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COMMUNITY CARE FOR PERSONS WITH SCHIZOPHRENIA IN INDONESIA

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Abstract: Mental healthcare services for people with mental illness have enhanced healthy family relationships, friendships, and even interaction with colleagues at work for persons receiving the care services. Many factors influence the practice of the mental health profession, including family involvement, social support, and coordinated comprehensive care. This research aimed to explore the role of family and community in the practice of care for people with schizophrenia in Yogyakarta, Indonesia. Methods: This was qualitative research conducted in 2021, with interviews and Focus Group Discussions as data collection methods. The participants included eight family members of individuals with confirmed schizophrenia and members of the local community. The analysis employed an inductive thematic analysis to explore various roles in mental health handling. Results: Kinship patterns, cultural values, and religious practice greatly influence care. Care is generally perceived as an act of assistance to functional limitations. It often becomes an area of negotiation in the family and community, particularly on the issues of finances, roles, and responsibilities, and on how the method of care should be delivered. In some cases, families with their social capital created a care network that enables the community's support system. On the other hand, the community also has a formal and informal social organization to advocate for adequate treatment. Conclusion: Community and family support for persons with schizophrenia is an essential factor for optimal treatment. Nevertheless, there is a need to improve knowledge and awareness of mental health in the community to ensure proper treatment is delivered.

Keywords: care, community, role, mental illness

Introduction

Based on the 2018 Basic Health Research data, cases of severe mental illnesses in Indonesia are increasing. This increase can be seen from the rise in the prevalence of households with people with mental illness (PWMI) in Indonesia, namely, 7 per million households. This means that per 1000 households, there are seven households with PWMI, so the number is estimated to be 450 thousand severe PWMI (National Institute of Health Research and Development, 2019). Of all cases of mental illnesses, schizophrenia was estimated to be the highest among all Global Burden of Disease (GBD) studies for acute state of psychosis (GBD 2019 Mental Disorders Collaborators, 2022). The impact of schizophrenia on disability is a complex and multifaceted issue that encompasses various aspects of

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an individual's life. Studies have shown that schizophrenia can lead to significant disability, affecting real-life functioning, cognitive impairment, and social functioning (Bhati, 2005; Galderisi et al., 2014; Twamley et al., 2003). Cognitive deficits are considered to play a central role in social disability and other problems in daily living experienced by patients with schizophrenia (Twamley et al., 2003). Furthermore, the influence of illness-related variables, personal resources, and context-related factors on the real-life functioning of people with schizophrenia suggests that addressing neurocognitive and social cognition impairment should be part of integrated treatment packages for schizophrenia (Galderisi et al., 2014).

Not all PWMI have been treated; only 85% of patients have received treatment at a health facility even once in their lifetime, and the majority of PWMI who have received treatment are those who live in urban areas (National Institute of Health Research and Development, 2019). The lack of access to appropriate health services results in patients having deplorable treatment-seeking behavior, thus further worsening their condition. Based on the Human Rights Watch report in 2020, hundreds of thousands of PWMI are shackled in 60 countries around the world. Apart from shackling, the visible impact is less than optimal treatment, and there is a high recurrence rate of patients who have been declared cured and returned to their families(Human Rights Watch, 2020). The 2018 Basic Health Research also shows that the rate of regular medication was only 50% of all patients with severe mental illnesses(National Institute of Health Research and Development, 2019).

The Special Region of Yogyakarta was one of the provinces in Indonesia with a high prevalence of mental illness (10,4%) (National Institute of Health Research and Development, 2019). However, the number of mental health professionals is quite low (Tjandrarini et al., 2019). This imbalance may have serious consequences, for example, delayed or not providing adequate care to those in need. The lack of mental health professionals may lead to increased waiting times for services, limited access to specialized care, and a strain on existing professionals who may be overwhelmed by the growing demand.

Mental disorders are also often associated with things that are mystical, supernatural, or with the belief that mental illnesses occur due to a curse. These beliefs are one of the causes of the high level of stigma toward people with mental disorders. This stigma also has an impact on the families of people suffering from mental illnesses, which also makes the treatment given inappropriate.

In the field of mental health, community involvement plays a key role. Lestary's research (Lestari et al., 2020) concluded that the community is an appropriate support system for improving care for people with severe mental disorders. The recovery process for serious mental disorders requires strong motivation and commitment from sufferers, families, all members of the surrounding community, the mental health service team, and related policymakers. Therefore, this article aimed to depict the role of family and community in delivering care to persons with mental illness.

Materials and Methods

The study took place in Yogyakarta Province, Indonesia, in 2021. Notably, in Gunung Kidul and Sleman Regency. This exploratory study used a qualitative method as the primary data collection strategy. Creswell stated that Qualitative research is an investigation of understanding based on qualitative analysis, Particular methodological traditions of inquiry that explore social or human aspects. The researcher puts together a comprehensive, holistic picture and analyses its words and reports on information, conducting the study in a natural setting(Creswell, 2009). We coordinated with the local health offices to gain information on caregivers of patients with mental illnesses in the area and invited them to participate in the study. Then, we conduct individual interviews on their experiences in delivering care to their family members. We also conduct Focus Group Discussions (FGD) with community and religious leaders, village representatives, health cadres, and village securities to gain information on the management of mental illnesses in the area. This study has gained an ethical approval number: LB.02.01/2/KE.321/2021 from the ethics committee of the National Institute of Health Research and Development, Ministry of Health Republic of Indonesia.

Results and Discussion

Care in the Family

Caregivers are individuals whose activities are related to social and health services, where their main task is to be responsible for sick people. Often, this task is carried out by family members or close friends of the patient. Barker (2013) also explains that caregivers meet the physical, emotional, and social needs of other individuals who cannot fulfill them because of their conditions (Barker, 2013). WHO differentiates caregivers into two types: formal and informal (Heavens, 1999). Formal caregivers are nurses from formal institutions, while informal caregivers are usually people closest to the patient or sufferer who provide care (Heavens, 1999). Meanwhile, other definitions categorize caregivers into primary caregivers and secondary caregivers. Primary caregivers are nurses or care providers who directly carry out formal and informal care functions and take full responsibility. Meanwhile, secondary caregivers are care providers who do not have primary responsibility for the patient. In this study, researchers will focus on the burden felt by the family as the party who is fully responsible for caring for people with mental disorders.

Table 1: Caregivers and the Relationship with Patients

Caregivers	Age	sex	Occupation	Relationship with Patients
MU	58	M	Farmer	Stepbrother
SU	54	M	Farmer	Husband
AM	45	F	Unemployed	Wife
RI	45	F	Unemployed	Daughter
IR	38	F	Unemployed	Mother
S	35	M	Unemployed	Brother
SM	50	M	Self Employed	Uncle
G	48	M	Self Employed	Father

All study participants in this study have a close relationship with the patients. They could be the parents, son, daughter, brother, or uncle. As primary caregivers, their tasks include day-to-day assistance to the patients. This includes meal preparation and hygiene housekeeping, as necessary. Apart from that, they also become the manager for the patients, ensuring the medication schedule and keeping track of any potential side effects. However, all participants in this study stated that prescribed medicine from a mental health professional was not the first option when the first symptom occurred.

"We use traditional medicine first, but later on, we take him to the hospital. They gave me medicine and referred to the local public health clinic. Sometimes we give the medicine, sometimes not. It depends on the circumstances" (Interview with SM)

Caregivers sometimes have difficulty managing their time and schedule to keep on track with medication for their family patients. SU and MU said that they find it challenging to manage their time between their daily routine at the farm and keeping up with the medication schedule. AM stated different experiences with medication. She said that her husband would refuse it. Delays in medicine could affect the patient's emotional stability. AM mentioned that her husband sometimes would get aggressive with others around him. Sufferers of severe mental disorders such as schizophrenia generally show positive and negative symptoms. Hallucinations and delusions are sensory experiences that often appear in people with schizophrenia. This then impacts the individual's level of independence, ultimately making them dependent on the presence of caregivers to help with their daily activities.

The consequences of mental disorders are not only felt by the patient but also by the family and other parties involved in treatment. These consequences can manifest as positive and negative things. Positive consequences are when the family or primary caregiver successfully overcomes all the difficulties faced in the caregiving process, creating a sense of satisfaction that can increase the sense of belonging in the family. Meanwhile, negative consequences are the emergence of feelings of helplessness, anger, or high anxiety. The caregiving process brings a range of emotions, mixed and tumbled, varying daily as they volunteer in this role. SU stated the experience as he took care of his wife daily.

"I think it's normal. I always try to control my emotions. After all, I'm taking care of my wife. I can handle her. But sometimes it comes when there's another problem around me. But I always try to control it in my way, as a husband. But it seems like the neighbors think that I'm too emotional." (Interview with SU)

The emotional stake SU stated in expressing his situation with his wife was caused by his burden. On the one hand, he must struggle to meet his family's needs. On the other hand, he must also take full responsibility for caring for his wife. This situation often leads to the limitation of social and leisure time activities. Some studies have shown that schizophrenia remarkably restricts caregivers and makes them concerned about the future (Ozlu et al., 2015). The burden felt by caregivers often affects their well-being and mental health quite seriously. This often makes them ignore their physical and psychological condition. So, in the end, it could impact their physical and mental health (Tristiana et al., 2019).

The importance of neighbor support is becoming apparent by the day. Building a solid network within the community can be a crucial lifeline for individuals like SU, who find themselves juggling the demands of both providing for their family and caring for a loved one with a severe health condition. One of our study participants also stated the experience of having a supportive neighbor who can support care delivery.

"We have done our role to take care of our family. But what is also important is the neighborhood around us. Because every trouble or happiness that we feel, they can feel it too. I am grateful that my neighbors are very kind. They never make fun of my brother (because of his condition)." (Interview with S)

The study participant's emphasis on maintaining a positive relationship with their neighbors highlights the significance of social support in coping with the challenges associated with schizophrenia care. For participants and other people faced with similar situations, building and nurturing ties within the community can be a crucial source of support. Similarly, a study by (Sawab et al., 2023) revealed that caregivers of individuals with schizophrenia may experience feelings of helplessness and burden due to a lack of understanding about the care and treatment of severe mental disorders within their families, as well as the absence of social support from their communities. Another study in Surabaya, Indonesia, depicted that providing psychoeducation to the patient's family about schizophrenia and the importance of medication adherence is crucial for the patient's long-term well-being. By understanding the condition and its treatment, family members can become active partners in supporting the patient's adherence to medication, thereby improving symptom management, preventing relapse, and enhancing the patient's overall quality of life (Jessica et al., 2021).

Care in the Community

The recovery process for mental disorders does not only focus on medical treatment but also adapts to the sufferer's needs. Recovery from mental illnesses will be more effective if one pays attention to the uniqueness of the sufferer and involves family and community as a support system (Suryani et al., 2019).

Our study finds that a collaborative effort involving various aspects has been established in the village setting concerning treating patients with schizophrenia. Each of these plays an individual role in the treatment process. The local authorities will contribute by facilitating resource access and coordinating Community Based Initiatives. Health professionals are essential in delivering clinical expertise, treating administration, and monitoring patients' progress. A network of local organizations provides a necessary mechanism for supporting patients and their families by fostering community understanding and empathy while organizing a collective effort to help them. Village security personnel may play a role in ensuring the safety and well-being of individuals with schizophrenia, contributing to a secure environment.

Table 2: Actors Role Description

No.	Actors	Role	Description
1	Village officials	Regulations and planning	Set up regulations, mitigation, and budget for mental health management in the village.
2	Health workers, Health Cadres, or mental health workers	Case identification and clinical services	Carry out detection programs in the village, case management, and referral.
3	Community or Religious leaders, neighborhood association	Psycho-support and Psychoeducation	Supporting the family in delivering care and
4	Village Security	Crisis Management, or handling emergency	Anticipate, guard, and act in the event of disturbances related to problems with mental health.

“Suppose there is a case of relapse patients; we quickly coordinate with the village officials. We ask for help from Pak Babin (Village Security) and Pak Lurah (Village Chief). Then, they will coordinate with the health workers from the Public Health Clinic for possible medical intervention. We certainly need the help of the village security to safeguard against any possible extreme event. If the patient doesn’t have an ID card or health insurance, they (village officials) will also assist with that. “ (village health cadre)

The issue of ID card possession poses a notable challenge for individuals with mental illnesses, especially those who lack a caregiver to assist them. Identification cards are crucial for daily life, including accessing healthcare services, participating in community activities, and even legal matters. For individuals with mental illnesses, the absence of a caregiver compounds the difficulty of managing and maintaining possession of their ID cards. The challenge may be related to cognitive impairment, memory loss, or problems in organizational skills, which can affect certain mental health conditions. Without proper identification, individuals may face barriers to receiving appropriate care.

One of the most pressing challenges faced by individuals with schizophrenia is the stigma of mental illness. This problem often leads to discrimination, isolation, and exclusion from society. The study participant mentioned that their family members lost the opportunity to rejoin the work that he was part of after returning from the mental hospital. In addition, the stigmatization also contributes to some families concealing their relatives with mental illness from society (Marthoenis et al., 2016). The denial and secrecy to avoid stigma affected patients not likely to get psychiatric treatment and social support for recovery (Wiener et al., 1999).

The impact of societal stigma on individuals with schizophrenia extends beyond the patients themselves, significantly affecting their families as well. The discrimination and isolation resulting from the stigma surrounding mental illness can create an atmosphere of exclusion, making it challenging for both patients and their loved ones to reintegrate into their communities. In the case of the study participant's family member who lost the opportunity to rejoin work after returning from a mental hospital, the repercussions are not confined to the individual alone; instead, the entire family unit becomes entangled in the web of social prejudice.

Conclusion

In conclusion, families play a pivotal role in the care and treatment of individuals with schizophrenia, and this responsibility can be burdensome. Caring for a person with schizophrenia can have both positive and negative effects. When families or primary caregivers successfully manage the challenges of caregiving, it can lead to a sense of fulfillment and strengthen family bonds. However, adverse consequences may arise, such as feelings of helplessness, frustration, and increased anxiety. Moreover, this study also underscores the significance of social support in addressing the difficulties associated with caring for someone with schizophrenia. In addition, social stigma also contributes to the challenges of the care and treatment of people who have schizophrenia. Therefore, it is essential to highlight the importance of a collaborative approach involving various aspects of schizophrenia patient care and treatments and reducing stigma in the community.

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Declaration of Interest Statement

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