



Experience Caring for People with Schizophrenia in Families in West Sumatera

Dewi Eka Putri^{1*}, Afrizal Afrizal², Dachriyanus Hamidi³, Elmeida Effendy⁴

¹Department of Mental and Community Health, Faculty of Nursing, Universitas Andalas, Padang, West Sumatera, Indonesia;

²Department of Sociology, Faculty of Social and Political Science, Universitas Andalas, Padang, West Sumatera, Indonesia;

³Department of Pharmacy, Faculty of Pharmacy, Universitas Andalas, Padang, West Sumatera, Indonesia; ⁴Department of Psychiatry, Faculty of Medicine, Universitas Sumatera Utara, North Sumatera, Indonesia

Abstract

BACKGROUND: Schizophrenia is a severe neurobiological brain disorder that continues and has poor insight so that it affects the functioning of the lives of individuals, families, and communities. Caregivers of people with schizophrenia had more stressed because of the nature, symptoms, and prolonged duration of illness of people with schizophrenia.

AIM: This study aimed to determine the family's experience in the practice of caring for people with schizophrenia in the family in West Sumatra.

METHODS: The research population was families who cared for people with schizophrenia in Sumatera Barat and have been caring for people with schizophrenia for more than a year. It had determined with the purposive-sampling method with an in-depth interview technique. The researchers, the main instrument, explore the caregiver's experience through five family development tasks.

RESULTS: The results of this study obtained five major themes, namely, recognizing problems, making treatment decisions, how families treat people with schizophrenia, difficulties faced by families, and utilization of health services.

CONCLUSION: In caring for people with schizophrenia, the family has carried out care tasks in the family, namely, recognizing problems, making decisions about treatment, families caring for sick family members, and families can take advantage of health services optimally.

Edited by: Branislav Filipović

Citation: Putri DE, Afrizal A, Hamidi D, Effendy E. Experience Caring for People with Schizophrenia in Families in West Sumatera. Open-Access Maced J Med Sci. 2022 Feb 15; 10(G):166-170. <https://doi.org/10.3889/oamjms.2022.8254>

Keywords: Caregiver; Schizophrenia; Indonesia; Family; Health services

*Correspondence: Dewi Eka Putri, Faculty of Nursing, Universitas Andalas, Padang, West Sumatera, Indonesia. E-mail: dewiekaputri@nrs.unand.ac.id

Received: 13-Dec-2021

Revised: 23-Jan-2022

Accepted: 05-Feb-2022

Copyright: © 2022 Dewi Eka Putri, Afrizal Afrizal, Dachriyanus Hamidi, Elmeida Effendy

Funding: This research did not receive any financial support

Competing Interest: The authors have declared that no competing interest exists

Open Access: This is an open-access article distributed under the terms of the Creative Commons Attribution-NonCommercial 4.0 International License (CC BY-NC 4.0)

Introduction

The prevalence of schizophrenia in Indonesia every year always increases. According to the WHO [1], there are 23 million who have schizophrenia. This number increased from 21 million in 2017. Results of the 2013 Basic Health Research in Indonesia prevalence of people living with schizophrenia of 1.7/1000 population increased to 6.7/1000 households in 2018 [2], [3]. According to the Basic Health Research in 2018 in Indonesia, schizophrenia in West Sumatra was in the 4th rank with a prevalence of 9.1/mile.

The results of Chen's research [4]; 50–80% of people with schizophrenia will live with their caregivers and depend on housing, emotional and financial support. The quality of parenting greatly influences the care of people with schizophrenia. Several studies report a high level of burden experienced by caregivers of people with schizophrenia [5], [6], [7], [8]. Research in China found that caregivers who live with people with schizophrenia feel more burdens in the form of difficulties in caring for, disrupted routines, and assistance provided by caregivers (home and housing management) [9].

Caregivers with schizophrenia spend more time caring for them. This condition interferes with work, conflicts with children and other relatives, and increases the emotional and psychological burden associated with depression on caregivers [10]. Depressed caregivers can influence their behavior toward care recipients by producing physical violence or verbal abuse against people with schizophrenia [11], [12].

Based on the above background, the research problem could formulate through the following research questions: How is the experience of practicing people with schizophrenia care in families in West Sumatra?

Methods

This study aimed to determine family experiences in the practice of caring for people with schizophrenia in families in West Sumatra. The research population is the entire people with schizophrenia family residing in West Sumatra and has cared for people with schizophrenia for more than a year. It was

determined with the purposive sampling, and based on that, eight caregivers had determined as respondents. The inclusion criteria in this study were caregivers living in one house with schizophrenic patients, had Minang ethnicity, and resided in West Sumatra. Meanwhile, the exclusion criteria were family members who were not yet adults and did not take care of them directly. The researcher collected data using the instrument in qualitative research, interview guidelines, written notes that the researcher met about what was heard and seen during the interview, and a voice recorder.

Results and Discussion

In this study, we got an overview of the experience of caring for people with schizophrenia in families in West Sumatra in the form of five significant central themes as follows:

Identifying problems

Families who care for people with schizophrenia at home are familiar with the problems faced by family members well, such as recognizing the signs and symptoms of recurrence.

“... His anger likes to say dirty words, sometimes he stomps his feet, he once hit me, he gets angry for no reason...” (R2).

“...If the emotions are out of whack and say dirty words...” (R4)

Caregivers with more knowledge and skills are more likely to adopt positive coping strategies. This situation indicates further evidence of a positive relationship between knowledge and skills care with various health outcomes and inform subsequent psychoeducational interventions to improve care outcomes for people with schizophrenia [9]. Several previous research results show that when caregivers can recognize the problems people face with schizophrenia, the perceived burden of care will decrease [13]. The present studies also show that increasing parenting knowledge and skills can relieve psychological stress, such as stress, anxiety, and depression [9].

Caregivers were who did not know experienced disease people with schizophrenia, which was expressed by Respondent 1:

“...Yes, for information on home care, I do not know how I should just pay attention...” (R1).

Caregivers who are not familiar with schizophrenia are more likely to hold false beliefs about schizophrenia. They think that the cause of schizophrenia is the result of witchcraft or drug abuse. Caregivers usually have a pessimistic view of people

with schizophrenia [14] and lose hope for people with schizophrenia recovery, which causes psychological distress [15]. Thus, increasing knowledge about schizophrenia and skills can help caregivers change their attributions about the causes of schizophrenia to understand better the challenges faced by people with schizophrenia and take more active steps when a crisis occurs [9].

Taking care decisions

In carrying out the role of care in the family, caregivers of sick families must provide care.

“.....If it relapses, I take it to the primary health care and ask for a referral to the RSJ...” (R6)

Usually, family members do not leave their sick relatives, take responsibility, and take care of other family members, even though they face financial difficulties and social [16]. Higher levels of parenting knowledge and skills allow them to assume more responsibility and provide better support for their loved ones with schizophrenia, leading to a higher sense of self-fulfillment [17].

Increasing caregiver knowledge about schizophrenia will improve the ability to care through monitoring the signs and symptoms displayed. The caregivers' ability also helps collaborate with mental health professionals, thus leading to increased self-efficacy [18]. In dealing with a recurrence, some caregivers ask for help other than health workers such as:

“....I want to take it to a smart person so that it does not relapse...” (R4).

In caregivers who are not familiar with schizophrenia are more likely to hold erroneous beliefs about schizophrenia, such as thinking that it is the result of witchcraft. When magic had seen as a cause of schizophrenia, caregivers usually have a pessimistic view of medical treatment [14].

How to take care of people with schizophrenia

Appropriate caregiver behavior in caring for schizophrenic patients includes giving medicine, reminding them to take medicine, and encouraging schizophrenic patients to do positive activities.

“....We remind him but by making him not offended...” (R3)

“....Tell him to do positive activities such as pulling grass...”(R7)

Caregivers of patients with schizophrenia play a variety of roles. They are responsible for patients' basic needs such as bathing, medical and drug monitoring, housework (cooking and house cleaning), functional tasks, and transportation [19]. The role of the caregiver

is not easy and can affect the personal life of *caregivers*, and the accumulation of these tasks burdens the *caregiver* [20]. Millier *et al.* reported that patients who have schizophrenia require home care for 24 h [21].

In carrying out their role in caring for sick family members, *caregivers* still make mistakes in caring for people with schizophrenia at home.

"... if you have a tantrum, just let it go and lock it in your room until it calms down, and all family members leave the house." (R2)

Lack of knowledge, fear, and stigma related to mental illness, caregivers are often the reason; *caregivers* are confused about how to take care of their children [22].

Difficulties facing families

The burden and stigma felt by the family indicate the difficulties families face in caring for people with schizophrenia. Many participants felt the burden of caring for people with schizophrenia, including economic, physical, and emotional burdens. Respondents stated that they experienced an economic burden caused by costs and distance, which was expressed by Respondents 2 and 8 through the expression:

"...Yes ma'am, she is my family, she also has a family. Usually he has money..." (R2)

"....The trouble is, it is far away to get medicine. I just left at 4 in the morning..." (R8)

Caregivers have many responsibilities in caring for people with schizophrenia. In addition to managing the unpredictable behaviors of people with schizophrenia, such as aggression and violence, they must play a dual role in caring for those who burden them [20]. The burden felt by the caregiver affects the physical, mental, social relationships, economic status of caregivers of the family of schizophrenia patients and causes various disorders such as depression, anxiety, obsessive-compulsive disorder, and other neurotic disorders [23]. In this study, the caregiver felt a physical burden in the form of fatigue, fatigue, and sometimes pain. The physical burden felt by the caregiver, they also complained about the emotional burden such as being annoyed and sometimes feeling like dying.

Research conducted by Tamizi *et al.* [24] shows that caregivers of schizophrenic patients have dual responsibilities in the parenting process and help patients carry out daily life and self-care activities. In addition, the duration of contact with patients and long-term care is one of the factors that affect the burden of family caregivers of schizophrenic patients. Involvement in the care and practical support of schizophrenic patients contributes to the caregiver burden. They require additional hours and commitment to caregiving activities which often lead to consequences for caregivers such as job loss, decreased social activities,

and restriction of leisure time activities. Then, the caregiver experiences a heavy burden [21].

Research conducted by Durmaz and Okanlı, caregivers also experience anger, feelings of guilt, fear, hopelessness, sadness, and negative feelings and attitudes toward patients [25]. Most of this evidence comes almost exclusively from studies conducted in high-income countries that lead to many additions, while it becomes big challenges by caregivers in low- and middle-income countries [13]. The caregivers who provide care to people with schizophrenia in the family experience significant stress, anxiety, and financial difficulties and have many needs because of their parenting role [26].

The stigma faced by caregivers in this study resulted in negative responses from the environment occupied by people with schizophrenia and their families. The stigma of mental disorders is the result of four components processes: Cognitive (labeling and stereotyping), emotional (prejudice), behavioral (discrimination), and structural (the accumulated organizational policies and practices) causing injustice to people with a mental disorder such as people with schizophrenia [27]. This condition, which had expressed verbally and non-verbally, is expressed by Respondent 6 through the statement:

"Two months ago someone called him crazy." (R6)

The previous studies also reported more significant stigma among parents than spouses and other siblings/relatives [18]. Research conducted by Grover *et al.* [16] also found a negative stigma associated with experienced by *caregivers* in carrying out people with schizophrenia care. The association of higher stigma with caregivers only as family members and caregivers as head of the family can be understood from caregiver burden and inability to avoid social roles and ties.

Significant stigma can be seen from the presence of other family members to share the caregiver role. The stress process model argues that sources of stress, such as family conflict and financial problems, are essential domains that contribute to caregiver burden. Lack of understanding of psychotic symptoms may lead to conflict between caregivers and people with schizophrenia, resulting in the high levels of psychological distress among caregivers [9].

The American Psychological Association [28] reports that caregivers' families experience role tension between having high levels of depression and anxiety. Social environment, the impact experienced by the family in isolation from others or being ostracized from the surrounding environment. The research by Hanzawa *et al.* [29] states that the stigma obtained by families with schizophrenia is a rejection of the surrounding community; the surrounding environment considers schizophrenic patients to be dangerous. They choose to avoid it, even do not want to be in the same environment with families who have family members schizophrenic family.

Utilization of health services

In providing care to family members with schizophrenia, all respondents in the study were able to take advantage of existing health services using health assurances (BPJS) and access health services in the form of primary health centers or mental hospitals as expressed by Respondent 7

“...I use Health Insurance from the government for treatment...” (R7)

Accessible health services are in the form of primary health centers, and hospitals are expressed by Respondent 2 through the expression:

“...I went to the primary health centres first then I went to the hospital...” (R2)

The limited utilization of health services by *caregivers* caused a lack of knowledge about available services and a shortage of professionals [30]. The results of research conducted by Tamizi *et al.* [24] also found that many factors influence *caregivers* in utilizing health services, not only by care activities *caregiver* but also by challenges in providing mental health-care services.

Health-care providers, especially mental health professionals, should develop more innovative programs for *caregivers*. Involve them as active members of the health-care team by assigning specific tasks to design and implement programs such as post-discharge supervision and home visits can significantly reduce the burden on *caregivers* and create opportunities to involve families in the parenting process.

Conclusion

In caring for patients, families have carried out care tasks in the family, namely, recognizing problems, making decisions on treatment, families caring for sick family members, and families can optimally take advantage of health services. During caring for family members with schizophrenia, there are responses or changes experienced by the family, especially *caregivers* that can affect family resilience. These changes occur in physical, psychological responses, social stigma, and family financial circumstances.

Recommendation

It had hoped that health workers providing care for schizophrenic patients would focus on the patient and the families who care for them. Family empowerment could do to increase family resilience. It strengthens family resilience by increasing the

family's belief system in dealing with difficult situations, organizational patterns, and effective communication or problem-solving so that treatment for schizophrenia is optimal and prevents relapse.

References

1. World Health Organization. Mental Disorders Fact Sheets. Geneva: World Health Organization; 2021. Available from: <http://www.who.int/mediacentre/factsheets/fs396/en/-2018> [Last accessed on 2021 Oct 08].
2. Ministry of Health. RISKESDAS National Report 2013. Ministry of Health Republic of Indonesian. Jakarta, Indonesia: Ministry of Health; 2013. Available from: <https://www.kemkes.go.id/resources/download/info-terkini/hasil-riskesdas-2013.pdf> [Last accessed on 2021 Sep 25].
3. Indonesian Ministry of Health. Basic Health Research Results Report (RISKESDAS). National 2018. Indonesia: Indonesian Ministry of Health; 2018. Available from: <https://www.litbang.kemkes.go.id/laporan-riset-kesehatan-dasar-riskesdas> [Last accessed on 2021 Sep 25].
4. Chen LF, Liu J, Zhang J, Lu XQ. Non-pharmacological interventions for caregivers of patients with schizophrenia: A meta-analysis. *Psychiatry Res.* 2016;235:123-7. <https://doi.org/10.1016/j.psychres.2015.11.037> PMID:26639649
5. Adeosun II. Correlates of caregiver burden among family members of patients with schizophrenia in Lagos, Nigeria. *Schizophr Res Treatment.* 2013;2013:353809. <https://doi.org/10.1155/2013/353809> PMID:24222848
6. Gutiérrez-Maldonado J, Caqueo-Urizar A, Kavanagh DJ. Burden of care and general health in families of patients with schizophrenia. *Soc Psychiatry Psychiatr Epidemiol.* 2005;40(11):899-904. <https://doi.org/10.1007/s00127-005-0963-5> PMID:16245190
7. Mitsonis C, Voussoura E, Dimopoulos N, Psarra V, Kararizou E, Latzouraki E, *et al.* Factors associated with caregiver psychological distress in chronic schizophrenia. *Soc Psychiatry Psychiatr Epidemiol.* 2012;47(2):331-7. <https://doi.org/10.1007/s00127-010-0325-9> PMID:21165597
8. Ozlu A, Yildiz M, Aker T. Burden and burden-related features in caregivers of schizophrenia patients. *Dusunen Adam J Psychiatry Neurol Sci.* 2015;28(2):147.
9. Zhou Z, Wang Y, Feng P, Li T, Tebes JK, Luan R, Yu Y. Associations of caregiving knowledge and skills with caregiver burden, psychological well-being, and coping styles among primary family caregivers of people living with schizophrenia in China. *Front Psychiatry.* 2021;12:631420. <https://doi.org/10.3389/fpsy.2021.631420> PMID:34122169
10. Rodrigo C, Fernando T, Rajapakse S, De Silva V, Hanwella R. Caregiver strain and symptoms of depression among principal caregivers of patients with schizophrenia and bipolar affective disorder in Sri Lanka. *Int J Ment Health Syst.* 2013;7:1-5. <https://doi.org/10.1186/1752-4458-7-2> PMID:23302516
11. Robson D, Spaducci G, McNeill A, Stewart D, Craig TJ, Yates M, Szatkowski L. Effect of implementation of a smoke-free policy on

- physical violence in a psychiatric inpatient setting: An interrupted time series analysis. *Lancet Psychiatry*. 2017;4(7):540-6. [https://doi.org/10.1016/S2215-0366\(17\)30209-2](https://doi.org/10.1016/S2215-0366(17)30209-2)
PMid:28624180
12. Smith V, Reddy J, Foster K, Asbury ET, Brooks J. Public perceptions, knowledge and stigma towards people with schizophrenia. *J Public Ment Health*. 2011;10(1):45-56.
 13. Vermeulen B, Lauwers H, Spruytte N, van Audenhove C. *Experiences of Family Caregivers for Persons with Severe Mental Illness: An International Exploration*; 2015.
 14. Kate N, Grover S, Kulhara P, Nehra R. Relationship of caregiver burden with coping strategies, social support, psychological morbidity, and quality of life in the caregivers of schizophrenia. *Asian J Psychiatr*. 2013;6(5):380-8. <https://doi.org/10.1016/j.ajp.2013.03.014>
PMid:24011684
 15. Martin-Carrasco M, Fernandez-Catalina P, Dominguez-Panchon AI, Gonçalves-Pereira M, Gonzalez-Fraile E, Munoz-Hermoso P, *et al*. A randomized trial to assess the efficacy of a psychoeducational intervention on caregiver burden in schizophrenia. *Eur Psychiatry*. 2016;33(1):9-17. <https://doi.org/10.1016/j.eurpsy.2016.01.003>
PMid:26852375
 16. Grover S, Avasthi A, Singh A, Dan A, Neogi R, Kaur D, *et al*. Stigma experienced by caregivers of patients with severe mental disorders: A nationwide multicentric study. *Int J Soc Psychiatry*. 2017;63(5):407-17. <https://doi.org/10.1177/0020764017709484>
PMid:28537123
 17. Singh A, Mattoo SK, Grover S. Stigma and its correlates among caregivers of schizophrenia: A study from North India. *Psychiatry Res*. 2016;241:302-8. <https://doi.org/10.1016/j.psychres.2016.04.108>
PMid:27232551
 18. Singh A, Grover S, Mattoo SK. Validation of Hindi version of internalized stigma of mental illness scale. *Indian J Soc Psychiatry*. 2016;32:104.
 19. Csoboth C, Witt EA, Villa KF, O'Gorman C. The humanistic and economic burden of providing care for a patient with schizophrenia. *Int J Soc Psychiatry*. 2015;61(8):754-61. <https://doi.org/10.1177/0020764015577844>
PMid:25823542
 20. Hsiao CY, Tsai YF. Factors of caregiver burden and family functioning among Taiwanese family caregivers living with schizophrenia. *J Clin Nurs*. 2015;24(11-12):1546-56. <https://doi.org/10.1111/jocn.12745>
PMid:25488264
 21. Millier A, Schmidt U, Angermeyer MC, Chauhan D, Murthy V, Toumi M, *et al*. Humanistic burden in schizophrenia: A literature review. *J Psychiatric Res*. 2014;54:85-93. <https://doi.org/10.1016/j.jpsychires.2014.03.021>
PMid:24795289
 22. Grandón P, Jenaro C, Lemos S. Primary caregivers of schizophrenia outpatients: Burden and predictor variables. *Psychiatry Res*. 2008;158(3):335-43. <https://doi.org/10.1016/j.psychres.2006.12.013>
PMid:18280584
 23. Caqueo-Urizar A, Gutiérrez-Maldonado J, Ferrer-García M, Darrigrande-Molina P. Burden of care in Aymara caregivers of patients with schizophrenia. *Rev Psiquiatr Salud Ment*. 2012;5(3):191-6. <https://doi.org/10.1016/j.rpsm.2011.07.001>
PMid:22854614
 24. Tamizi Z, Fallahi-Khoshknab M, Dalvandi A, Mohammadi-Shahboulaghi F, Mohammadi E, Bakhshi E. Caregiving burden in family caregivers of patients with schizophrenia: A qualitative study. *J Educ Health Promot*. 2020;9:12. https://doi.org/10.4103/jehp.jehp_356_19
PMid:32154307
 25. Durmaz H, Okanlı A. Investigation of the effect of self-efficacy levels of caregiver family members of the individuals with schizophrenia on burden of care. *Arch Psychiatr Nurs*. 2014;28(4):290-4. <https://doi.org/10.1016/j.apnu.2014.04.004>
PMid:25017564
 26. Chadda RK, Ramshankar P, Deb KS, Sood M. Metabolic syndrome in schizophrenia: Differences between antipsychotic-naïve and treated patients. *J Pharmacol Pharmacother*. 2013;4(3):176-86. <https://doi.org/10.4103/0976-500X.114596>
PMid:23960422
 27. Sarfika R, Effendi N, Malini H, Nurdin AE. Personal and perceived stigmas in adolescents toward peers with mental disorders in West Sumatra Indonesia. *Open Access Maced J Med Sci*. 2021;9(E):1010-6.
 28. American Psychological Association. 2015 Survey of Psychology Health Service Providers. Washington, DC: American Psychological Association; 2016.
 29. Hanzawa S, Nosaki A, Yatabe K, Nagai Y, Tanaka G, Nakane H, *et al*. Study of understanding the internalized stigma of schizophrenia in psychiatric nurses in Japan. *Psychiatry Clin Neurosci*. 2012;66(2):113-20. <https://doi.org/10.1111/j.1440-1819.2011.02307.x>
PMid:22353324
 30. Gülseren L, Cam B, Karakoç B, Yiğit T, Danacı AE, Çubukçuoğlu Z, *et al*. The perceived burden of care and its correlates in schizophrenia. *Turk Psikiyatri Derg*. 2010;21(3):203-12.
PMid:20818508