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Including families in schizophrenia treatment: a systematic review

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ABSTRACT

The family as one of system support for schizophrenia treatment in the primary care setting has been a challenge in integrating family services into mental health. This study aimed to review the urgent of family involvement during the treatment of schizophrenia in health mental services using the Family-Centered Care approach. A systematic review was performed using the population, intervention, comparison, outcome, study design (PICOS) framework within Scopus (27 articles), ProQuest (151 articles), Science Direct (93 articles), EBSCO (124 articles), and Springer (149 articles) published databases in the last five years using the keywords of "Family-Centered Care, nursing, AND Schizophreni*". The articles were empirical quantitative, qualitative, or mixed-methods studies published within 2017-2021 where study participants were clinically diagnosed with schizophrenia and intervention approaches were within the scope of family involvement. Twenty-four articles met the inclusion criteria for review. Evidence supports a professionally engaged relationship between patients, families, and providers with open knowledge exchange, communication, and collaboration. Family-centered care requires empathy, understanding, respect, and empowerment to choose, control decisions, and empower in the treatment of schizophrenia. This study concludes the importance of family involvement in the treatment of schizophrenia from the start. Health care providers help families through the admissions process.

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1. INTRODUCTION

Mental disorders are psychological conditions in which individuals experience a decrease in body function, feel depressed, uncomfortable, and a decrease in the function of individual roles in society. One type of disorder in mental health is schizophrenia. Schizophrenia is a mental health disorder that is chronic and requires a long period of recovery. Schizophrenia is a mental disorder that is a major problem in countries where schizophrenia is a type of psychosis that ranks at the top of all existing mental disorders [1], [2]. The prevalence of schizophrenia or psychosis in Indonesia is 6.7 per 1,000 households based on the 2018 Basic Health Research (*Riset Kesehatan Dasar*/*Riskesdas*) of Indonesia. It means there are 6.7 households from 1,000 households that have household members with schizophrenia/psychosis. The highest prevalence distribution was in Bali and Yogyakarta with respectively 11.1 and 10.4 per 1,000 households members with

schizophrenia/psychosis. The prevalence of Schizophrenia in Indonesia was seven cases per mile in 2018 (an increase of 0.18%) [3].

Globally, more than 20 million people have schizophrenia, more than 69% of people with schizophrenia do not receive proper treatment and 90% of untreated schizophrenics live in low- and middle-income countries. In this case, lack of access to mental health services is an important issue. In addition, Schizophrenia tends to seek treatment than the general population [4]–[7].

Schizophrenia as a lifelong illness requires long-term care which is usually carried out by the family [8]. Re-admission of schizophrenic patients to mental health services for less than one day has become a popular issue for intervention from both service providers, families as part of the closest unit of sufferers and needs attention from the community. There are various factors that cause the return of schizophrenic patient to be re-admitted in mental health services, such as unmarried status, previous history of forced entry, longer forced entry days, and shorter total days of admission, which were associated with an increased risk for one year re-enrollment [9]–[11]. The impacts of re-admission include; increased cost of care, longer treatment, increased burden on family and clients, decreased quality of life and cognitive, and disease severity. Meanwhile, the specific impact for the family include family stress due to stigma, burden of care, and frequency of recurrence [2], [12], [13]. The interventions conducted have been more focusing on recovery in mental health services and the lack of family involvement in care. This is consistent with the finding of previous research that the quality of family-centered care perceived by primary family caregivers regarding the provision of general and specific information, such as: empowerment and partnerships, coordination and comprehensive care, respectful and supportive care, is relatively inadequate in schizophrenic family caregivers [14], [15].

Lack of care information to families, lack of cooperation between service providers, and social wokers/cadres, patients and families are the findings of obstacles in the recovery of schizophrenia patients in primary care in mental health [16]. The finding that family involvement has not been optimal so far in the recovery-oriented service process will have an ineffective impact. It is proven that the basic perceived recovery orientation of the service significantly predicts the condition of schizophrenia to be better when family involvement is carried out optimally since the beginning (B=0.26, p=0.03, 95% CI [0.02-0.48]) [17]. The challenges of family involvement in the care of schizophrenia are caused by limited health professional and resources, patient dependence, time constraints to provide care, the nature of chronic illness, and medical paternalism [18]. For this reason, it is necessary to develop partnerships between patient family members and health care providers. Understanding recovery from multiple perspectives to develop mental health care, incorporating family caregivers in recovery-oriented services can improve service outcomes [19]. Therefore, in this systematic review, we discuss family-centered nursing in treating schizophrenic patient in primary mental health services as an effort to provide integrated care.

2. RESEARCH METHOD

A systematic review was used as a synthesis of relevant studies about the involvement of families in taking care for people with schizophrenia using a Family-Centered Care approach. We used PRISMA checklist of items to evaluate the study quality with The Centre for Review and Dissemination and the Joanna Briggs Intitute Guideline.

2.1. Search strategy and inclusion criteria for systematic reviews

This study identified various research articles in the databases that matched the theme. The systematic review was performed using the population, intervention, comparison, outcome, study (PICOS) design framework Table 1 utilizing Scopus, Proquest, CINAHL, and Springer Link databases in the last five years within keywords “Family-Centered Care, nursing, AND Schizophreni*”. The keywords were also changed to synonym keywords such as mental illness and mental health. Reviews were also carried out on abstracts and references from articles collected. A detailed explanation of the complete search strategy can be seen in supplementary Appendix. A flowchart of the search strategy and organization of the journal citation report (JCR) can be seen in Figure 1.

Table 1. Description of PICOS systematic review

P	Patient, Population, Problem	Schizophrenia, Mental illnes
I	Intervention	Family centered care
C	Comparison intervention (if appropriate)	NA
O	Outcome to measure or achieve	Family involvement in the treatment
S	Study design	Quantitative, qualitative, and mix method

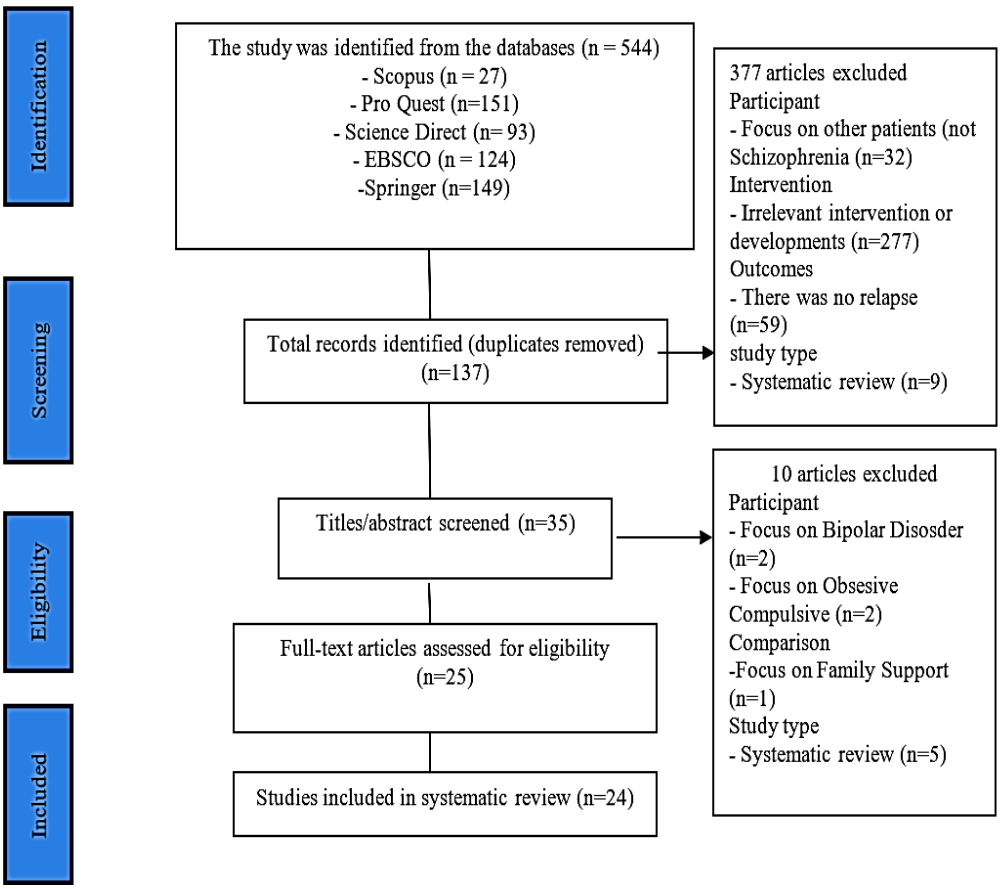

Figure 1. PRISMA flow diagram of included studies

The inclusion criteria was used to assess titles and abstract of manuscript for relevance to the topic, including: i) empirical studies including quantitative, qualitative, or mixed-methods published in peer-reviewed journals between 2018-2021, written in English; ii) study participants were clinically diagnosed with schizophrenia; iii) family centered care was identified as intervention approaches; iv) family involvement in caring for schizophrenic patients with a Family centered care approach was measured.

If the relevance found was not clearly demonstrable on the basis of the initial review, then the full article was read to determine whether it should be included. After the initial cohort of articles was collected, the full text was read to ensure final inclusion in the review. In this case, 24 articles met the inclusion criteria. Data were extracted into a JCR to review study characteristics and rate levels of evidence for each article. Articles assigned levels of evidence 5, 15 (professional standards), and 5 (recommendations) were not included in this study, because the purpose of this review is to investigate original, empirical studies.

2.2. Study selection, data extraction, and management

We collected the data about the publication year, the databases searched, the study population, and the family centered care approaches from each full-text. The authors independently screened titles, abstract, and full-texts of articles. The authors retrieved full-text versions of potential articles and determined final inclusion in the review based on relevance to the question, study quality, level of evidence, as well as inclusion and exclusion criteria. Disagreements were resolved by discussion or by consulting another author if necessary.

Each retained article was appraised and key information extracted to an evidence table that provide a summary of the methods and findings of the article. Supplemental table summarizes the characteristics, including methodology, Family centered care, result, and recommendation. The risk of bias assessment of each studies used Cochrane Collaboration's tool adapted from Sterne *et al*. [20]. Again, disagreements were resolved through discussion.

2.3. Outcome measures

We focused on articles that considered family involvement in providing schizophrenia care with a Family centered care approach in mental health primary care.

3. RESULTS AND DISCUSSION

3.1. Study characteristics

Twenty-four articles met the inclusion criteria for review Figure 1. Evidence supports the professional engagement relationships between patients, families, and service providers with an open exchange of knowledge, communication, and collaboration. Family-centered care requires empathy, understanding, respect, and empowerment, allowing opportunities for choice, decision control, and empowerment in schizophrenic treatment.

3.2. Readmission of patients

There are various factors that cause the return of schizophrenic patients to be re-admitted in mental health services, including unmarried status, previous history of forced entry, longer days of forced entry, and shorter total days of admission, which were associated with an increased risk for one year re-enrolment [9].

3.3. Family involvement

Family stress was predicted by family structure (p=0.029), stigma (p=0.000), burden of care (p=0.000), and patient recurrence frequency (p=0.005). Nursing burden was the strongest predictor of family stress (Beta=0.619). Relapse frequency and patient stigma are other types of family stressors. Stressors stimulate negative perceptions, which is called load treatment. The limited adequacy of family structure-function will hinder the family in using other resources, creating family stress [12].

3.4. Family-centered care

The quality of family-centered care perceived by primary family caregivers regarding the provision of general and specific information, such as: compared to empowerment and partnership, coordinated and comprehensive care, and respectful and supportive care, is relatively inadequate. Younger and primary family caregivers who are more educated, have relatives with schizophrenia in the acute ward, the attitude of nurses who are less supportive schizophrenia, and the importance of the family in correlated nursing care with poor primary family caregivers' perceptions of family-centered qualities care. Nurse's supportive attitude towards schizophrenia and chronic psychiatric rehabilitation ward where the patient receives care is a key factor in determining the quality of being better than family-centered care [21].

Some challenges in implementing the family centered treatment extracted in limited health resources, health professions, patient dependence, time constraints to provide treatment, the nature of chronic disease and medical paternalism [18]. Family-centered care as a health care approach in mental health that engages patients and families in self-care efforts, involving families as collaborative partners in all aspects of care and decisions about care through mutually beneficial supportive partnerships with health care providers; to help patients make progress towards recovery [22].

Family as a source of support is an essential aspect in the convalescence process of schizophrenia patients. The family involvement in patient daily to complete their healing process includes supervision of taking medication, providing continuity and optimized care, and empowering people with schizophrenia.

4. DISCUSION

4.1. The burden of family care

Family members are the primary caregivers of mental health patients, taking on responsibilities traditionally under the purview of hospital and medical professionals. The impact of this shift on the family is high as well as has an emotional and economic burden [23]. Families with schizophrenia experience the strongest stressors on the burden of care borne, in addition to stigma and the frequency of sufferer relapse [12], [24].

Family as the main caregivers often recognizing that caring for a loved one with schizophrenia is difficult and struggle with social isolation, physical and emotional exhaustion, and also cost burden [8], [13]. This is reinforced that the burden of household care is high for people living with schizophrenia in low-income settings [25]. The family feel the burden of care costs due to the length of recovery at the health service and the frequency of recurrence, resulting in shorter re-admissions. The findings suggest that low income, stigma, and quality of family care are critical determinants of health-related quality of life, so efforts to increase life satisfaction focus on reducing stigma, increasing family income and strengthening the quality of family-centered care [21], [26].

The psychosocial burden experienced by the family raises emotional expressions that can be a barrier factor for care between patients and families, nursing interventions that are carried out to minimize emotional expressions have been widely studied and the majority recommend providing psychoeducation and

the results are proven to reduce family emotional expressions [27], [28]. Another approach used to reduce the burden experienced by families in treating schizophrenia is to develop family resilience (resilience), which can increase the capability of families in treating schizophrenia. The model helps families through stress management by controlling burdens and stigma so that families are able to survive and grow stronger and better at treating people with schizophrenia [12]. The results of another study stated that strengthening family coping resources (SFCR) can guide service providers on how to implement family-centered care programs to reduce the burden of caring for schizophrenic patients through family support in efficient care [1], [29]–[32].

Family psychoeducation (FP) as one of the recommended guidelines for the pharmacological treatment of schizophrenic patients, has been shown to reduce the burden on families. FP is also considered to increase the role and function of the family as a caregiver who supports the patient's recovery, thereby reducing the rate of recurrence and hospitalization [8]. However, FP is often poorly implemented due to various obstacles such as scheduling difficulties and lack of access to care from specialists [6], [33], [34]

Burden's family caring for a family member with schizophrenia has demanded the development of guidelines for the care of schizophrenia. However, the development of a guideline implementation strategy was insufficient and was examined in only a few studies. Although the barriers to improving guideline compliance have not been generalized, several reports suggest that low awareness and dissemination of guidelines, as well as inadequate supply systems, may affect their implementation [13], [35].

4.2. Family centered care

Families play an important role in meeting the care needs of individuals who need assistance due to illness and/or disability, including those with mental disorders. However, without adequate support, the health and welfare of the family will be disrupted. This study highlights the need for family-centered care to increase their resilience, which impacts the ability to care for family members with mental problems [36].

Family centered care is an approach to mental health care that recognizes patients and families as experts in themselves, involving families as collaborative partners in all aspects of care and decisions about care through mutually supportive and beneficial partnerships with healthcare providers to assist patients towards recovery in primary service. Key components to facilitate family-centered care include collaboration between family members and health care providers, consideration of the family context, policies and procedures, and education of patient, family, and health care professionals Figure 2 [36], [37]. Some of these aspects are universal and some of them are disease specific [36].

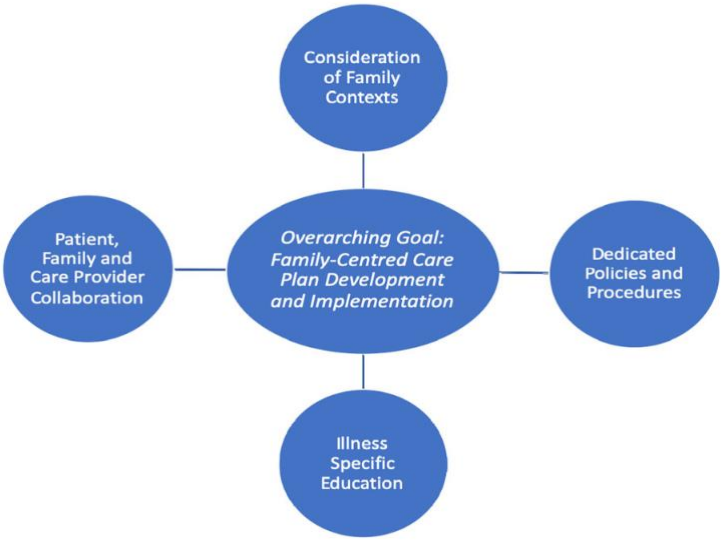

Figure 2. Model theory of family centered care [36]

Family centered care approach will increase accessibility, better relationships and less stigma associated. Health care service in the community should involve families in a variety of ways, such as providing psychoeducation, behavioral family assessment or family therapy, supporting the family's physical, emotional and social needs. Fulfillment of basic needs both physical (eg nutrition) as well as emotional and social is then associated with problems in body systems such as the heart, breathing, and other systems,

which require care from the family [38]. The family also plays a role in shaping the habits of family members so that family involvement strengthens the effectiveness of care [39]–[41].

4.3. Barriers in implementing family-centered care

Family involvement in taking care for schizophrenic patients is not always implemented in the recovery phase in primary care. Some of the obstacles faced in this implementation include the lack of family knowledge in the involvement of patient care. besides the lack of family support for sufferers can be caused by problems experienced by families in treating schizophrenia. This is supported by the results of research that mental health professionals have tried to apply a family-centered approach to care, but the complexity of the problems experienced by families, then face dilemmas and obstacles in their ambition to involve the family as a whole as a system [8], [42], [43]. The findings of the study found that many barriers were felt by families, such as: poor quality care, conflicts with health professionals about treatment, and the lack of family roles in treatment. Families also identify with their community's isolation from the mental health care system. Emphasis on their role as caregivers and their need for support. On the other hand, health professionals also raised concerns about system-based barriers, professional practice-based barriers, and family-based barriers to care. Patients expressed the need for their families to be more educated about mental illness [44]. In addition, the barriers reported by schizophrenia families are: lack of awareness of the disease in patients and families, scarcity of information on primary care from service providers, stigmatization, lack of cooperation between service providers and social workers, patients and families [8], [16]. In another studies, family involvement is still a concern because it has not been widely included in the clinical training section [45].

4.4. Implementation of family-centered care

There are different views on recovery management in schizophrenia, where sufferers consider independence as something more important while families view recovery as the main goal. This is reinforced by research that the dominant component of recovery for patients and caregivers is independence (72.5%), general hope for recovery (51%), and social relationships (43%). Families are different in two respects: sufferers have much greater expectations for independence ($p<0.01$), while caregivers focus more on recovery ($p<0.001$) [46]. If you look at the results of these different views, involving families in the recovery phase is the basis for providing integrated services between service providers and families. The results of the study also found that it was important for family members who cared for people with schizophrenia to be involved in their care early on, and that they are guided through the admissions process [47].

The family as the closest unit in taking for patients when they are recovering from health services. In this case, family intervention strategies that can be given to schizophrenia are addressing needs, followed by increasing coping skills, advice, and emotional support [48]. Families can also provide collaborative, long-term care, focused on increasing accessibility to mental health care, utilizing community-based health workers and volunteers as untapped resources to support adherence and engagement with services [49]. Family intervention for schizophrenia consists of a combination of psychotherapy strategies that aim to develop a working relationship between the family and the medical team to support the patient's recovery so as to prevent relapse and hospitalization, improve medication adherence, maintain satisfying family interactions, and have a positive impact on patient and quality of life [23].

Family-centered nursing requires reciprocity between patient, family and service provider with an open exchange of knowledge as well as communication and cooperation of supportive professional engagement relationships characterized by empathy, understanding, respect and empowerment, allowing opportunities for choice, decision control and empowerment [22]. The functioning of family involvement in family-centred care (FCC) can also be caused by factors such as the level of education of patients and family caregivers, the number of previous hospitalizations, and the quality of family-centered care that correlates with the function of the patient's family and primary caregivers of the family [50]. Family centered care approach will increase accessibility, better relationships and less stigma associated. Care providers in the community can involve families in a variety of ways, such as providing psychoeducation, supporting the family's physical, emotional and social needs, and behavioral family assessment or family therapy [39]. Key components for facilitating family-centered care includeing collaboration between family members and health care providers, consideration of family context, policies and procedures, and professional education of patient, family, and health care [36].

Mental health care implementation carried out by the family pays attention to the culture that is owned by the family as a source of strength. This is supported by the finding that the practical application of family-oriented mental health interventions requires culturally conscious practice based on an understanding of dynamic family relationships and a cultural understanding of mental illness [51], [52]. Examination of family perceptions informs psychiatric care providers of the importance of being culturally

sensitive in developing effective practices of working with family caregivers, particularly casual caregivers in attribution, impact of stigma, and parenting experiences [53], [54].

In this regard, the Effectiveness of Guidelines for Dissemination and Education (EGUIDE) psychiatric treatment project has been developed to serve as a guide in the strategy for treating patients with schizophrenia, and as a means of dissemination and education of effective guidelines. The EGUIDE project, as a dissemination and education program for clinical practice guidelines for schizophrenia and major depressive disorder, has the potential to contribute to improving the clinical behavior of psychiatrists [55]. Another study of several psychological therapies can be recommended as a guide in the management of schizophrenia patients. One of the emotional therapies that has been widely studied is forgiveness therapy. This therapy can support patients to turn negative relationships into positive ones. Individuals who have forgiveness can also change negative thoughts that turn into better thoughts and individuals who can establish good relationships with others because that person has been hurt. However, emotion-focused therapy requires a strong trust between the therapist and client. In this case the therapist must build trust in the relationship as an important prerequisite for increasing self-reflection and feelings addressed to the client [56].

5. CONCLUSION

Family-centered care is an approach in mental health, including in the treatment of schizophrenia. This model involves the family as a collaborative partner in all aspects of care and decision making about care. Partnerships are built on mutually supportive and beneficial relationships with healthcare providers at the primary level to help patients to recover.

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