

Overview of family behavior and community stigma towards mental disorders in west Sumba Regency

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ABSTRACT

Stigma and discrimination exacerbate the psychological conditions of individuals with mental illness, discouraging them from seeking professional help and complicating their recovery. This stigma can lead to severe consequences, including shackling and suicide. Families who understand the needs of people with mental illness play a crucial role in providing support and accelerating recovery. This qualitative research was conducted in the Puuweri and Weekerou Puskesmas work areas of West Sumba Regency in June 2024, involving 18 participants, including 10 families of individuals with mental illness and 8 community leaders, selected through purposive sampling. Data collection employed interviews, field notes, and sound recordings, following ethical protocols. The study identified significant challenges in mental health management in Sumba, including limited health facilities and medical personnel. External support from health centers, foundations, and traditional healers emerged as vital in assisting families and ensuring proper treatment. Despite reliance on traditional beliefs, these external resources act as crucial bridges for effective care. The findings of this study offer valuable insights for policy development to address mental health challenges in West Sumba, emphasizing the importance of collaborative efforts between families, healthcare providers, and community resources.

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INTRODUCTION

Stigma can worsen the psychological state of a person with mental illness, making them reluctant to seek professional help. A family that understands the condition and needs of a person with mental illness can provide significant support, helping to speed up the healing process (Corrigan & Niewegłowski, 2019; Mannarini & Rossi, 2019; Reupert et al., 2021).

A family that does not understand or even blames the person with ODGJ can worsen their psychological condition. Although it does not directly cause death, ODGJ affects activities that result in decreased productivity (Kemenkes RI, 2020). WHO 2020 reports that mental disorders

experienced by around 450 million people worldwide are predicted to increase in developing countries. 27% of the adult population aged 16-65 years in Europe experience mental disorders, (WHO, 2021). Riskesdas 2013, the number of people with mental disorders in Indonesia amounted to 6%, in 2018 it increased to 9.8%. The highest prevalence occurred in the age group > 75 years at 15.8% and the lowest at the age of 24-25 years at 8.5%. Meanwhile, according to gender, the prevalence of incidence in women (12.1%) is higher than that of men (7.6%) (Indonesian Ministry of Health, 2020). NTT is one of the provinces experiencing an increase in people with mental disorders. The 2018 Riskesdas recorded that the number of people with mental disorders in NTT increased by 15.7% compared to 7.8% in 2013 (Kemenkes RI, 2020). In West Sumba Regency in 2021, the number of ODGJ was 17 people and data as of March 2022 recorded 21 people experiencing mental disorders (Care Ministry West Sumba, 2022).

According to Indonesian Law No. 18/2014 on Mental Health, the treatment of people with mental disorders is carried out comprehensively through several approaches, involving families, communities with promotive/preventive efforts (Suhermi & Jama, 2019). However, in reality, the handling of mental disorders at the family and environmental levels is not so optimal because of the stigma factor that hinders the provision of support to people with mental disorders (Herdiyanto et al., 2017). Stigma is a negative view of a person due to religion, culture, level of knowledge, misinformation received by individuals, the environment, lack of experience in dealing with mentally ill people directly (Hanifah, 2021).

Angermeyer & Matschinger (2015) stigma occurs when someone is given labeling, negative judgment, prejudice, separation, discrimination, exclusion. Pamungkas et al. (2016) stigmatization complicates the healing process and the welfare of mentally ill people. The impact of stigma can also lead to violence such as confinement and death by suicide (Tania, 2021). Subu et al. (2018) stated that stigma results in fear felt by sufferers and others, resulting in violent behavior committed by families, communities, health workers and patients against themselves such as suicidal ideation or self-harm (Adu et al., 2021).

The result of stigmatization for ODGJ leads to relapse, slowing recovery (Asti, et al., 2016). Stigma is not only felt by the mentally ill, but also by the family such as acts of violence such as feeling threatened by the mentally ill, getting different treatment such as separation, losing status in the environment, and other social discrimination (Frias et al., 2018) (Adu et al., 2023). Stigma increases the burden on families due to feelings of shame of having a family member with mental illness (Corrigan & Niewegłowski, 2019).

RESEARCH METHOD

An appropriate research methodology to explore the portrayal of community stigma and family behavior in people with mental illness is qualitative research. This research will allow researchers to gain a deeper understanding of the experiences of people with mental illness and how stigma and family behaviors affect their daily lives. Qualitative research can be conducted through in-depth interviews with people with mental illness and their families, participatory observation, and document analysis such as medical and family records. With this approach, researchers can obtain a more complete and detailed picture of the experiences of people with mental illness and how stigma and family behavior affect their lives. In this research, the term participant is used to refer to respondents. The research will be conducted in West Sumba Regency. The estimated number of participants is 7 to 10 participants. The sampling technique used is *purposive sampling* with the following participant criteria: Qualitative research on families with mental disorders does require an appropriate interview strategy to obtain accurate data. Data collection tools in this research are interview guidelines, voice recorder (cellphone), stationery and field notes.

RESULTS AND DISCUSSIONS

Results

Informant data was obtained through in-depth interviews to understand their perspectives and experiences related to mental disorders in Sumba. Informants included a variety of parties, including patients' families, community leaders, volunteers, village heads and lurah, thus providing diverse viewpoints. This is important to capture the dynamics between family, community and institutional support in dealing with mental illness. The age range of informants from 19 to 50 years shows a broad spectrum of experience and roles. In addition to patients' families, informants also included community leaders and religious figures, providing insight into cultural and spiritual influences. Most informants were family members of patients, reflecting the central role of families in patient care and how they deal with mental health challenges in the local cultural context. The involvement of religious leaders and volunteers demonstrates the existence of social networks that support patients, although this is not always despite the stigma attached. Initial responses to mental illness where families showed emotional reactions such as confusion, fear and helplessness. This response is influenced by the lack of information about mental illness. Initial views of mental illness are influenced by cultural and spiritual beliefs, with many believing that mental illness is related to supernatural forces or violations of custom. The majority of families opt for traditional medicine (dukun/paranormal) before turning to formal health facilities such as puskesmas. Relationships with patients tend to be minimal, as families feel confused or afraid of making mistakes in their interactions. However, some families maintain positive interactions with patients.

Discussion

The results of this study's data analysis provide a comprehensive picture of how families and communities in Sumba respond to, care for, and support patients with mental illness in a distinctive socio-cultural context. This research identified various themes that reveal patterns of behavior, beliefs, challenges and strategies used in dealing with mental health issues. A family's initial response to a family member with mental illness is often influenced by factors such as culture, education level and access to information. Families usually feel confusion, fear and hopelessness when they first encounter mental illness in a family member. This is due to a lack of understanding of the condition and the social stigma attached to mental illness.

Traditional beliefs where many families tend to attribute mental illness to spiritual or supernatural factors, such as curses or violations of customs, especially in communities with strong traditional beliefs. These beliefs often lead families to seek help from traditional healers before accessing formal medical services. Research shows that family support can help patients overcome emotional burdens and stigma. For example, in Jambi Province, 97.2% of families provided both emotional and instrumental support to patients, despite limited understanding of mental health. Economic and educational factors also influence family responses. Families with low income or lower education levels tend to be slower to seek formal medical help, opting for traditional means first. This was seen in the study in Pandeglang, where the majority of families caring for patients were farmers and had an income below IDR 1,000,000 per month. Families' initial views on mental illness are often influenced by stigma and limited understanding of the condition. Research shows that many families view mental illness as a condition that is difficult to cure or even as a result of supernatural factors such as curses or customary violations.

This view can lead to inappropriate decision-making in the treatment of patients, such as relying on traditional healers before seeking formal medical help. Stigma and Negative Perception: A study at Lampung Regional Mental Hospital found that strong stigma influenced families' decisions to treat patients with mental illness. Families who held negative views tended to leave patients without proper treatment as long as they did not disturb the environment. This study underscores the importance of education to change family perceptions to support better care

(Viana et al., 2023). A literature review showed that most families still have misconceptions about mental illness, with around 52.6% of families having unfavorable perceptions. This has an impact on attitudes and support towards patients, which is often suboptimal (Marningsih, 2020). Other research notes that cultural and traditional factors have a major influence on how families understand mental illness. Belief in supernatural forces is often a barrier to seeking effective medical treatment (Edna et al., 2018).

This study emphasizes the need for a holistic approach to mental health education, involving local communities, religious leaders and health workers to reduce stigma and improve family understanding of mental illness. Initial family actions towards patients with mental illness reflect spontaneous efforts that are influenced by understanding, access to information and availability of resources. Based on recent research, family actions generally consist of three main stages: traditional help-seeking, adaptation to the situation, and seeking medical care. Most families tend to seek help from traditional healers as a first step. This is often influenced by cultural beliefs and the view that mental disorders are related to supernatural forces or violations of custom. Research in Banten Province shows that stigma and lack of understanding about mental illness reinforce this tendency before families decide to seek formal medical treatment. Adaptation and Initial Care where in this phase, the family tries to provide basic care at home. Steps such as keeping the patient safe, providing basic needs, and seeking additional information are taken. Research shows that family support, including emotional and instrumental support, has a positive impact on the patient care process. When traditional methods are deemed ineffective, families begin to seek help from health services such as puskesmas or hospitals. Research at RSUD and Puskesmas in Bali showed that most families chose medical services as the next step after the patient's condition showed no improvement. Emphasis on family education is needed to help them understand the importance of medical treatment in the long term. These studies highlight the important role of the family as part of the patient support system. Effective support not only aids the recovery process but also reduces the stress level of the family caring for the patient (Muryani, 2023; Faletahan Health Journal, 2023).

The pattern of interaction between families and patients with mental disorders (ODGJ) is strongly influenced by the burden of caregiving experienced by families as caregivers. Research shows that the physical, emotional, and financial burden of caring for patients with mental disorders can reduce the quality of interactions between family members and patients. This burden often arises from unexpected patient behavior, social dysfunction, and the patient's inability to be independent. The Family Strategy in Dealing with Mental Disorders where the family has an important role in managing mental disorders in family members. Some of the strategies applied include traditional approaches, emotional support, and collaboration with health services. Traditional and Medical Approaches: In many cases, families combine traditional methods with medical assistance. Traditional approaches often reflect local culture, such as the use of traditional healers or traditional rituals before seeking medical treatment at a health facility. This is common in communities with strong cultural beliefs, such as Sumba, Indonesia. Meanwhile, formal mental health services at puskesmas provide pharmacological treatment and counseling, although access is uneven across the region.

Emotional and Functional Support: Families provide support through maintaining the patient's emotional stability, assisting with daily activities, and creating a supportive home environment. Studies show that these strategies can improve the quality of life of patients as well as families. However, the burden of care often causes emotional distress to families, so external support is also needed. Collaboration with professionals: Recent research highlights the importance of collaboration between families and healthcare professionals. This approach includes counseling about mental disorders, involvement in treatment planning, and assistance by health centers through home visits or early detection. However, these services have not been consistently implemented in all puskesmas. These strategies demonstrate that the treatment of mental illness

requires a holistic approach involving families, health services, and communities to overcome stigma and improve access to quality care. The form of family care for mentally ill patients can vary widely, depending on the understanding, knowledge and resources available to the family. Recent research has shown that many families treat their mentally ill members with different approaches, which include both medical and non-medical care. Some families rely on more structured medical assistance, including the use of medication and regular visits to health facilities.

This is often influenced by the family's knowledge of the importance of regular medication and a better understanding of the patient's mental state. However, many families also opt for traditional approaches, such as relying on traditional healers or psychics, especially if they have a view that mental disorders can be caused by supernatural forces or other cultural factors. In addition, the study also found that some families who are more educated or who have access to better health information tend to be more active in caring for patients, noting the importance of regularity in medical treatment and seeking support from mental health providers. Meanwhile, some families still had limited understanding and were more likely to think that patients only needed treatment if their condition worsened. Emotional and social support from the family also plays an important role. Most families showed good emotional support, such as giving attention and appreciation to patients, although some still faced challenges in terms of instrumental support such as helping patients undergo routine medical treatment.

Overall, family care for patients with mental illness is strongly influenced by their level of knowledge, access to information, and attitudes towards mental health. This also reflects the importance of health education and counseling programs to improve family understanding of how to care for family members with mental illness. The impact of medical treatment on patients with mental illness, as seen in the study, plays an important role in the management of the patient's condition, but also presents certain challenges. One study revealed that antipsychotic medications are essential for patients with mental disorders such as schizophrenia, as they help control symptoms of psychosis and prevent relapse. However, non-adherence to treatment-such as stopping taking medication-can lead to a relapse of symptoms, which can be even more severe than before, including motor impairments that hinder the patient's movement. In addition, medical treatment often requires close monitoring, especially in terms of adherence to medication schedules. Research shows that many patients do not adhere to their prescribed treatment, with factors such as disbelief in the effectiveness of the medication, unwanted side effects, or lack of understanding of their condition being major barriers.

For example, a study in Indonesia found that medication adherence in schizophrenia patients was very low, with 90% of patients having low adherence rates. This reflects a major challenge in the management of mental disorders, as without appropriate treatment, patients risk developing more severe symptoms. However, medical treatment also has the potential to have a significant positive impact, especially in helping the patient's family understand the patient's condition more rationally. While some still rely on traditional medicine or spiritual beliefs, medical treatment can provide a more evidence-based understanding, which in turn can improve the patient's quality of life and improve family interactions with the patient. Community response to people with mental illness (ODGJ), which shows the importance of increasing understanding and reducing stigma. Based on recent research, it was found that the majority of the community has a high stigma towards people with mental disorders. Research at the Samata Health Center showed that 90.8% of respondents had high stigma and 91.1% of respondents showed negative attitudes towards ODGJ.

Stigma towards ODGJ often leads to social rejection, discrimination, and neglect, which in turn can worsen the patient's condition. This study shows that community counseling is essential to increase knowledge on how to properly care for and treat ODGJ. In addition, the role of the family in the care of ODGJ is also very crucial, including supervision of treatment and emotional support that can accelerate the recovery process. To overcome stigma, collaborative efforts are

needed between health workers, educational institutions, and the government in disseminating more accurate information about mental disorders. Outreach aimed at reducing stigma needs to be expanded so that the community can have a more positive and supportive attitude towards the treatment of ODGJ.

CONCLUSION

The conclusion of this study shows that family and community approaches to people with mental illness (ODGJ) are strongly influenced by various factors, such as cultural beliefs, access to information, and education level. The family's initial response to a mentally ill member is often characterized by confusion and seeking traditional care before accessing medical services. Studies have found that community attitudes tend to be negative, with the majority of individuals showing stigma towards ODGJ. Social discrimination often worsens the patient's condition, while some communities show empathy and emotional support that can aid recovery. The role of community education is crucial to change this stigma. Counseling conducted by health workers, educational institutions, and communities can increase public understanding of the importance of supporting ODGJ. In addition, limited mental health facilities in rural areas, such as in Sumba and South Sulawesi, add to the challenges in handling mental disorders. Collaboration between families, communities, and health care providers is necessary to provide holistic care and promote faster recovery for ODGJ. Despite these barriers, collaborative efforts through education, stigma reduction, and improved access to health services can create a more inclusive and supportive environment for people with mental disorders. Communities need outreach programs that emphasize the importance of removing stigma against people with mental illness (ODGJ). This can be done through social awareness campaigns involving community, religious, and local community leaders. Communities are advised to collaborate with local organizations or health institutions to create more effective community-based support networks. Families need to be involved in educational programs related to mental disorders to improve understanding of the causes, symptoms, and importance of medical treatment. More educated families can provide better emotional support for patients. Puskesmas are advised to run mental health counseling programs that are integrated with local culture, to ensure the community can better receive information. Puskesmas need to work closely with patients' families and surrounding communities in the treatment of mental disorders to create a multidisciplinary approach.

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