



Family Perception and Adaptation in Caring for Members with Schizophrenic Mental Disorders: An Ethnographic Study in Surabaya Rural Communities

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ABSTRACT

Schizophrenia is a severe mental disorder that creates a significant burden on families, especially in rural communities with limited access to services. Previous research has focused on family burdens and stigma, but few have explored in depth cultural perceptions and family adaptation strategies in rural Indonesia. Specifically, help-seeking pathways, duration of untreated psychosis (DUP), and adaptation patterns unique to rural Surabaya remain underexplored. This study aims to identify family perceptions of schizophrenia, explore the adapted strategies developed, and analyze the interaction between perception, stigma, and family dynamics in shaping treatment patterns in rural communities in Surabaya. The research uses an ethnographic qualitative design. Sampling was carried out purposively and snowball, involving 18 families as participants. Data were collected through in-depth interviews, participant observations, and document studies. Data analysis uses thematic analysis. The findings of the study revealed that family perceptions are dominated by cultural beliefs (guna-guna, santet) and religious beliefs (God's test). Social stigma drives social strategies of concealment and withdrawal. Behind these challenges, families demonstrate resilience through complex adaptation strategies, including emotional (acceptance), practical (role sharing, integrative treatment), and spiritual (worship, resignation) dimensions. The study concluded that families in rural communities develop unique and layered adaptation mechanisms, where culture acts as a source of resistance as well as a source of resilience. The implications of the findings emphasize the need to develop culturally sensitive and local strengths-based mental health interventions, as well as policies that support strengthening the role of families as primary caregivers.

Keywords: Schizophrenia, Family Perception, Adaptation, Rural Community, Ethnography, Family Resilience

INTRODUCTION

Schizophrenia is a severe mental disorder characterized by distortions of thoughts, perceptions, emotions, and behaviors, often causing a significant burden of disease for individuals and their families (World Health Organization, 2022). This

disorder is chronic and remitting, requiring long-term treatment that focuses not only on medical but also psychosocial aspects (American Psychiatric Association, 2013). Worldwide, more than 24 million people live with schizophrenia, with the greatest burden being in low- and middle-income countries,

where access to mental health services is often limited (GBD Mental Disorders Collaborators, 2022).

In Indonesia, the prevalence of severe mental disorders, including schizophrenia, is estimated to reach around 1.7 per 1,000 population, or the equivalent of hundreds of thousands of people (Riskesdas, 2018). This reality shows that schizophrenia is not a rare phenomenon, but rather a real public health challenge that requires serious attention. The majority of care for People with Mental Disorders (ODGJ) is actually carried out in the family and community, not in health facilities, making the family the forefront of the mental health care system (Keliat et al., 2021).

The context of family care becomes increasingly complex when applied in a rural setting. Rural areas of Surabaya, defined administratively as sub-districts with population densities below 5,000 per km² and agricultural land dominance (BPS Surabaya, 2021), although geographically adjacent to the metropolitan city center, often still hold strong cultural values, traditional belief systems, and have unique socio-economic characteristics (Nursalam et al., 2020). Limited access to professional mental health services, deeper stigma, and dense community dynamics make the experience of families in rural areas distinct and need to be understood in depth (Maulana et al., 2022).

Understanding family dynamics in caring for ODGJ is the key to building an

effective support system. Families who do not have adequate capacity and knowledge can experience a high caregiver burden, which has an impact on the decrease in the quality of care for ODGJ and the mental health of the caregiver itself (Caqueo-Urizar et al., 2020). The economic impact of lost productivity and maintenance costs is also increasingly burdensome for families, especially in areas with limited resources (Jönsson et al., 2019).

In addition, the stigma of society towards mental disorders is still a big barrier for families to seek help. This stigma can manifest in the form of discrimination, social isolation, and shame, which ultimately encourages pasung practices or hides sick family members (Minas & Diatri, 2018). This research is urgent to be conducted to uncover how families in rural communities navigate through the complexities of burdens, stigma, and local belief systems.

Without evidence-based and culturally sensitive interventions, the cycle of disability and suffering will continue. This ethnographic research is important to give a voice to these families, document their struggles, and identify strengths and weaknesses in the care systems they build independently (Dixon-Woods, 2020).

National data show large gaps in treatment coverage and the burden of family care. Most of the burden of care is still borne by the family.

Table 1. Mental Health Data and Service Capacity in Indonesia

| Indicator | Prevalence / Quantity | Information |
|--|------------------------------|--|
| Prevalence of Severe Mental Disorder (Schizophrenia) | 1,7 ‰ | Equivalent to ~460,000 people |
| Treatment Coverage of ODGJ | < 15% | The majority of formal services are unaffordable |
| Psychiatrist Ratio | 0.3 per 100,000 population | Well below the WHO standard (1 per 10,000) |

| | | |
|---------------------------|-------|---|
| Family as a Primary Nurse | > 70% | The family becomes the main pend system |
|---------------------------|-------|---|

(Source: Riskesdas, 2018; Ministry of Health of the Republic of Indonesia, 2021)

The theoretical framework guiding this study integrates the Family Stress-Coping Model of Lazarus and Folkman (1984) and Ecocultural Theory (Weisner, 2002). Operationally, Lazarus-Folkman's model examines three sequential processes: (1) primary appraisal how families interpret schizophrenia as a stressor, (2) secondary appraisal evaluation of available resources (economic, social, spiritual), and (3) coping strategies emotion-focused (acceptance, spiritual reliance) versus problem-focused (treatment seeking, role reorganization). Ecocultural Theory contextualizes these processes within ecological constraints (service accessibility, poverty) and cultural scripts (belief systems, stigma norms), analyzing how daily routines and family sustainability activities adapt under these pressures. This theory is relevant for analyzing the family adaptation process (Savitri et al., 2021).

As many studies have examined family burden in caring for ODGJ. Research by Caqueo-Urizar et al. (2020) in Chile and Bolivia quantitatively documented the high level of burden and its impact on caregiver quality of life. In Indonesia, a similar study by Nurhayati and Anna (2019) in West Java also found a correlation between the duration of treatment and the level of burden felt by families. Other research focuses on stigma, such as a qualitative study from Lestari et al. (2021) that describes the experiences of structural and public stigma faced by ODGJ and their families in Yogyakarta. Meanwhile, from a cultural perspective, several researchers

such as Marthoenis et al. (2021) explore the beliefs of the Acehnese people regarding the causes of mental disorders that are often associated with spiritual factors.

Although there is a lot of research on family burden and stigma, there are some significant gaps. First, the majority of research is quantitative and focuses on burden measurement, so it is less able to capture the depth of narrative, meaning, and the process of adaptation holistically from the perspective of the family itself. Second, research in Indonesia is often conducted in urban settings or health facilities, so that the voices of rural communities that actually have limited access are still poorly documented. Third, critical knowledge gaps remain unaddressed: (a) help-seeking pathways the trajectory from symptom recognition through traditional healers to formal psychiatric services, (b) duration of untreated psychosis (DUP) in rural contexts and its implications for family burden, and (c) rural-specific adaptation mechanisms shaped by agrarian economic patterns and Javanese cultural values unique to Surabaya's periphery. Therefore, ethnographic research investigating how these three aspects intersect and shape the daily life experiences of families in rural communities is still very rare, especially in the Surabaya area.

This research offers novelty or novelty in several aspects. Methodologically, the ethnographic approach used allows for a rich and contextual deepening of family life, not only seeing them as research subjects but as the main narrator of their own experiences. Contextually, this study specifically maps the

unique mental health landscape in the rural community of Surabaya, an area that is still very underexplored academically. In terms of substance, this study seeks to integrate the perspective of perception, which includes cultural beliefs, stigma, and knowledge, with concrete actions in the form of adaptation strategies, coping strategies, and treatment patterns in one coherent framework. Thus, this research does not only stop at describing the burden beared, but further explains the process of family dynamics and adaptation in responding to mental disorders, as well as revealing how local culture can play a role as a source of resistance as well as a source of resilience.

The purpose of this study is to identify and analyze the perception of families in rural communities in Surabaya towards schizophrenia, explore the adaptation strategies and coping mechanisms they develop in caring for their family members, and analyze the interaction between cultural perceptions, community stigma, and family dynamics in shaping these treatment patterns. The benefits of this research are to provide theoretical contributions to the development of psychiatric nursing science and health anthropology, practical benefits in the form of evidence bases for community nurses in designing culturally sensitive interventions, and policy benefits as considerations for local governments in formulating policies and allocating resources for community mental health services that are more targeted.

RESEARCH METHODS

This study uses a qualitative approach with ethnographic research to deeply understand the perception and adaptation of families in caring for members with schizophrenia in rural

communities of Surabaya. Ethical approval was obtained from the Health Research Ethics Committee, Faculty of Nursing, Universitas Airlangga (Certificate No. 2156-KEPK, 2023). All participants provided written informed consent, and data were anonymized using participant codes (P01-P18) to ensure confidentiality. The lead researcher's positionality as a psychiatric nurse with 8 years of community mental health experience facilitated rapport-building, while regular reflexive journaling addressed potential biases. Prolonged engagement lasted 9 months (March-November 2023), including 3 months of pre-fieldwork community immersion through local health centers. The study population included families caring for schizophrenic ODGJ in rural areas of Surabaya, with samples taken using purposive techniques and snowball sampling until it reached the data saturation point, which is estimated to be around 15-20 families who meet the criteria as the main caregiver with a minimum treatment period of one year. Inclusion criteria specified: (1) primary caregiver aged ≥ 18 years, (2) caring for a family member diagnosed with schizophrenia (ICD-10 F20) for ≥ 1 year, (3) residing in rural sub-districts (Gunung Anyar, Rungkut, Sukolilo). Exclusion criteria: (1) caregivers with severe physical/mental illness, (2) temporary residents (< 6 months). Eighteen families across three sub-districts participated; data saturation was confirmed when no new themes emerged after the 15th interview, with three additional interviews for validation. The main research instrument is the researcher himself who is equipped with in-depth interview guidelines, observation guidelines, recording tools, and field notes to document the entire data collection process.

Data collection techniques were conducted through in-depth interviews with primary caregivers and related family members, observation of participants with moderate levels of involvement to witness firsthand care practices in a natural setting, and study of relevant supporting documents. The research procedure was carried out through the preparatory stages including ethical licensing and community approach, the initial exploration stage for area mapping, the core data collection stage with verbatim transcription, and the member check stage to validate the findings. Data analysis followed Braun and Clarke's (2006) six-phase thematic analysis: (1) familiarization through repeated reading and initial noting, (2) generating initial codes using NVivo 12 software with a codebook developed iteratively (examples: "cultural attribution," "treatment delay," "role redistribution"), (3) searching for themes by clustering codes, (4) reviewing themes against raw data, (5) defining and naming final themes, and (6) producing the report. Two independent coders achieved 89% intercoder agreement (Cohen's kappa = 0.85). An audit trail documented all analytical decisions, code evolution, and theme refinement processes.

RESULTS AND DISCUSSION

The majority of families (14 out of 18) initially perceive mental disorders experienced by their family members not as a medical illness, but as a result of non-medical causes. Through the lens of Lazarus-Folkman's primary appraisal, families initially appraised schizophrenia symptoms not as illness requiring medical intervention, but as spiritual threats or moral consequences a misattribution that directly influenced resource mobilization (secondary appraisal) toward traditional

healers rather than psychiatric services. The most commonly cited causes are *guna-guna* or witchcraft (known locally as "tenung", 10 families), and the consequences of sin or lack of faith (6 families). A mother (P12, age 54) stated, "*This must be something that someone sends, Mbak. My son is quiet, and all of a sudden it's like this. At that time there was a neighbor who was irrigating...*". This perception strongly determines the first step they take in seeking help (Angermeyer & Matschinger, 2003; Marthoenis et al., 2021).

Field observations reinforced the interview findings. The houses of the participants were often found to have certain objects or symbols that were believed to ward off evil influences, such as a mountain of chili peppers in front of the door, or certain oils applied to the body of ODGJ. Mapping help-seeking pathways revealed a predictable sequence: symptom onset → family conferencing (1-2 weeks) → traditional healer consultation (2-6 months, median 4 visits) → persistence of symptoms → biomechanical explanations introduced by extended family/neighbors → first psychiatric contact. Mean DUP was 14.3 months (range: 6-36 months), significantly longer than urban samples (Riskasdas, 2018: 7.2 months), reflecting both geographic barriers and deep-rooted cultural explanatory models. This reflects how local knowledge systems address unexplained problems (explanatory models) before seeking biomedical explanations (Kleinman, 1980).

Religious narratives are also the dominant framework of understanding. Some families interpret this condition as a test from God, divine provision (destiny), or the result of past sinful deeds. A husband (P07, age 48)

said, *"This may be a test from the One on High, let us be more patient and worship more. Sometimes I also think, this is because I used to smoke and drink a lot..."*. This perception, although it can initially cause feelings of guilt, in the end often becomes a powerful

mechanism of acceptance, turning the burden into a worship or a way to get closer to God (Weiss, 1997; Ng, 2020).

Table 1. Perception of the Causes of Schizophrenia and the First Actions Taken

| Perception of Causes | Number of Families | The First Dominant Action |
|----------------------|--------------------|--------------------------------------|
| Use/Santet | 10 | Leads to a shaman/smart person |
| God's Test/Destiny | 6 | Increase worship, dhikr, resignation |
| Medical Diseases | 2 | Taking to the Health Center/Hospital |
| Total | | 18 |

This cultural perception is not static. Over the long course of the disease and after going through various means without satisfactory results, the 15 families finally began to receive a medical explanation, although not completely abandoning the initial belief. They developed an integrative model of understanding, in which schizophrenia could be "transmitted" by others, but affected the sick "brain" or "nerves." This process of perceptual evolution shows the dynamics and cognitive adaptations that families make sense of their experiences (Kirmayer & Sartorius, 2007; Maulana et al., 2022).

Stigma: A Double Burden in the Midst of a Dense Community Social System

Stigma experienced by families manifests in two main forms: associated stigma directed at the family, and perceived stigma that makes families anticipate rejection. Families are often shunned at social events, considered incapable of educating children, or

even associated with curses. A caregiver child (P03, age 28) said, *"Since my mother was sick, invitations from neighbors have become rare. If there is community service, you are usually given a task that is far from the crowd..."* (Angermeyer et al., 2004).

Families' responses to this stigma have been mixed. The most common strategy is to hide or conceal. Families limit the social interaction of ODGJ and are reluctant to tell outsiders. Some families even choose to "confine" their members in the home, not in the sense of being physically pampered, but socially restricting their access to public spaces to avoid sneers (Goffman, 1963; Sartorius, 2007). This action is a form of protection from the outside world that is considered threatening.

However, observations found that the level of stigma varies between communities and is strongly influenced by the role of community leaders and gender/age dynamics. In Gunung Anyar hamlet, where the village

head (male, age 62) actively socialized mental health awareness through monthly religious gatherings (*pengajian*), families reported 40% fewer incidents of overt discrimination. Conversely, in Rungkut, where leadership turnover created policy discontinuity, stigma remained entrenched. Caregiving burden also varied by relationship: elderly mothers (n=7) exhibited higher resignation and spiritual

coping, while younger spouses (n=4) pursued more active treatment-seeking and income-generating strategies. This shows that stigma is not a fixed entity, but can be eroded through appropriate cultural intervention from respected figures (Thornicroft, 2008; Lestari et al., 2021).

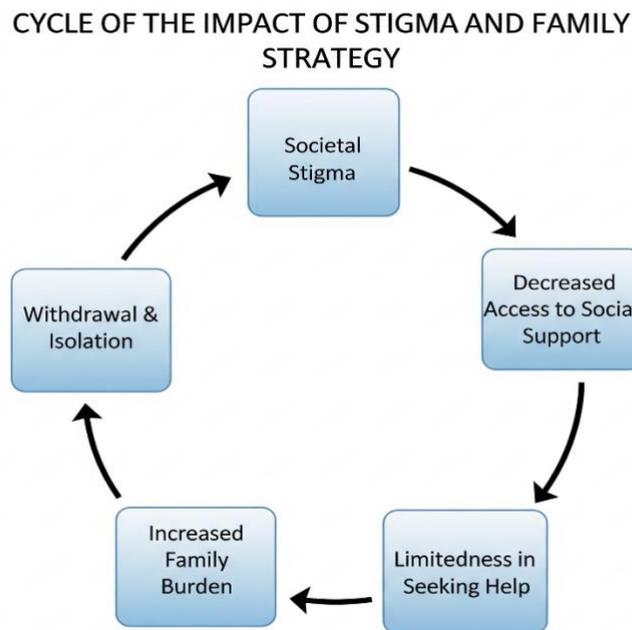


Figure 1. Stigma Impact Cycles and Family Strategies Source: Developed by researchers from the Corrigan & Watson model (2002)

Another interesting finding is that in some cases, after a very long period (decades), the stigma can diminish and turn into acceptance. ODGJ, who have lived in the community for decades, are gradually becoming part of the accepted "social landscape", albeit with the label of "insane". Their status shifted from a threat to someone who needed to be pitied and protected by their community. This shift shows the adaptive capacity of the rural community itself (Link & Phelan, 2001; Pescosolido et al., 2008).

Adaptation Strategies: Family Resilience in the Face of Layered Challenges
 Adaptation strategies mapped onto Lazarus-Folkman's coping framework reveal a tripartite structure: emotion-focused coping (acceptance, reframing), problem-focused coping (treatment adherence, economic restructuring), and meaning-focused coping (spiritual rituals). Ecocultural constraints limited cash income (76% below provincial minimum wage), 3-hour travel to psychiatric hospitals, and agricultural seasonal labor

shaped daily routines: caregivers synchronized medication administration with prayer times, scheduled clinic visits during harvest breaks, and mobilized extended kin networks for respite care. The most prominent emotional strategy is acceptance based on religious understanding ("sincerity") and the adjustment of expectations. Families learn to live with their "new reality" and no longer compare it to other family lives (Greeff & van der Walt, 2010; Caqueo-Urizar et al., 2020).

Practical strategies involve role division, strict economic regulation, and the use of surrounding natural resources for medicine. Some families who have limited access to formal medicines develop their own regimens

by combining medicines from the health center with traditional herbs to soothe symptoms (Nurhayati & Anna, 2019; Keliat et al., 2021).

Spiritual strategy is the backbone of resilience for many families. Activities such as praying together, reading the scriptures, or making a pilgrimage to the tomb of the saint, are not only done for healing, but more as a source of strength and calm for the caregiver himself. Worship becomes a coping mechanism to manage stress and find meaning in suffering (Büssing et al., 2012; Ng, 2020).

Table 2. Types of Adaptation Strategies and Examples of Their Implementation

| Types of Strategies | Examples of Observed Implementations | Number of Families |
|----------------------------|---|---------------------------|
| Emotional | Acceptance (sincerity), lowering expectations | 16 |
| Practical | Role Sharing, Tight Economy, Combining Medical & Herbal Medicines | 18 |
| Spiritual | Praying together, Zikir, Pilgrimage, surrendering to God | 15 |
| Social | Limiting Interactions, Seeking Support from Fellow Caregivers | 12 |

The limited social network built with fellow families who have experienced similar fates is also an important source of emotional support and information. They exchange experiences, treatment tips, and even shuttle for control to the health center. This informal network is a crucial support system in the midst of limited formal services (Wong & Song, 2008; Chien & Norman, 2009).

Practical implications require actor-specific, time-bound interventions: (1) Primary care level develop culturally adapted

psychoeducation modules delivered by community health workers (*kader*) integrating biomedical and religious frameworks (pilot: 6 months, 3 villages); (2) Community level establish anti-stigma campaigns co-led by village heads and religious leaders (*kyai*) during communal gatherings (quarterly); (3) Policy level mandate community mental health referral mechanisms linking *puskemas* (health centers) with psychiatric hospitals, subsidizing transportation costs (implementation: 2025-2026 fiscal year).

These context-bound recommendations acknowledge that culture operates simultaneously as resistance (delayed treatment through supernatural attributions) and resilience (spiritual coping sustains caregiving commitment across decades).

CONCLUSION

This ethnographic research succeeded in revealing the complexity of perception and dynamics of family adaptation in caring for members with schizophrenia in rural communities in Surabaya. The findings suggest that family perceptions of schizophrenia are dominated by cultural and religious frameworks, where the disorder was initially understood as the result of a divine use, curse, or test, rather than simply as a medical condition. This understanding directly shapes their initial response, which is to seek help from a shaman or through a spiritual approach, before finally turning to formal health services after traditional efforts have been fruitless. Furthermore, the study managed to map how the stigma inherent in society creates a double burden, encouraging families to hide their members' conditions and limiting social interactions as a form of protection.

Substantially, this study succeeded in integrating the perspective of perception and action by documenting various adaptation strategies developed by families as a form of resilience. The strategy is multidimensional, including emotional adaptation through the acceptance and adjustment of expectations, practical adaptation through role sharing and strict economic management, and spiritual adaptation which is the main source of strength. The key finding of this study is that local culture is not only a source of challenge

through stigma and misperception, but also a source of solutions and resilience through religious values, limited support networks, and local wisdom in care. Thus, this study concludes that the success of mental health interventions in rural communities must be based on a deep understanding of the local cultural context and building on the strengths and adaptation mechanisms that families already have.

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