



A systematic review : emotional impact as a family's experience caring for schizophrenic patients

Tinjauan sistematis: dampak emosional sebagai pengalaman keluarga dalam merawat pasien skizofrenia

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ABSTRACT

Background: The emotional impact experienced by families of schizophrenic patients who are treated at home is considered a community mental health problem that does not receive serious attention from health professionals. Families or caregivers who care for schizophrenic patients at home have the risk to experience mental disorders due to the emotional impact they experience.

Objective: To review the journal that comprehensively explain the emotional impact on the family life of schizophrenic patients.

Methods: The database in this review are studies in Scopus, Science Direct, Proquest, and EBSCOhost from 2017 to 2022. Critical appraisal in research that appropriate the inclusion criteria be conducted dependently by author and adviser using the CASP checklist for review.

Results: Six articles met the inclusion criteria for review show that families or caregivers of schizophrenic patients are affected emotionally, significantly on their lives especially their mental health. They feel overwhelmed, stressed, frustrated, angry, depressed, and/or anxious, irritable, painful emotions, getting pressured, wanting to end life, showing poor quality of life in terms of physical, emotional, and mental health.

Conclusion: Most of family with schizophrenic patient emotionally affected and have the risk for mental disorders

Keywords: *emotional impact, family, schizophrenia*

ABSTRAK

Latar belakang: Dampak emosional yang dialami oleh keluarga pasien skizofrenia yang dirawat di rumah dianggap sebagai masalah kesehatan jiwa masyarakat yang belum mendapat perhatian serius dari tenaga kesehatan. Keluarga atau caregiver yang merawat pasien skizofrenia di rumah memiliki risiko untuk mengalami gangguan jiwa akibat dampak emosional yang dialaminya.

Tujuan: Untuk mereview jurnal yang secara komprehensif menjelaskan dampak emosional pada kehidupan keluarga pasien skizofrenia.

Metode: Basis data dalam tinjauan ini adalah penelitian-penelitian yang ada di Scopus, Science Direct, Proquest, dan EBSCOhost dari tahun 2017 hingga 2022. Penilaian kritis dalam penelitian yang sesuai dengan kriteria inklusi dilakukan secara dependen oleh penulis dan penasihat dengan menggunakan daftar periksa CASP untuk ditinjau.

Hasil: Enam artikel yang memenuhi kriteria inklusi untuk ditinjau menunjukkan bahwa keluarga atau pengasuh pasien skizofrenia terpengaruh secara emosional, secara signifikan dalam kehidupan mereka, terutama kesehatan mental mereka. Mereka merasa kewalahan, stres, frustrasi, marah, depresi, dan/atau cemas, mudah tersinggung, emosi yang menyakitkan, merasa tertekan, ingin mengakhiri hidup, menunjukkan kualitas hidup yang buruk dalam hal kesehatan fisik, emosional, dan mental.

Kesimpulan: Sebagian besar keluarga dengan pasien skizofrenia terpengaruh secara emosional dan memiliki risiko untuk mengalami gangguan jiwa.

Kata kunci: dampak emosional, keluarga, skizofrenia

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INTRODUCTION

Schizophrenia is a severe mental disorder characterized by three major symptom categories, namely positive symptoms, negative symptoms, and cognitive symptoms. The manifestations of schizophrenia that often appear are hallucinations, delusions, paranoia, and the experience of this thought disorder characterized by various forms of sensory disturbances and abnormalities in all aspects of thought, cognitive, and emotional.¹ Psychotic symptoms that arise have a dangerous potential which is characterized by a failure of logic, habits, intentions, and organizations that usually accompany human thinking. Psychologically it is not a loss of function, but a malfunction that is a psychotic characteristic. In addition, these features are volatile and affect the sensory system. The World Health Organization states that the prevalence of schizophrenia in the world is increasing, it is a severe and chronic mental illness that affects about 20 million people globally, and affects 1 person in every 100 individuals.²

Families or caregivers of schizophrenic patients experience a high level of care burden.³ The burden of care felt by families of schizophrenic patients is confusion about illness, emotional, physical, time, financial and social which results in a decrease in the quality of family life.⁴ Families of schizophrenic patients experience stigma in the form of labeling, stereotyping, separation, and discrimination. Stigma causes families to

experience psychological, social, and interpersonal relationship problems. Stigma has an impact on decreasing quality of life, function, and worsening family resilience.³ The statistics of the burden of care in families with schizophrenia patients illustrate that the burden of care is influenced by age, gender, education level, quality of relationship, duration of illness, and frequency of care. While the burden of care affects income, relationships, frequency of care, to cause job loss due to caregiving responsibilities. Treatment of schizophrenic patients burdens the family's emotional health, states that they have a less than satisfactory personal life, and feels disturbed by their lives.⁵ The family is also confused by the patient's behavior; one time they look normal, but at other times the patient looks abnormal.⁴ The emotional burden is felt by the whole family, they feel sad because of the patient's uncontrolled behavior, feel afraid because of the patient's dangerous behavior, ashamed because of the bad behavior of the patient in society, worrying about the patient's future, to anger because of the patient's uncontrolled behavior and make the family lose control of their emotions.

Care and emotional burden did not show a statistically significant correlation, both represented positive and negative emotional responses to the stress of the same condition, but they are different aspects of care that can be affected by the quality of the caregiver-patient relationship.⁶ Families of schizophrenic patients often complain of how complex the emotional impact is when providing care to

patients. The emotional impact is felt to greatly affect the quality of life which is decreasing from various aspects.

The description above encourages researchers to explore by analyzing research articles related to the emotional impact experienced by families who care for schizophrenic patients so that they are able to comprehensively explain how the emotional impact on the family life of schizophrenic patients. A systematic literature review is expected to be able to answer how the emotional impact felt by families / caregivers with schizophrenia

METHODS

Systematic search following PRISMA guidelines.⁷ Article search following database : Scopus, Science Direct, Proquest, and EBSCOhost from 2017 to 2022. Search for papers using the above-mentioned web-based electronic database published until August 2022.

Search term included : emotional impact, family, and schizophrenia. Title, abstract, original title, and terms also include: emotional burden, emotional response, emotional reaction, family or caregiver caring for schizophrenic patients at home. The list of included research references was manually searched for further relevant research on the social impact experienced by families of patients with schizophrenia. The articles obtained were appraised using CASP and the results review are shown in Table 1.

Studies were included if the patient was diagnosed with schizophrenia, cared for

by a family or caregiver at home. The included studies are qualitative and quantitative studies that examine the social impact experienced by families of schizophrenic patients. Case report studies of the care of patients with schizophrenia were excluded.

Outcome measures focused on the experience of the family or caregiver in responding to the emotional impact of caring for family members who suffer from schizophrenia. Another focus included is how to measure the emotional impact experienced by families of schizophrenic patients using validated instruments. The results of the selection of the articles are presented in Figure 1.

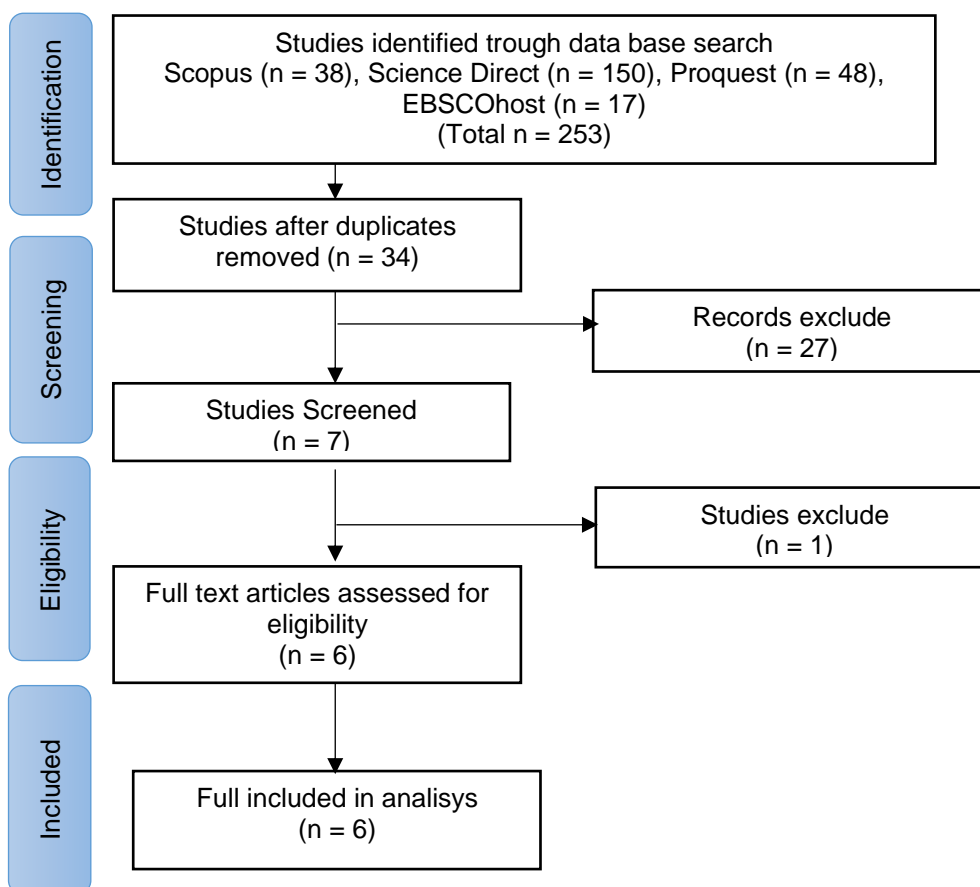


Figure 1. PRISMA article search flowchart

RESULTS AND DISCUSSION

Six studies with family participants schizophrenic patients at home and the total number of participants in this review was 578 families.^{3,8-12} Four studies investigated the emotional impact of family or caregiver experiences with schizophrenic patients.^{3,10-12} A study with mixed methods explored the emotional and mental health experiences of schizophrenic families.⁸

One study tested instruments and developed to detect stress experienced by caregivers or families of schizophrenic patients.⁹

One study uses 2 instruments to assess stress on family/caregivers of schizophrenia patients, namely the Distress thermometer and problem list for caregivers (DT-C) and the Depression Anxiety Stress Scale-21 items (DASS-21).⁹

To measure the emotional impact that families experience on the quality of life of patients' families, a study used the medical out-come survey (MOS) 36-item Short Form (MOS SF-36), and to measure social support used the Chinese version of the Social Support Rating Scale (SSRS).¹⁰ Three studies used semi-structured interviews, and one study used Zarit Burden Interview (ZBI-22) for measure the emotional burden of families of schizophrenic patients.

3,8,11,12

Two of the six studies used a qualitative design, one study with mixed methods design, cross sectional study design¹⁰, correlational study, and the descriptive cross sectional surveys.^{3,8-12}

Have a mental disorder

Five of the analyzed papers reported that families experienced mental disorders in the form of emotional distress while caring for family members with schizophrenia. Specifically¹², reported that the high level of stress experienced by the family, affecting family relationships to divorce.¹² The results of the study also reported that the results of the measurement using DT-C were 57.6% of families with schizophrenia patients experienced a decrease in quality of life in the emotional aspect.⁹

Tabel 1. Articles Reviewed

Study Name	Participant Detail	Aim and detail of the study	Instrument	Result
Brain et al. (2018)	Total of 27 caregivers of treatment-resistant schizophrenia patients	Investigate caregiver burden in treatment-resistant schizophrenia patients, understand their experiences and challenges, document their attitudes and perceptions of existing care. Qualitative Research.	Semi-structure interviews	The themes found were duration and responsibility of care, persistent symptoms of schizophrenia, impact of persistent symptoms and behavior of schizophrenia on patient caregivers, impact of persistent

Study Name	Participant Detail	Aim and detail of the study	Instrument	Result
				<p>schizophrenia on care recipients and caregiver safety, and treatment experience. All caregivers reported that it had a significant impact on their personal lives, especially on mental health who experienced mental/emotional stress during care. The emotional burden they feel results in feelings of being overwhelmed, stressed, frustrated, angry, drained, overwhelmed, and/or anxious. Other things that are affected are the social life and romantic relationships of the caregivers, some caregivers report leaving the date to end the marriage, and feeling socially isolated. Persistent positive symptoms and ineffective treatment result in caregivers having to spend a lot of time caring for patients, resulting in poor social activities and good relationships. Professional life is affected to the point of potential</p>

Study Name	Participant Detail	Aim and detail of the study	Instrument	Result
				loss of future income and a huge drop in productivity. Caregivers worry about the future of the patients being cared for.
Wong et al. (2018)	Eight of family dyads; 7 pairs of parents and children (3 daughters/father, 3 sons/mother, 1 daughter/mother) and 1 wife/husband. The average age gap is 25 years, and reflections the relationship status of family dyads.	Exploring the stigma felt by schizophrenic patients and their caregivers. Qualitative study integrating standardized scale data and narratives from the results of semi-structured interviews of eight family couples.	Semi-structure interviews	Schizophrenic patients and caregivers experience negative self-assessments of their social network and reduced engagement with society. Patient express shame, low self-esteem, and become a burden on the family, and are disappointed with the psychiatric diagnosis. Caregivers expressed high emotional distress due to mental illness that their family had experienced. Families have a central role in caring for patients with schizophrenia, given the increasingly community-based nature of mental health care delivery, so understanding family stigma is important to guide the development of culturally informed care.
Rahmani et al. (2022)	25 participants from the family of the main	Investigating the burden of caregiving and	Zarit Burden Interview (ZBI-22)	Family caregivers of schizophrenic

Study Name	Participant Detail	Aim and detail of the study	Instrument	Result
	caregivers were recruited from outpatient clinics affiliated with Psichyatric Hospital Razi from December 2018 to April 2019	factors related to the caregiver's family of a schizophrenic patient. Correlation study.		patients reported a high burden of care, 38.2% of caregivers felt a heavy burden related to their role. Regression analysis showed that age, gender, education level, income, loss of care work, relationship with patients, frequency of care and duration of illness were statistically significant predictors of the burden of care delivery. The regression model explains the existence of 54.4% of the burden of providing varied care.
Vanessa et al. (2022)	Numbers 13 Caregivers with severe mental disorders in Valencia Spain	Exploring the emotional and mental health experiences of families caring for people with severe mental disorders. Mixed-Methods Study.	Semi-structure interviews	Classified in two major themes; perceived emotional and mental health. Included in the emotional categories are irritability, painful emotions, pressure, coping-oriented emotions, and positive emotions. The five categories included in mental health status are; anxiety, burden and fatigue, needing psychological or psychiatric treatment, insomnia, and suicidal feelings.

Study Name	Participant Detail	Aim and detail of the study	Instrument	Result
				The emotions that are formed are starting from a lack of control or irritation that develops into resignation, peace, or contentment. Qualitatively reported conditions that reflect anxiety, depression, and insomnia experienced by the family.
Leng et al. (2019)	One hundred and eighty one (181) caregivers with family members with severe mental illness	Investigating the quality of life of families of patients with severe mental illness and evaluating the impact of social support on the quality of life of their families. Cross-sectional study.	The medical out-come survey (MOS) 36-item Short Form (SF-36), the Chinese version of the Social Support Rating Scale (SSRS)	The Quality of Life (QoL) score showed that 68.3% had poor quality of life, 61.3% in the physical aspect, 57.6% in the emotional aspect, 63.0% in the mental health of the caregivers. The study found that caregivers received low social support, especially objective support and the use of social support. The quality of life of caregivers in the physical component is significantly related to the patient's illness, time of care, financial burden and objective support. The mental component of the caregiver's quality of life is closely related to the patient's disease status, the patient's

Study Name	Participant Detail	Aim and detail of the study	Instrument	Result
				marital status, the caregiver's knowledge of the disease, the coordination of patient care, life and work, subjective support received and the use of support. Caregivers need the help of other family members and friends in providing care, especially when unemployment requires work. Health education and helping families to maintain and improve social networks are urgently needed by families caring for people with severe mental disorders.
Bai et al. (2020)	324 caregivers of children and adolescents diagnosed with schizophrenia collected from January 2017 to February 2018	Develop and psychometrically test the Distress Thermometer for Caregivers (DT-C) and document the perceived danger level of primary caregivers caring for children and adolescents diagnosed with schizophrenia. Diagnostic accuracy validation studies and descriptive cross-sectional surveys.	Distress thermometer and problem list for caregivers (DT-C) and the Depression Anxiety Stress Scale-21 items (DASS-21)	The DT-C psychometric test showed that the reliability, validity and internal consistency were good. The value of sensitivity, specificity, Youden index, positive predictive value, and negative predictive value were satisfactory and showed very good discrimination significantly. Caregivers who scored high indicated that they faced many significant problems in

Study Name	Participant Detail	Aim and detail of the study	Instrument	Result
				terms of practical, cognitive, emotional, and caring care for children and adolescents with a diagnosis of schizophrenia. The caregiver's level of distress is relatively high, so psychoeducation about special needs and a solid mutual support network are needed to reduce the distress experienced by caregivers and families of patients with schizophrenia.

Decreased productivity, income, physical condition, quality of relationships

Three studies reported that families with schizophrenic patients complained emotional experiences in caring for patients led to decreased productivity, income, job loss, quality of relationships, and poor physical condition.^{3,10,12} Research (Rahmani et al., 2013) showed that 38.2% of families reported the heavy burden of caring for schizophrenic patients, and a regression analysis of 54.4% of families of schizophrenic patients reported that the burden of care varied influenced by age, gender, occupation, level of care, education, frequency and duration of care for schizophrenic patients.³

DISCUSSION

This review attempts to review the literature that explores the emotional impact experienced by families in caring for schizophrenic patients. The results of the review show that the emotional impact felt by families in caring for family members who suffer from schizophrenia causes mental disorders and decreases productivity, income, physical condition, and quality of relationships with other people.

The emotional impact of the family of patients with schizophrenia is exacerbated by several things, the stigma associated with mental illness, family conflict, financial problems, social isolation, and lack of social support.^{13,14} This is in line with the opinion that the emotional impact experienced by families

of schizophrenic patients causes the family to have the potential to experience mental disorders.^{15,16}

Based on current findings reported that failure to manage emotions has an impact on various aspects of a person's life, that emotions and cognitions facilitate violent behavior in adolescents and adults, and can trigger suicidal behavior.¹⁷ Negative emotions such as lack of self-confidence and negative self-evaluation lead to despair and then suicide.¹⁸

In addition, two papers confirm that families express high levels of stress to experience mental illness as an emotional impact that is not managed properly.^{3,11} Specifically research explained that while caring for patients with schizophrenia, the family or caregiver experienced a decrease in my life, that 68.3% experienced a low quality of life.¹⁰ Emotional violence has a direct effect on depression and problem behavior, and indirectly affects psychopathology in the form of suppression of expression and anger, compared to physical violence, emotional violence is more detrimental and psychopathological.^{19,20} In the current review paper, it has not discussed the comparison of the impact caused by the emotions experienced by families of schizophrenic patients.

The emotional impact on social life has been reviewed in four papers, reported that families who care for schizophrenic patients experience social stigma, shame with the patient's illness, affecting the quality of

relationships with others.^{3,10-12} Some caregivers report leaving the date and ending the marriage. Study also reported that a person's emotions significantly affect life satisfaction as a result of social relations.^{8,21}

All of the articles in this review have not provided an explanation of the emotional impact on the spirituality of the family of schizophrenia patients, but other studies have reported that experience has a positive impact on spiritual intelligence, on emotional intelligence (managing other people's emotions and being able to take advantage of emotions), and is able to influence feelings of concern for others.²²

CONCLUSION

Although this review provides an explanation of the emotional impact on families in caring for schizophrenic patients, there are some limitations including : heterogeneity of the sample of study subjects, different sizes, typical main results which did not allow statistical synthesis of the meta-analyses. Finally, the existing literature does not sufficiently provide a clear explanation of the holistic impact on family life with schizophrenic patients.

Treatment of schizophrenia patients by the family provides the experience of a significant emotional impact. This is the first attempt to review the currently available evidence on the emotional impact that families of schizophrenia patients experience. Despite these limitations, the results show that families who care for schizophrenic patients

experience many burdens, problems, and are affected in various aspects of their lives. Future research is important to provide a comprehensive explanation of the emotional impact experienced by families of schizophrenia patients in the bio-psycho-socio-cultural-spiritual aspects. The magnitude of the emotional impact on the family life of schizophrenic patients needs to be measured with appropriate and valid instruments to determine intervention priorities in reducing the emotional impact on the families of schizophrenic patients.

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CREDIT AUTHORSHIP STATEMENT

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2. **Dian Veronika Sakti Kaloeti** : Supervision, writing review.

DECLARATION OF COMPETING INTEREST

The authors have no actual or potential conflict of interest including any financial, personal or other relationships with other people or organizations

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