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REVIEW

Factors Related to the Caregiver Burden on Families Caring for Clients with Schizophrenia: Scoping Review

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Abstract: Family caregivers play a crucial role in the long-term care of individuals with schizophrenia, yet they often face significant challenges. The responsibilities involved in caregiving can lead to a considerable caregiver burden, which may result in adverse outcomes for both the caregiver and the person with schizophrenia, so there will be a risk of experiencing caregiver burden which can give rise to new problems for the family. This research aims to identify factors that cause caregiver burden on families in caring for clients with schizophrenia. This research method uses a scoping review with PRISMA-ScR guidelines. Search for literature uses the PubMed, CINAHL, Scopus, and Google Scholar search engines, year range of the article from 2014 to 2023, full text, Indonesian and English language. This research used the PCC (Population, Concept and Context) framework. Search for keywords using the Boolean operators OR and AND in English is "family caregiver", "families carers", "informal caregiver", "burden of care", "stress of caring", "stress of caring", "burnout of caring", "schizophrenia", "individuals with schizophrenia disorder", and in Indonesian is "caregiving family", "caring burden", "care stress", "fatigue", "schizophrenia". The results of a scoping review of ten articles found sixteen factors of caregiver burden on families in caring for clients with schizophrenia, that is age, gender, marital status, level of education, employment, economics, relationship with the client, duration of care or length of care, duration of schizophrenia in patient, stress on the Family Caregiver, patient severity, decreased mutuality, family coping strategies, spiritual support, social support, and professional support. The findings of this study highlight the factors that cause caregiver burden in schizophrenia patients. These findings can be considered as information in finding solutions to reduce the burden on family members who are caregivers of schizophrenia patients.

Keywords: burden, caregiver, factors associated, family nursing, schizophrenia

Introduction

Schizophrenia is a mental disorder that is marked by non-coherent thinking, sleeplessness, anorexia, and hallucinations like pulling off skin.[1] Schizophrenia is a terrible mental condition that will develop in future generations and do harm to individuals who experience it. Schizophrenia is also perceived as a less illness particularly compared with other chronic medical ailments.[2] Schizophrenia enhances people's capacity to process information, feel, and act. Patients with schizophrenia may experience or perceive non-existent sensations or sights. Schizophrenia also significantly impairs multiple cognitive domains including attention, memory (short-term and long-term), auditory processing, and problem-solving abilities, which further increases the complexity of caregiving.[3] They recognize that others might engage in prayers, practice prayer, or feel they will be judged. This may cause individuals to get angry and disturbed, leading to withdrawal from social situations.

According to World Health Organization figures (2022), schizophrenia affects around 24 million individuals, or one in every 300 persons (0.32%) globally. In Indonesia, schizophrenia accounts for 99% of all mental diseases in mental institutions.[3] According the findings of the 2018 Primary Health Research, the incidence of individuals with schizophrenia among Indonesians is 6.7 every 1000 households. This indicates that of 1000 ladders, 6.7 families include household members with schizophrenia.[4]

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Schizophrenia remains an issue in Indonesia, since over 80% of schizophrenia patients are neither treated or not managed properly by their families or medical teams. Schizophrenic patients are abandoned on the streets; some are even passed over by their relatives. Conditions like this enable a rise in the number of persons with schizophrenia over time.[5] In accordance with Riskesdas (2018), up to 84.9% of patients diagnosed with individuals with schizophrenia throughout Indonesia have received therapy. About 48.9% of the patients took their medications on a regular basis. Up to 36.1% of the patients who had not taken medicine on a regular basis in the previous month believed they were healthy. In reality, the growth in individuals with schizophrenia cases is one of the causes behind the challenges in therapy for schizophrenia sufferers, such as patient noncompliance with medication.[6]

People with schizophrenia struggle to care for themselves, thus they will rely on others to assist them maintain themselves or satisfy their basic requirements. Consequently, family caregivers are highly crucial. A household caregiver is a person that care as well as support an ill family member in his or her daily life.[7] The engagement of family members in his life has a strong correlation with his schizophrenia recovery. Family members may reduce the problems of this major mental illness in ways that people outside the family structure cannot.[8]

The family's job in this situation is to assist in the rehabilitation process and avoid recurrence by providing emotional support to the individuals with schizophrenia client; nevertheless, the household must also be watchful and oversee the suffering at all times. Furthermore, they engage schizophrenia patients in everyday activities to relieve emotional stress and must participate in their care process by providing them medicine and taking them to check-ups.[9]

Although the role of the family in the healing process of clients with schizophrenia is very important, carrying out the role of caregiver is not easy. A caregiver will be faced with various demands and tasks in caring for clients or duties as an individual. At the beginning of the client's treatment journey with schizophrenia, the family revealed that there was an increase in psychological and social burden. This psychological load takes the shape of experiences of guilt, grief, wrath, dread, worry, and anxiety around the patient's situation.[3] A description of the type of anxiousness reported by close relatives which manage individuals in schizophrenia, namely that the majority of the participants have moderately to serious anxiety disorders ratings, ensuring indicators which appear among household participants that attention for schizophrenia cause disruptions in daily activities.[9]

Families can also feel stress, according to research findings, with the vast majority of families experiencing moderate levels of stress by 67.2%, families experiencing severe stress by 17.2%, and families experiencing light stress by 15.6%. Generally, the patient's family spends most of their time caring for the patient, providing support, providing medications, and other aspects of daily life. In addition, they also have to face the social burden in the form of stigma and angry reactions from neighbors and the surrounding environment. This stresses the family, especially because the sufferer does not heal for a long time.[10]

Families play a central role in the care of individuals with schizophrenia, often assuming long-term caregiving responsibilities. However, this role comes with significant emotional, psychological, social, and financial burdens. Family caregivers are frequently exposed to chronic stress, anxiety, depression, and social stigma due to the unpredictable and prolonged nature of the illness. Moreover, the limited access to mental health services and lack of formal support systems often intensify the burden. These cumulative challenges can negatively impact the quality of life and functioning of caregivers, making it crucial to understand the specific factors contributing to their burden. Therefore, this study aims to systematically map the various factors associated with caregiver burden in families caring for individuals with schizophrenia.

Based on the results of the study, it was found that the duration of treatment in the majority of individuals with schizophrenia clients during the period of 5–10 years was 70.3% and 1–4 years was 29.7%. This indicates that individuals with schizophrenia patients need long-term care at home. This is what makes the family burdened in carrying out care, where the family will be disturbed in activities, time wasted on care, burdened in the mind and burdened also in economic factors. This length of treatment is what makes the family stressful, because what is faced are people who always act unnaturally such as often getting angry at home, throwing things and can even disturb others.[3]

These conditions will cause a strain for a caregiver; the burden faced by volunteers more specifically is more widely recognized as the support burden or caregiver burden. One study,[11] There was no significant link found between self-management and family burden. Literature Review from,[11] A review of 22 research found that caregiver who take care of schizophrenia patients have a burden that is impacted by their caregivers, patient, and environmental variables. In

comparison with the results of the study, which indicated that out of 32 persons, the burnout rate among caregivers of schizophrenia clients was high (63%).[12] This shows a shift in the problem of schizophrenia which causes an increase in the burden of families in treating people with schizophrenia.

This review demonstrates the critical need of strengthening nurses' awareness of the prevention and management of family burden problems. It is critical to discover numerous sources and new study reports on elements that may impact families' burden in providing self-care for schizophrenia patients. As a result, the author aims to perform a scoping study of the elements that contribute to caregiver strain on families while taking care of clients with schizophrenia. Based on the concerns outlined in the background, the phrasing of the issue in this research is, "What are the elements associated to caregiver stress on families who participate in the care of clients with schizophrenia?"

Materials and Methods

Design

This review-based research uses a scoping review approach, which is a type of method to synthesize a research, systematically which aims to map a topic and identify key concepts, theories and knowledge gaps. According to Arksey & O'Malley in 2005, there are 5 steps in conducting a scoping review, namely: (1) Identifying research questions in the research, (2) Identifying related studies, (3) Ensuring that the research conducted is qualified, (4) Presenting data, and (5) Compiling, summarizing and reporting the results of the review that has been conducted.

This scoping review method is in accordance with the research to be conducted, because it can systematically map and identify factors related to caregiver burden in families in treating clients with schizophrenia. In addition, scoping reviews were chosen because the researcher's reference sources used a variety of journal articles.[2,13–15]

Search Strategy and Eligibility Criteria

In this study, secondary data obtained from the results of research that has been carried out previously by the researchers is used. The source of this research article is obtained from national and international articles with predetermined themes. The process of searching for literature in the form of scoping reviews uses databases in the form of PubMed, CINAHL, and Scopus, in addition to using a search engine, namely Google Scholar.

The keywords used to search for journals are using English and Indonesian. Journal searches are conducted using keywords and boolean operatives, namely "AND, OR NOT, or, AND NOT". This attempts to make the process of looking for articles easier and allows for greater specificity. With the aid of Medical Subject Heading (MeSH), the keywords were modified. Raw words are used in MeSh Term, a structured terminology that can be indexed in PubMed and other medical databases. Utilizing the PCC Grid for Search Strategy, keywords will be determined as below: as shown in Table 1.

The researcher created inclusion and exclusion criteria to make it easier to identify what needs to be explored in conducting a review. The following are the inclusion and exclusion criteria that will be used, as shown in Table 2.

Table 1 PCC and MeSH Terms

Variable	Description	MeSH Terms
Population	*Family Caregiver*	"family caregiver" OR "families carers" *OR* "informal caregiver"
Concept	*Burden of Caring*	"burden of care" OR "stress of caring" *OR* "fatigue of caring" *OR* "burnout of caring"
Context	*Schizophrenia*	"schizophrenia" OR "schizophrenic disorder"

Table 2 Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Families who have family members with schizophrenia	Families who have family members with anxiety disorders, depression, personality disorders, post-traumatic stress disorder (PTSD), Attention Deficit Hyperactivity Disorder (ADHD), and so on other than schizophrenia sufferers
Caring for family members with schizophrenia	Caring for family members with anxiety disorders, depression, personality disorders, post-traumatic stress disorder (PTSD), Attention Deficit Hyperactivity Disorder (ADHD), and so on in addition to schizophrenia sufferers.
Research journals in full text form	Research journals that are not available in full text form
Journals with the year of publication are 2014–2024 (last 10 years)	Journals with years of publication are less than 2014 and are only available in abstract form
Journals with quantitative research design	Journals with qualitative research design, systematic review
The language used in the journal is English and Indonesian	-

Data Collection

Finding literature is one of the processes in conducting a literature review, guidelines that can be adapted for this research are using PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analysis). PRISMA can be used to map and analyze the amount of literature found. Furthermore, the author will identify, include and exclude or call the inclusion and exclusion criteria, and can provide reasons why the literature is excluded.

The article selection process was conducted using the PRISMA-ScR guidelines. A total of 8282 records were initially identified through database and search engine searches. After removing 6876 duplicate articles, 1460 records were screened by title and abstract. Based on the inclusion and exclusion criteria, 1393 articles were excluded. Full-text screening was conducted for the remaining 13 articles, of which 3 did not meet eligibility criteria, resulting in 10 articles being included in the final review. The results of the selection can be seen in Figure 1 PRISMA Flow Chart. Each step of the screening and selection process was conducted independently by the authors to ensure objectivity and transparency.

Literature data mapping is used to analyze and collect literature tailored to the research topic, then presented in the form of groupings in the form of tables or descriptive formats by compiling and summarizing selected articles that are in line with the purpose of scoping review.[14]

Data Analysis

At this stage, after finding the article you are looking for, it is then prepared, identified and analyzed and summarizes the results as a form of results report. The results report is prepared in the form of a table with a narrative of the results of the research in selected articles related to the caregiver burden in families in caring for family members with schizophrenia by the framework of.[14]

Results

A total of ten articles met the inclusion criteria and were included in this review. The studies originated from Indonesia, China, Bangladesh, Brazil, Spain, Iran (2 articles), and Taiwan (3 articles). The majority used cross-sectional designs, with one descriptive-analytical study. All studies focused on families or caregivers of individuals with schizophrenia. The classification of caregiver burden factors was grouped into internal factors (eg, age, gender, marital status, education, occupation, economic condition, relationship with the client, stress, and coping strategies) and external factors (eg, treatment duration, illness duration, illness severity, decreased mutuality, spiritual, social, and professional support). These findings are summarized in Table 3.

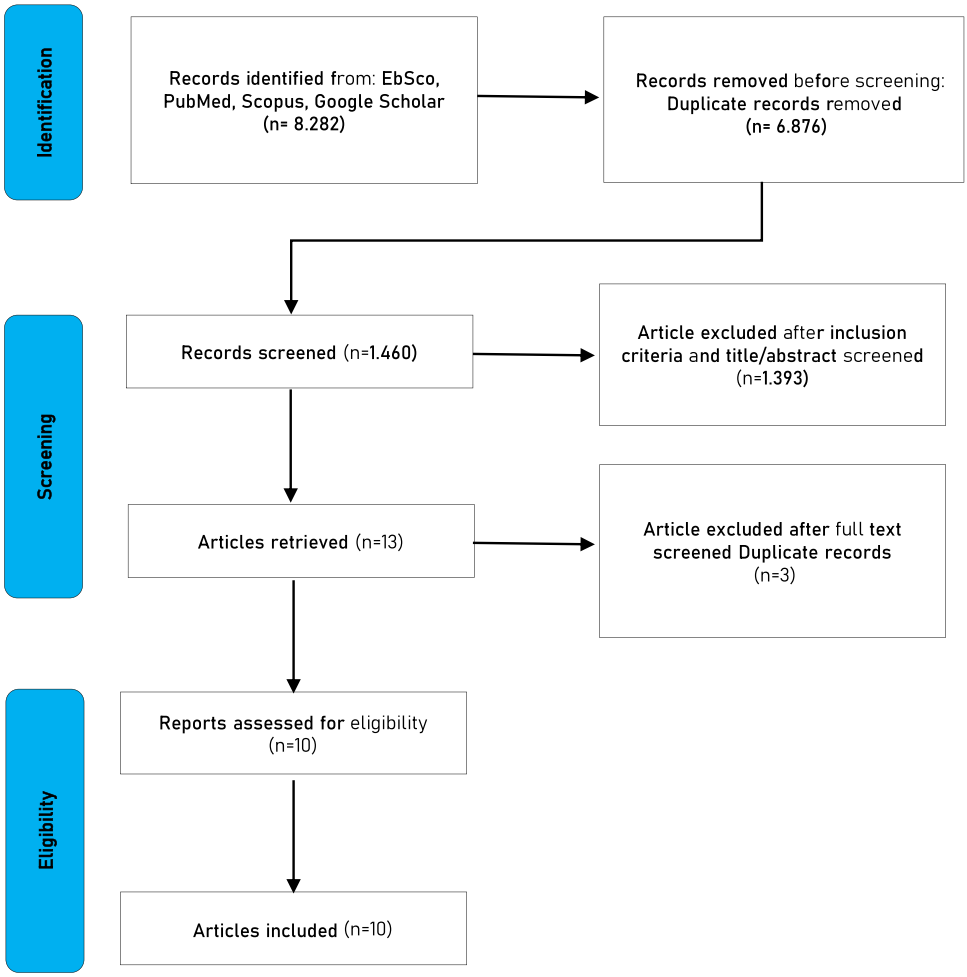

Figure 1 PRISMA Flow Diagram.
Notes: PRISMA figure adapted from Page MJ. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ*. 2021;372:n71. Creative Commons.[14]

Discussion

This scoping review identified 16 key factors associated with caregiver burden among families caring for individuals with schizophrenia. These factors were categorized as internal and external and are discussed as follows. This is because the older a person gets, the more mature he is in managing his life, including creating decisions, including in taking care of his family member who suffers from schizophrenia.[16] Age influences a person's capacity to sense and think. The older you become, the more mature your catchment and thinking will become. At an early age, intellectual capacity, problem-solving, and language skills are said to drop practically no.[17]

Gender has a major association with the strain of the caregiver family; someone who is a caregiver of the female gender is significantly at risk of feeling the load encountered as a caregiver than males in taking care of schizophrenia patients.[18] In contrast with the findings of studies from,[19] It shows that caregiver burden is not related to the patient's gender, duration of illness, caregiver's age, gender, education and marital status, kinship relationship with the patient, sharing of patient care, and previous experience with caregiving. The findings support the research data that there were no significant differences in caregiver burden when viewed from age, gender, and familial relationships. This is because the patient situation he faces is very different between physical and psychological disorders.

A marriage is one of the elements that adds to the strain for someone who serves as a caregiver, such as a married woman that works as a homemaker while simultaneously caring for families suffering from schizophrenia. This may be caused by the numerous requirements of responsibilities that must be completed by the individual in question, whilst in

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Table 3 Results of Article Analysis

No	Article	Research Objectives	Population & Sample	Types of Research & Research Instruments	Result
1.	**[31]**	To find out the factors related to the burden of family caregivers in caring for patients with schizophrenia.	**Population**: Families who have family members experiencing schizophrenia at Wonosalam 2 Demak Health Center **Sample**: 41 people	Cross-sectional.	There are several factors related to the burden on family caregivers, namely, age, gender, education level, occupation, length of care in caring for schizophrenia patients
2.	**[22]**	To test family functioning, particularly fit within the family of the patient-caregiver partner, and family-related factors as a person living with a schizophrenic client	**Population**: Patient-caregiver spouse family **Sample**: 131 couples.	Cross-sectional	Family function is considered impaired and there is a relationship in this regard. The level of education of patients and caregivers' families, the level of suicidal ideation in patients, the number of previous hospitalizations, and the quality of family-centered care are related to the functioning of the patient's family and the primary caregiver's family.
3.	**[28]**	To assess the level of caregiver burden and family functioning among family caregivers of people with schizophrenia in Taiwan and to test the relationship with demographic characteristics, family demands, sense of coherence and family resilience.	**Population**: family caregiver **Sample**: 137 Caregiver.	Cross-sectional	There are several factors that cause the burden on caregivers, these variables include gender, economy, duration of care, and level of education
4.	**[32]**	To investigate the burden factor and caregiver satisfaction among individuals and families and the relationship of caregiver burden to caregiver satisfaction in the care of Taiwan individuals with schizophrenia	**Population**: individuals and families with schizophrenia **Sample**: 140 families	Cross-sectional	Female caregivers, greater family demands, decreased sense of coherence, and low mutuality are associated with higher levels of caregiver burden, while being siblings or relatives of individual victims are associated with lower self-reported burden. Satisfaction is positively related to caregiver age, sense of coherence, and mutuality. Burden and satisfaction are not significantly related
5.	**[33]**	To identify factors related to the burden on caregivers.	**Population**: Caregivers **Sample**: 175 caregivers	Cross-sectional	The average ZBI score is 49.49±12.06, which indicates moderate to heavy loads. Factors significantly related to caregiver burden include age, gender, occupation, income, marital status, home conditions, relationship with patients, stage of illness, and duration.

6.	**[34]**	To evaluate the relationship between sociodemographic factors, stress and caregiver family burden of patients in psychiatric hospitals.	**Population**: caregivers over the age of 18. **Sample**: 112 caregivers	Cross-sectional	The burden of care on family caregivers in mental hospitals was significantly related to stress (p=0.000). The psychological symptoms of stress predict a heavy burden. Most caregivers experience moderate or heavy loads, with 52.7% in a phase of resistance to stress; 66.1% showed psychological symptoms
7.	**[35]**	To test the correlation between caregiver burden and health-related quality of life (HRQoL) among primary caregiver families of individuals with schizophrenia in inpatient psychiatric rehabilitation facilities	**Population**: Family Caregivers in inpatient psychiatric facilities, Taiwan **Sample**: 157 families	Cross-sectional	Primary family caregivers experience light to moderate burden and poor HRQoL. Older and unemployed primary family caregivers, caring for severe psychiatric symptoms of patients, and having low monthly incomes, decreased mutuality, and lower family coping strategies are associated with greater caregiver burden and poor HRQoL. Greater mutualistas and family coping strategies and seeking spiritual support are the most significant factors in increasing caregiver burden and all domains of HRQoL
8.	**[29]**	To find out the prevalence of family caregiver burden with schizophrenia patients	**Population**: caregivers from Farshchian Psychiatric Hospital in Hamadan, Iran **Sample**: 225 caregivers	Cross-sectional	The level of burden experienced by caregivers is significantly related to age, gender, level of education, relationship with patients, duration of care and duration of schizophrenia.
9.	**[30]**	To examine (a) the level of caregiver's quality of life; (b) the relationship between caregiver demographic characteristics, caregiver burden, family, social and professional support functions and their quality of life and (c) the best predictor of caregiver's quality of life	**Population**: caregivers **Sample**:100 caregivers	Cross-sectional	There is a significant relationship between caregiver burden and their quality of life. Regression Analysis shows that the best predictors of quality of life are seen from the burden experienced by caregivers, social support and professional support
10.	**[36]**	To assess the burden experienced by the caregiver of schizophrenia patients and to evaluate its correlation with some of the patient's demographic characteristics, caregivers in schizophrenia patients and the level of emotions expressed in the family.	**Population**: Schizophrenia patients and caregivers **Sample**: 172 schizophrenia patients and caregivers	Deskriptif-analitik	Based on the results of the study, several demographic factors of primary care providers, patients, and their families have a significant effect on the burden experienced by primary care providers. Most caregivers have a high emotional expression and a significant direct link exists between the emotions expressed and the burden experienced

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men whose activity a role as the leader of the household, they will experience the same way, specifically simultaneously a heads of the household who receives income and works their house will become.[20]

There is a significant relationship between education level and family caregiver burden. The higher a person's level of education, the higher the burden experienced by the family caregiver. The higher the level of education, the greater the sense of responsibility for the greater the perception of the complexity involved in the provision of care.[21] Employment also has a significant relationship between the burden of family caregivers. Caregivers who do not have a job are more at risk of feeling burdened compared to caregivers who have a job in caring for schizophrenia patients.[22]

Economic position is also one of the aspects that contributes to a caregiver's burden; it is not only caregivers that bear the load if someone's economic level is below average. Whenever a person gets the caregiver, they will experience a huge weight as they are forced to take care of others while also working.[23]

The duration of care, or length of care, has a substantial association with the strain that the family caregiver will bear. The period of time someone who cares for provided care for a schizophrenia patient, the greater the strain on the caregiver.[24] The duration of a person's schizophrenia will influence the workload of a caregiver; the longer the schizophrenia, the greater the load that a caregiver will bear. The severity of the sickness has a greater impact on a caregivers burden than the period of care.[25]

A person who experiences a burden as a caregiver is one of them caused by stress factors. The stress experienced is the presence of psychological symptoms, such as excessive anger, apathy, depression, prolonged anger, excessive tiredness, and anxiety.[26] That is caused by severe weariness and disordered thinking.

Patient severity demonstrated a substantial link between symptom intensity and caregiver load.[27] The caregiver load increases with the intensity of the patient's symptoms.

To improve the HRQoL of main caregiver families that care for clients with schizophrenia, family coping mechanisms for efficiently managing caregiver load must be used.[27] If family coping is not effective, the higher the burden will be felt by a caregiver and this will reduce the quality of life in the caregiver family in caring for clients with schizophrenia.

Spiritual assistance has shown to be a helpful technique to cope with families enduring stress while caring for them.[27] Social support influences a family's dedication to care,[28] Social support can help withstand stress and excessive burden by lowering its impact.[29] As a result, social support is critical in reducing the load that a caregiver bears when taking care of a client suffering from schizophrenia. Support from professionals is a predictor of the happiness of life dimension, emphasizing the necessity of giving knowledge about diseases and therapy services accessible to relatives, and having a compassionate approach towards their burden.[29]

Limitations

This research still has some limitations that have the potential to cause bias in the research findings. In this study, only three databases and one search engine were used, did not use article quality assessment instruments, thus potentially causing bias in quality assessment results, not being able to access some full-text articles and limiting references only in English and Indonesian which may have limited the results of the research.

Conclusion

This scoping review identified sixteen factors contributing to the burden experienced by family caregivers of individuals with schizophrenia. These factors were classified into internal (eg, age, gender, education, occupation, economic condition, stress, and coping strategies) and external factors (eg, illness severity, treatment duration, spiritual and social support, and access to health services). Understanding these factors is crucial in developing effective family-centered mental health care interventions. Nurses and healthcare providers should design culturally sensitive support strategies that strengthen coping skills, enhance social support, and reduce caregiver strain. Further research is needed to explore intervention models tailored to caregivers' needs in various cultural and healthcare contexts.

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