



## FAMILY BURDEN IN CARING FOR FAMILY MEMBERS WITH SCHIZOPHRENIA : A SYSTEMATIC REVIEW

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### ABSTRACT

**Introduction** Schizophrenia cases are increasing worldwide, especially in low- and middle-income countries. Schizophrenia is a serious and chronic mental illness that requires care for family members, but in practice, this becomes a burden for the family, both objective and subjective.

**Objective** This systematic review aims to identify the main focus regarding the burden on families as caregivers of family members with schizophrenia.

**Method** The research method uses PRISMA with a systematic approach and selection process with literature sources searched from the Scopus, PubMed, ScienceDirect, and ProQuest databases and manual searches with the keywords "Caregiver Burden OR Family Burden AND Schizophrenia". The results of the articles that were filtered and obtained were then evaluated using the Joanna Briggs Institute (JBI) tool.

**Result** Related to the burden on the family, three key themes were identified as caregivers of a family member with schizophrenia. The three themes are caregiver burden, stigma, and health services.

**Conclusion** Findings suggest that family burden on caregivers influences the family's ability to care for patients with schizophrenia. The family's burden as caregivers is an important indicator for the provision of mental health services.

**Keywords:** family burden, caregiver burden, schizophrenia

## ABSTRAK

**Pendahuluan** Kasus skizofrenia meningkat di seluruh dunia, terutama di negara-negara berpenghasilan rendah dan menengah. Skizofrenia merupakan salah satu penyakit jiwa serius dan kronis yang memerlukan perawatan anggota keluarga, namun dalam praktiknya hal ini menjadi beban bagi keluarga, baik obyektif maupun subyektif.

**Tujuan** Tinjauan sistematis ini bertujuan untuk mengidentifikasi fokus utama mengenai beban keluarga sebagai pengasuh anggota keluarga dengan skizofrenia.

**Metode** Metode penelitian menggunakan PRISMA dengan pendekatan sistematis dan proses seleksi dengan sumber literatur dicari dari database Scopus, PubMed, dan ScienceDirect serta pencarian manual dengan kata kunci "Beban Caregiver OR Beban Keluarga AND Skizofrenia". Hasil artikel yang telah disaring dan diperoleh kemudian dievaluasi menggunakan alat Joanna Briggs Institute (JBI).

**Hasil** Berkaitan dengan beban pada keluarga, tiga tema utama diidentifikasi sebagai pengasuh anggota keluarga penderita skizofrenia. Tiga tema tersebut adalah beban pengasuh, stigma, dan layanan kesehatan.

**Kesimpulan** Temuan menunjukkan bahwa beban keluarga pada pengasuh mempengaruhi kemampuan keluarga dalam merawat pasien skizofrenia. Beban keluarga sebagai pengasuh menjadi indikator penting dalam pemberian layanan kesehatan jiwa.

**Kata Kunci:** beban keluarga, beban pengasuh, skizofrenia

## INTRODUCTION

A person's ability to manage life's challenges, reach their full potential, study and work effectively, and give back to their community is a sign of their mental health (WHO, 2022a). Mental disorders will appear if this condition is disturbed. Schizophrenia is among the most prevalent types of mental illness. Schizophrenia is a complex mental illness that affects the way a person thinks, feels, behaves, and relates to other people. As many as 51 million people worldwide have schizophrenia, including more than 280,000 people in Canada. People experience symptoms including delusions and hallucinations, which make them lose touch with reality. This experience can be confusing and distressing for people with schizophrenia, family members, friends, and others who often do not understand what is happening or know how to relate to someone who has schizophrenia (Ernest et al., 2017). According to WHO (WHO, 2022b) in the 2019 Global Health Data Exchange, it is stated that around 24 million people, or 1 in 300 people (0.32%) worldwide, suffer from schizophrenia. This figure is 1 in 222 people (0.45%) among adults. According to the 2018 Riskesdas data, schizophrenia is a psychotic mental disorder with a prevalence of 6.7 cases per 1000 households in Indonesia (Kemenkes RI, 2018). According to research Charlson et al. (2018) the number of schizophrenia cases is very high and continues to increase throughout the world, especially in low- and middle-income countries.

Although recurrence data in Indonesia cannot be known with certainty, the increase in the number of patients with mental disorders from 2013 to 2018, which then increased in 2018, indicates the possibility of an increase in the recurrence rate every year. According to Fadli & Mitra (2013), the causes of relapse in schizophrenic patients are the family's inability to control emotions and the presence of stressful family life problems. The high recurrence rate in schizophrenic patients indicates that the family has not been able to care for family members who have schizophrenia. As many as 70% of mental disorders in Indonesia have symptoms of violent behavior. Schizophrenia clients usually experience feelings of worthlessness, fear, and rejection by their environment, which causes feelings of discomfort and panic (Sulistiowati et al., 2014).

Schizophrenia is a difficult and ongoing mental condition that requires care from the patient's family members, especially as they are the people closest to the patient. People around people with mental disorders often stigmatize and discriminate against them, which has negative impacts on sufferers and their family members, including exclusionary attitudes, denial, and abandonment. Human rights violations occur more frequently among individuals with mental disorders (Usraleli et al., 2020).

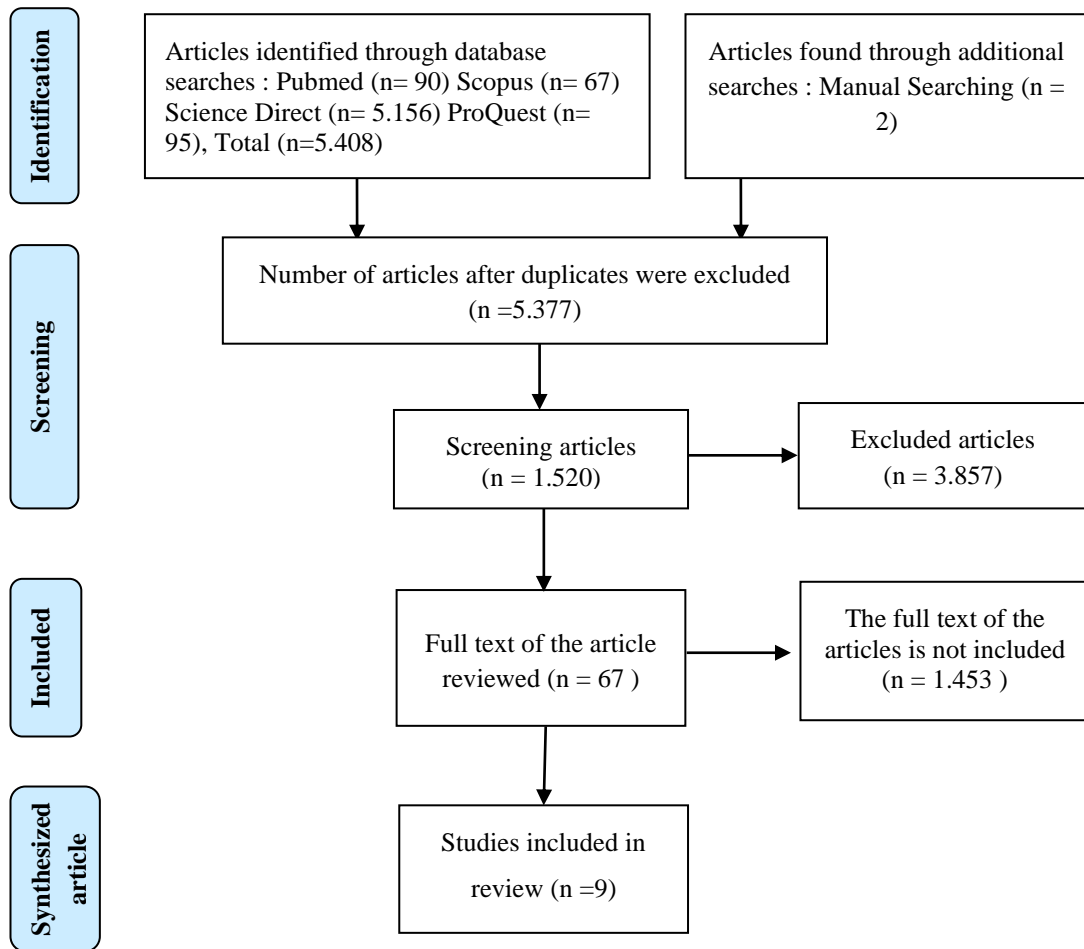
Families have a responsibility to care for family members who suffer from mental disorders. Individuals with mental disorders need more attention, help, and support from all members of their family. Family members with mental health issues might benefit greatly from the support of their families. Family members, for instance, frequently offer care, including both practical and emotional assistance (Pratiwi et al., 2023). Paredede et al. (2020) states that the family is the closest person to the client and is responsible for caring for him, but in doing so, they face challenges, both objectively and subjectively. Objective burden includes problems in the family, restrictions on social activities, societal stigma, and economic problems in going to health services. Meanwhile, subjective burdens include frustration, depression, anxiety, helplessness, and hopelessness. Significant stress and emotional hardship are experienced by those who care for individuals with schizophrenia (Wan & Wong, 2019).

Daily chores for a caregiver might become too much to handle, which can result in psychological issues (Budiarto et al., 2023). Family feelings and fears lead to a lack of family participation in care and a lack of acceptance. If this burden is not followed up on immediately, this will result in decreased family participation and hamper the patient's treatment process. Apart from that, health workers also need information regarding the burden felt by families in caring for family members with schizophrenia in order to carry out appropriate interventions to increase family participation in caring for patients. Based on the situation above, the impact of this burden often creates obstacles in the patient treatment process, especially increasing patient recurrence. The aim of the systematic review is to conduct a research review to find out what the burden is on families when caring for family members with schizophrenia.

## **METHOD**

The method is a review with library sources searched from national and international databases. The databases used are Scopus, PubMed, Science Direct, and ProQuest database and manual searching with the following keywords: "Caregiver Burdens OR Family Burdens AND Schizophrenia." This study employs a methodical methodology and a four-stage selection process: identification, screening, feasibility, and outcomes obtained. The article selection process uses Preferred Guidelines for Reporting Systematic Reviews (PRISMA). Inclusion criteria were the burden on families or caregivers who care for family members with schizophrenia, qualitative journals published in the last 10 years (2012–2022), and full-text journals with free access. Exclusion criteria are abstract-only journals, review journals, and books or journal editorials that do not match the required literature.

The results of the articles that were filtered and obtained were then evaluated using the Joanna Briggs Institute (JBI) tool. These results were obtained from databases, namely Scopus (N = 67), PubMed (N = 90), ScienceDirect (N = 5,156), ProQuest (N = 95), and manual searching (N = 2).



**Figure 1: Diagram of the PRISMA flow**

## RESULTS AND DISCUSSION

After the researchers carried out data selection and extraction, the results of this literature study found the burden of family caregivers in caring for family members with schizophrenia, namely the burden of caregivers, stigma, and health services, which are summarized in the table:

**Table 1. Extraction Data**

No	Author & Year	Country	Title	Aims	Participant	Method	Data Analysis	Findings	Conclusion
1	(Fitryasari et al., 2018)	Indonesia	Family members' perspective of Resilience's risk factors in taking care of schizophrenia patients	The purpose of this study is to characterize the family resilience risk variables when caring for schizophrenia patients.	15 family members provide care to schizophrenic patients at the Menur Mental Hospital in Surabaya, Indonesia.	Qualitative design with an interpretive phenomenological approach, with in-depth interviews.	Colaizzi's analytical analysis consists of nine steps.	The risk factors for resilience identified for families caring for schizophrenia patients are as follows:  1. The burden of care consists of confusion about the disease, emotional, physical, financial, time, and social burdens.  2. Stigma consists of labeling, stereotyping, separation, and discrimination.	This research explains how families must address the burden of care and stigma if they are to survive, recover, and become better at caring for schizophrenia patients. To help families survive, nurses have an important role in determining the level of care burden and stigma.
2	(Tamizi, Fallahi, et al., 2020)	Iran	Impacts of informal caregiving among the family caregivers of patients with schizophrenia: A qualitative study	The purpose of this study was to investigate the effects of informal caregiving among family caregivers of schizophrenia patients.	15 family caregivers of inpatient and outpatient schizophrenia patients from Razi Psychiatric Hospital and Imam Hossein Psychiatric Clinic in Tehran, Iran	Qualitative design with semi-structured interviews	Graneheim and Lundman's 5-step method	Family caregivers caring for schizophrenic patients face significant challenges and have different consequences.	This study might broaden the understanding of schizophrenia and its effects on family caregivers among mental health and psychiatric nurses. It could also assist in identifying family caregivers who may be at risk of adverse outcomes and developing suitable family-based therapies.
3	(Gater et al., 2014)	US	“Sometimes It’s Difficult to Have a Normal Life”: Results from a Qualitative Study Exploring	To study the subjective experiences of caregivers of people with schizophrenia as a way to gain a	19 English-speaking informal caregivers in the US who have been diagnosed with schizophrenia by a	Qualitative design with face-to-face, open, and semi-structured interviews	Grounded theory method analysis	The life of a caretaker for someone with schizophrenia is significantly impacted, which manifests emotionally, physically, financially, in daily activities, and in	The care of individuals with schizophrenia has a substantial impact on the lives of informal carers; relieving caregivers of some of the load is essential to

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Caregiver Burden  
in Schizophrenia

better  
understanding of  
the “caregiver  
burden” that exists  
in this population.

medical  
professional

relationships with others.

controlling costs to  
individuals and society.  
Future research should  
concentrate on developing  
valid and reliable techniques  
for evaluating caregivers'  
burden among individuals  
with schizophrenia, in order  
to inform the creation and  
assessment of treatments  
aimed at reducing that  
burden.

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4 (Chen et al., China  
2019)

The burden,  
support and needs  
of primary family  
caregivers of  
people  
experiencing  
schizophrenia in  
Beijing  
communities: a  
qualitative study

To learn more  
about the  
perspectives and  
methods of care  
that family  
caregivers of  
individuals with  
schizophrenia in  
Beijing have for  
their loved ones, as  
well as the support  
that they require in  
order to advise  
healthcare  
professionals on  
how best to target  
therapeutic  
interventions for  
families dealing  
with schizophrenia  
and to suggest  
changes to policies  
that would allow  
families to receive  
services and  
preventive

20 family  
caregivers of people  
with schizophrenia  
from six  
communities in  
Beijing

Qualitative  
design with  
face-to-face  
and semi-  
structured  
interviews

Colaizzi's 7-  
step method of  
analysis of  
phenomenolog  
ical data

Three main themes emerged  
from the caregiver  
perspective:  
  
1. Caregiver burden includes  
costs, daily household chores,  
limited social  
communication, and  
psychological stress.  
  
2. Support includes financial  
support, medical support, and  
information and educational  
support.  
  
3. Additional needs include  
respect, rehabilitation support  
(institution), and financial  
support.

There is currently little help  
for family caregivers of  
individuals with  
schizophrenia, who confront  
both psychological and  
physical difficulties. Better  
services and social attitudes  
should be taken into  
consideration for individuals  
with schizophrenia and those  
who care for them.

				measures.					
5	(Kalayci et al., 2022)	Turkiye	Caregiver burden experiences of caregivers of patients with schizophrenia: A qualitative inquiry	To find out the burden of caregivers experiences of parents who tend to patients with schizophrenia and to furnish comprehensive data on their emotions, ideas, and perspectives regarding this matter.	13 family caregivers with schizophrenia	Qualitative design of phenomenological method with in-depth interviews	Menggunakan program Maxqda 2020	Caregiver burden: 1. The emotional burden of caregivers 2. The social burden of caregivers includes being stigmatized by their environment, being exposed to social isolation, and stigmatizing themselves. 3. The economic burden of caregivers	Family-based interventions and group work are necessary.
6	(Tamizi, Fallahi-Khoshknab, et al., 2020)	Iran	Caregiving burden in family caregivers of patients with schizophrenia: A qualitative study	The aim of this research is to increase understanding of the caregiving burden experienced by family caregivers of schizophrenia patients and the factors associated with this problem.	12 family caregivers of schizophrenic patients who visited a psychiatric hospital in Tehran	Qualitative design with face-to-face and semi-structured interviews	Graneheim and Lundman's 5-step method	Family caregivers of patients with schizophrenia face problems: 1. A caregiver's heavy burden includes many time-consuming care tasks. 2. Health system challenges include neglected caregiver educational needs, less effective medical and health care services, and limited access to services.	Families caring for schizophrenic patients face many difficulties due to the dual responsibility in the care process as well as difficulties in obtaining mental health services. These findings may help psychiatric and mental health caregivers learn more about the caregiving issues facing family caregivers of schizophrenia patients and the associated factors.
7	(Sreeja & Anne, 2013)	India	Family Caregiver Burden in Schizophrenia: A Qualitative Study	The aim of this research is to determine the difficulties faced by people who provide care to patients suffering from schizophrenia.	20 family caregivers of patients diagnosed with schizophrenia	Qualitative studies were carried out using focus group discussions (FGD).	Focus Group Discussion (FGD)	The caregiver burden identified was family functioning, economic problems, emotional burden, social isolation, and caregiver health problems.	It is also recognized that most caregivers need education, advice, information, counseling, and motivation, especially for mentally ill clients with higher levels of stress.

Developing an empirically based approach to assist these caregivers requires additional effort.

8	(Riley-McHugh et al., 2016)	Jamaica	Schizophrenia: its psychological effects on family caregivers	To study the psychological impact and coping strategies of families diagnosed with schizophrenia on kin caregivers in developing countries.	5 primary family caregivers of individuals with schizophrenia who have been diagnosed (based on DSM IV)	Phenomenological descriptive qualitative research.	Thematic content analysis.	Feelings of anger, sadness, loss of libido, loss of appetite, depression, feelings of fear, guilt, stigma, and stress associated with the financial responsibility of caring for their relative are among the burdens of psychological distress and ineffective coping experienced by caregivers.	Participants reported experiencing a lot of emotional distress and ineffective coping. Strategies to support family caregivers should be part of the community-based management of individuals with schizophrenia.
9	(Von Kardorff et al., 2015)	Iran	Family caregiver burden in mental illnesses: The case of affective disorders and schizophrenia – a qualitative exploratory study	Exploring the unique challenges faced by caregivers of individuals with affective disorders and schizophrenia was the purpose of this study.	45 caregivers patients with schizophrenia and affective disorders	Qualitative research was conducted using semi-structured interviews.	Inductive approach according to grounded theory	Ambiguity, unawareness, emotional burden, stigma and blame, financial burden, physical burden, restrictions on routine, disruption of routine, dissatisfaction with family, relatives, and new people, problems with patient non-adherence to treatment, and problems with health services and government support are the nine themes that are burdensome.	Caring for someone with a mental illness affects the caregiver emotionally, physically, and financially, and this causes some difficulties in their routine. This ultimately causes conflict within the family. Despite the fact that caregivers for affective disorders and schizophrenia interpret their burdens differently, comparable patterns of hardship may be found. Consequently, competent authorities must provide adequate psychosocial, educational, and financial support for those treating mental illness.

Table 2. Checklist developed by the Joanna Briggs Institute (JBI) for qualitative research

Criteria	(Fitryasari et al., 2018)	(Tamizi, Fallahi, et al., 2020)	(Gater et al., 2014)	(Chen et al., 2019)	(Kalayci et al., 2022)	(Tamizi, Fallahi-Khoshknab, et al., 2020)	(Sreeja & Anne, 2013)	(Riley-McHugh et al., 2016)	(Von Kardorff et al., 2015)
1	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
2	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
3	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
4	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
5	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
6	Yes	Yes	Yes	Yes	Yes	Unclear	No	Yes	Yes
7	Yes	Yes	Unclear	Unclear	Unclear	Unclear	No	No	Yes
8	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
9	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes
10	Unclear	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	Yes

### Care Burden

Problems related to care burden are illness, physical, financial, emotional well-being, psychological stress, caregiver concerns, physical impact, impact on leisure time, daily routine activities, impact on relationships with relatives, and social and social burden (Chen et al., 2019; Fitryasari et al., 2018; Gater et al., 2014; Kalayci et al., 2022; Riley-McHugh et al., 2016; Sreeja & Anne, 2013; Tamizi, Fallahi-Khoshknab, et al., 2020; Tamizi, Fallahi, et al., 2020; Von Kardorff et al., 2015). Family caregiver burden has negative consequences not only for the caregiver but also for the patient, other family members, and the health care system (Annisa, 2016). Caregivers have to care for patients around the clock, so they don't have time to relax and rest. Continuous physical fatigue, accompanied by psychological and emotional problems, worsens the family's health status. The family plays a crucial role in providing the patient with care and companionship in their everyday lives, but this position isn't always ideal, which has an impact on the family's minimal involvement in the patient's at-home care (Agustriyani et al., 2022).

Research by Ozen et al. (2018) found that most schizophrenia caregivers experienced an emotional burden of 69%. Low-level loads are the most common. In addition, the government health insurance program does not cover all medical costs for schizophrenia patients. Transportation costs are also a problem due to routine visits to the hospital for treatment, which places an additional burden on the family (Tristiana et al., 2019). According to a study Bademli & Lök (2020), most caregivers lived a very pleasant life before the patient's relapse, but after the relapse, they felt that their social life was limited and that they had no life of their own. One of the fundamental ideas of social cognitive theory's growth is self-efficacy (Rahmawati et al., 2020). Families can increase their self-efficacy and self-confidence if they know about patient care and treatment. According to research conducted by Ramzani et al. (2019) increasing self-efficacy leads to a decrease in caregiver burden.

### Stigma

The stigma experienced by caregivers is in the form of labeling, stereotypes, alienation, discrimination, and self-stigma (Fitryasari et al., 2018; Gater et al., 2014; Kalayci et al., 2022;

Sreeja & Anne, 2013). Stigma is a type of social injustice that causes psychosis in schizophrenia spectrum disorders, hindering treatment, stress, social isolation, maladaptive coping behavior, and a greater risk of complications for those with schizophrenia (Hoftman, 2016). In research by Grover et al. (2017), stigma was higher in schizophrenia patients compared to patients with bipolar disorder and recurrent depression. Neha et al. (2021) stated that schizophrenic caregivers were isolated by relatives and neighbors. Tribal, religious, and educational variables were found to be social stigma factors in patients with schizophrenia (Putri & Tania, 2021). Everyone shuns them and treats them badly. The study conducted by Chai et al. (2018) found a strong relationship between stigma and depression among caregivers. According to research conducted by Gater et al. (2014), caregivers believe that they should stay at home or near home. They don't want their friends to see their condition because they don't want their friends to see people with schizophrenia. This is due to caregivers' belief that, due to negative stigmatization, they are considered a social burden (Kalayci et al., 2022).

According to Usraleli et al. (2020), to be able to provide education to the public, health workers must remember the fact that the public does not understand the signs and symptoms of mental disorders. Public knowledge is very important to shape attitudes toward and acceptance of people with mental disorders. Both naturally and systematically, this knowledge can be obtained through education. Apart from education, people also need to become self-aware and have good knowledge in order to create a positive stigma towards people with mental disorders in their environment. Reduced self-esteem caused by self-stigma and self-ineffectiveness can be corrected with several techniques. Groups can protect against negative self-statements, which are essentially self-stigma, by providing support and a positive identity (Larson & Corrigan, 2008). According to Corrigan and Penn (1999), there are three ways to eliminate public stigma: protest, education, and contact. The protest is a moral appeal to society to end the stigma against people with mental disorders and their families. Education faces its own challenges in balancing societal myths about how mental disorders develop with scientific discoveries, and contact is an action that includes building relationships between people with mental disorders and society.

## **Health Services**

According to research conducted by Chen et al. (2019), rehabilitation institutions can ease the burden on caregivers and help patients recover and return to social life, but they are hampered by high costs. In addition, caregivers feel confused about the illness of a family member who suffers from schizophrenia because the patient's behavior changes quickly and shows no symptoms of recovery, and the family continues to hope that the patient will recover completely (Fitryasari et al., 2018). According to Tamizi et al. (2019), family caregivers do not know much about medication, patient care at home, and management of the patient's high-risk behavior. They also don't know how to treat patients who are resistant to treatment, such as by not taking their medication or refusing to see a doctor.

According to research by Charlson et al. (2018), the health system in most countries is not ready to improve mental health services. As a result, the lack of effective treatment for mental disorders will have a negative impact on individuals and families. Supported by research by Tristiana et al. (2019), which shows that access to mental health services is not always easy for people who care for families with mental disorders. In some countries, there are no centralized mental health services in big cities or rural areas. To ensure that mental health services can be accessed everywhere, the government must establish policies that provide equal distribution of health workers with special skills and mental health facilities.

In some countries that lack social welfare systems and mental health services, family caregivers' function becomes increasingly significant. No psychiatric beds, a lack of knowledge about mental illness and its treatment, and nurses' lack of awareness of care responsibilities are the biggest problems faced by caregivers in this situation. To improve mental health services, it is also very

important for family caregivers to be involved in policymaking and service planning. Programs such as home visits and post-discharge supervision can help families ease the burden they are experiencing. They can also provide families with opportunities to participate in the caregiving process (Shamsaei et al., 2015)

## CONCLUSIONS AND SUGGESTIONS

After reviewing nine articles, it can be concluded that family caregivers have difficulties in the form of burdens as caregivers, stigma in the family and community, and related health services. Exploring the burden of family caregivers can be useful for health workers, especially those related to mental health, in obtaining information regarding the perceived burden on families so that they can develop appropriate interventions for families or caregivers as the basic unit of family care. Health care providers, especially mental health professionals, must engage families as active team members by developing more innovative programs for families and providing them with specific tasks and the resources necessary to perform those tasks.

## ETHICAL CONSIDERATIONS

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### Conflict of Interest Statement

A conflict of interest does not exist.

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