associated with burdens at baseline or a year later. Criticism was a significant predictor of burden at follow-up through load at baseline
Caregiver Criticism, Help-giving and the Burden of Schizophrenia Among Mexican American Families (Villalobos et al., 2017)	2017	United States of America	Explanatory study design	60 caregivers	Key Relative's Attributions of Symptoms Scale, Camberwell Family Interview, Arizona Social Support Interview Schedule, Burden Assessment Scale	Contrary to hypotheses, attributions were not associated with caregiver criticism, and criticism was positively related to administered support. In addition, caregiver support was not related to burden at either baseline or a year later. Criticism was a significant predictor of burden at follow-up through burden at baseline.	In particular, attributions of responsibility negatively predict caregiver warmth, which in turn predicts more support provided. In addition, caregiver support was not associated with burdens at baseline or a year later. Criticism was a significant predictor of burden at follow-up through load at baseline
Burden experienced by caregivers of schizophrenia patients and its related factors (Hajebi et al., 2019)	2019	Iran	Descriptive-analytic study design	172 respondents	The Zarit Burden Interview and the Family Questionnaire	The level of burden experienced by most of primary caregivers was higher than moderate. The scores obtained in the subscales of emotional over involvement and critical comments were	Based on the results of the study, several demographic factors of primary caregivers, patients, and their families significantly influence the burden experienced by primary caregivers. Most caregivers have

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Caregiver Burdens Associated with Treatment-Resistant Schizophrenia: A Quantitative Caregiver Survey of Experiences, Attitudes, and Perceptions (Velligan et al., 2019)	2019	United States of America	Case control study design	177 caregivers	A pilot questionnaire, Schizophrenia Caregiver Questionnaire	higher than the cutoff point in 51.7% and 64.5% of caregivers, respectively, and the scores had a significant direct correlation with the burden experienced by the caregivers. The findings of multiple linear regression showed that lower family income), higher duration of disorder, and younger age at onset of the disorder were predictive of higher burden of disease on caregivers. Caregivers in both groups reported high levels of everyday involvement in most aspects of daily life, including assistance with basic tasks, housekeeping, and in providing emotional support. There were no significant differences between groups on overall social life or health.	high emotional expression and there is a significant direct relationship between emotional expression and the burden experienced.
Factors that Impact Caregivers of Patients with Schizophrenia (Strunoiu et al., 2019)	2019	Romania	A cross-sectional study design	124 caregivers	Zarit interview questionnaire	The average Zarit score in our study was 42.36±8.64, which shows moderate to high burden. Several factors that influence the perceived burden of the caregiver have been identified, such as patient gender, age of onset, patient and caregiver marital status, patient level of education and social functioning, caregiver age, somatic comorbidities and therapeutic compliance of the patient.	There were no significant differences between groups in social life or overall health. However, caregivers of persons living with TRS were among caregivers in the TRS group, correlation analysis revealed a moderate positive correlation between reported individual persistent positive symptom load and overall caregiver burden. Several factors that influence the perceived caregiver burden have been identified, such as patient gender, age of onset, patient and caregiver marital status, patient education level and social function, caregiver age, somatic comorbidity and patient therapeutic adherence.
Stigma and burden of mental illness and their correlates among family caregivers of mentally ill patients (Ebrahim et al., 2020)	2020	Egypt	A cross-sectional study design	425 caregivers	Caregivers of people with mental illness (CPMI), Explanatory model interview catalogue stigma scale (EMIC-Stigma scale)	The significant correlates for affiliate stigma were being parents of patients, having higher associate stigma, and aggressive behavior of mentally ill patients. The significant correlates for associate stigma of the study caregivers were being caregivers' relatives other than parents, having high affiliate stigma, having poor knowledge and negative attitude towards	Caregivers studied suffered from stigma and high levels of burden. Psycho-educational programs for family caregivers are highly recommended.

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A survey of caregiver burden in those providing informal care for patients with schizophrenia or bipolar disorder with agitation: results from a European study (Blanthorn-Hazell et al., 2018)	2018	Spain	A cross-sectional study design	297 respondents	Involvement Evaluation Questionnaire (IEQ)	mental illness, and aggressive behavior of mentally ill relatives. The correlates for the high burden were being male, non-educated caregiver, having high affiliate stigma, having high associative stigma, having poor knowledge and negative attitude toward mental illness, seeking traditional healers and non-psychiatrist's care from the start, and caring after young mentally ill relatives. Caregivers provided 38.3 h a week of support to the patient with 20% providing 50 h or more.	The substantial burden reported by these caregivers is influenced by factors including the number of hours of care provided, patient behavior and state.
A cross-sectional study on spouse and parent differences in caregiving experiences of people living with schizophrenia in rural China (Yu et al., 2020)	2020	China	A cross-sectional study design	264 caregivers	Global Assessment of Functioning scale (GAF), Zarit Burden Interview (ZBI), 9-item Patient Health Questionnaire (PHQ-9), 7-item Generalized Anxiety Disorder Scale (GAD-7), caregiving rewarding feelings (CRF) scale, Family Adaptation, Partnership, Growth, Affection and Resolve Index scale (APGAR)	parent caregivers report significantly higher subjective burden than spouse caregivers, which is also reflected in significantly higher depression and anxiety, and lower family functioning. Despite these differences, both groups of caregivers report comparable rewarding feelings about caregiving.	This research finds implications for family caregivers globally, especially for countries that adhere to Confucian cultural values and provides guidance for future family intervention programs.
The burden, support and needs of primary family caregivers of people experiencing schizophrenia in Beijing	2019	China	A phenomenology study design	20 caregivers	Semi-structured interview guidelines	Most participants reported that they were suffering from heavy life burdens and had negative experiences with respect to obtaining social support, and they emphasized that they would	Respondents reported that they had a heavy life burden and had negative experiences with regard to social support, and they emphasized that they would need more support. Economic burdens and daily

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communities: a qualitative study (Chen et al., 2019)						require more support. Economic and daily housework burdens, limited social communication, and psychological stresses were the principal burdens. Support including financial, medical and information and educational support did not satisfy the needs of the caregivers and their patients. More financial support, respect, and rehabilitation institutions were reported to be needs of the caregivers.	homework, limited social communication, and psychological stress are the main burdens.
Experiences, attitudes, and perceptions of caregivers of individuals with treatment resistant schizophrenia: a qualitative study (Brain et al., 2018)	2018	United States of America	A phenomenology study design	27 caregivers	Semi-structured interview guidelines	Caring for individuals with treatment resistant schizophrenia (TRS) impacts many caregivers' finances, career prospects, social relationships, and a sense of freedom. In addition, many treatment failures caused feelings of despair for many nurses.	Persistent positive symptoms caused significant perceived burden, feelings of being overwhelmed and having no relief, and substantial negative impacts on caregivers' emotional and physical health. To address these substantial unmet needs, policy makers should be aware of the need for practical, social, and emotional support for these caregivers and their families. Additionally, new treatment options for TRS should be developed.
Effectiveness of the Japanese standard Family psychoeducation on the mental health of caregivers of young adults with schizophrenia: a randomized controlled trial (Shiraishi et al., 2019)	2019	Japan	A randomized controlled trial study design	74 caregivers -	State-trait anxiety inventory (STAI), Japanese version of the Zarit burden interview Short version (J-ZBI_8), Family attitude scale (FAS), Link's stigma scale (LSS), Global assessment of functioning (GAF)	Direct effects of the intervention were observed in the caregivers of chronic patients as significant improvements of their overall mental health state at 10 weeks, which indirectly continued until 14 weeks. However, such intervention effects were not observed in the caregivers of recent-onset patients	The lack of effectiveness in the recent-onset stage suggests that the usefulness of the standard model of family psychoeducation (SM-FPE) needs to be corroborated by further research.
Experiences of caregivers of family member with schizophrenia in China: A qualitative study (Liu & Zhang, 2020)	2020	China	A phenomenology study design	16 caregivers	Semi-structured interview guidelines	The change findings encompassed five major themes: (a) loss of personal life, (b) mixed emotions, (c) changes in family relationships, (d) the need for professional support and help, and (e) coping strategies.	The change findings cover five main themes: loss of personal life, mixed emotions, changes in family relationships, need for professional support and help, and coping strategies.