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Shame and Burden: Family Stigma in Caring for Shackled Individuals with Mental Disorders

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ABSTRACT

Introduction: Mental disorders remain a significant public health concern, often leading to stigma and social discrimination, particularly for families caring for affected individuals. In some cases, shackling (physical restraint) is still practiced due to limited access to mental health services, further intensifying the burden on caregivers.

Objective: This study aims to explore the family experiences of stigma and emotional burden in providing care for shackled individuals with mental disorders.

Method: A qualitative research design with a phenomenological approach was employed. The study was conducted within the scope of the Pamekasan District Health Office, involving families of mentally ill patients as participants. Inclusion criteria included participants who had cared for restrained family members for over a year, were above 20 years old, willing to participate, and able to communicate verbally. A snowball sampling technique was used, where key informants assisted in identifying additional participants.

Results: Participants reported experiencing stigma related to their role in caring for family members with mental disorders who had been restrained. The findings highlight psychological and emotional reactions, as well as how participants navigate daily life amid societal stigma. A key subtheme, "Emotions," describes their emotional responses, which include sadness, anger, shame, and guilt—common experiences among participants.

Conclusion: This study concludes that family caregivers of individuals with mental illness face significant psychological distress due to stigma, primarily manifesting as sadness, anger, shame, and guilt. These emotional responses stem from discrimination, stereotyping, and societal labeling. Effective emotional management is crucial in helping caregivers cope and respond constructively to stigma. The findings emphasize the need for supportive interventions to enhance caregivers' emotional resilience and overall well-being.

Keywords: emotional burden, family experience, mental disorders

Introduction

People with mental disorders often face various forms of social stigma that negatively impact their lives. This stigma arises from a lack of understanding and knowledge about mental disorders, as well as widespread myths and stereotypes. Additionally, the discomfort society feels when interacting with individuals with mental disorders reinforces this stigma, causing them to be treated differently and even ostracized, sometimes by their own families (Deshpande, 2018) . Families, as the closest support system and primary caregivers, are also affected by this stigma. When caring for family members with mental disorders, they often experience similar stigmatization, which can limit their access to social support, healthcare services, and other opportunities that could improve their quality of life (Darban, 2021).

The stigma faced by families can be both external and internal. External stigma occurs when families experience discrimination or negative attitudes from society, such as rejection, ostracism, stereotyping, or even verbal abuse (Maiocco, 2017). On the other hand, internal stigma arises when family members feel ashamed or develop negative self-perceptions due to their caregiving role. The fear of societal stigma often discourages families from seeking professional help or social support, which are crucial for providing optimal care. Furthermore, this stigma can affect the quality of care they provide, as they may feel burdened or uncertain about their role as caregivers (Philip,2009).

The prevalence of mental disorders continues to rise globally. According to WHO (2015), the number of people with mental disorders worldwide has reached 516 million. In Southeast Asia, about one-third of the population has experienced neuropsychiatric disorders (Yosef & Titin, 2014). In Indonesia, data from the 2013 Basic Health Research (Riskesdas) revealed that approximately 6% of the population aged 15 and older, or about 14 million people, experience symptoms of emotional mental disorders such as depression and anxiety. Meanwhile, the prevalence of severe mental disorders, such as schizophrenia, is 1.7 per 1,000 population, or around 400,000 individuals. In East Java, the prevalence of severe mental disorders is recorded at 0.22%, while the prevalence of emotional mental disorders reaches 6.5%.

Understanding the forms of stigma experienced by families caring for individuals with mental disorders, especially those who have undergone physical restraint, is crucial. Identifying these forms of stigma can serve as a foundation for designing interventions to reduce its negative impact and improve the quality of care provided by families. Research on social stigma and the emotional burden faced by caregivers is highly relevant, as it provides a deeper understanding of their experiences and helps formulate strategies to enhance social support and public awareness of mental disorders. Moreover, this research is expected to offer recommendations for improving healthcare services and providing more effective support systems for families, empowering them in their caregiving roles.

Objective

This study aims to explores family experiences of stigma and emotional burden in caring for shackled individuals with mental disorders.

Method

This qualitative study explores the social stigma and emotional burden of families caring for restrained mentally ill patients. Using a phenomenological approach, it aims to identify relationships and meanings related to this experience. Conducted within the Pamekasan District Health Office, the study involves families of mentally ill patients as participants.

Participants meet the following criteria: (1) caring for a restrained family member for over a year, (2) aged over 20, (3) willing to participate, and (4) able to communicate verbally. The study employs a snowball sampling technique, with key informants guiding participant selection.

Result

Sociodemographic of participants

This study involved 11 family members (Table 1) who met the inclusion criteria: caring for individuals with mental disorders for at least six months, aged over 20, and able to share their experiences. Participants were selected through purposive sampling from the Pamekasan District Health Office.

Tabel 1. Distribution of Respondents' Data Characteristics (Family Members)

Characteristic	***N***	***%***
Sex		
Male	*3*	*27%*
Female	*8*	*73%*
Age		
36-45	*2*	*18%*
46-55	*5*	*46%*
56-65	*0*	*0%*
>65	*4*	*36%*
Employment Status		
Unemployed	*4*	*36%*
Private sector worker	*3*	*27%*
Laborer	*1*	*9%*
Civil servant	*1*	*9%*
Farmer	*2*	*18%*
Education Level		
No formal education	*4*	*36%*
Elementary school	*1*	*9%*
Junior high school	*1*	*9%*
Senior high school	*3*	*27%*
Higher educationn	*2*	*19%*
Relationship with the Patient		
Mother	*4*	*36%*
Father	*1*	*9%*
Sibling	*5*	*46%*
Child	*1*	*9%*

Descriptive statistics of participant characteristics are presented in Table 1. The study included 11 family caregivers of individuals with mental disorders (8 females, 3 males), aged 42 to 80 years. Their education levels varied from no formal education to higher education. Most participants (7 individuals) were employed as civil servants, self-employed workers, laborers, or farmers, while 4 were unemployed. The participants' relationships with the patients included parents (4 mothers, 1 father), 5 siblings, and 1 biological child.

Psychological Responses

A single theme emerged from family members' experiences of the emotional burden of caring for individuals with mental disorders: **Emotions** (Table 2). The details are provided in Table 2.

Table 2. Theme of Psychological Responses (Emotions) Identified and Significant Statements from Family Members

Theme	Subtheme	Significant Statements
Emotions	**Sadness**	"Yes, I feel sad. My sibling hasn't recovered, is confined. And this affects my parents and other siblings too. People think we have a family, but we don't care for them." (P5)
		"I'm sad, sir. People in the neighbourhood think our whole family is crazy." (P7)
		"Sometimes I feel tired, sad, angry, but what can I do? I just accept it as God's will." (P10)
	Anger	"I feel angry, but I suppress it." (P3)
		"Yes, but what else can I do? It's natural to feel angry. My child gets mocked, and I'm sometimes treated poorly. I hate it at times." (P7)
		"People only know how to blame. Do they think I asked for my child to be sick? It makes me angry." (P11)
	Guilt	"I feel like this happened because of my own mistakes in the past. I once did something wrong. Maybe this is Allah's way of repaying me." (P10)
		"I feel guilty, sometimes I feel useless as a sibling." (P2)
	Shame	"I feel ashamed, sir. If I could choose, I would rather my sibling were dead." (P6)
		"When I meet people, I just want to hide." (P8)
		"I feel ashamed, yes, because of my sibling, because of the insults from the neighbours." (P9)

These themes illustrate participants' psychological and emotional responses to stigma while caring for restrained family members with mental disorders, along with their coping strategies. One subtheme, Emotions, captures feelings of sadness, anger, shame, and guilt, which arise due to social stigma directed at them and their affected family members.

Sadness

Several participants expressed feelings of sadness when they and their families were treated differently by society because they had family members with mental disorders. This sadness stemmed not only from the condition of the ill family member but also from the stigma they felt from others. The following quotes reflect the sadness experienced by participants:

> *"Yes, I feel sad. My sibling hasn't recovered, is confined. And this affects my parents and other siblings too. People think we have a family, but we don't care for them." (P5)*

> *"I'm sad, sir. People in the neighbourhood think our whole family is crazy." (P7)*
> *"Sometimes I feel tired, sad, angry, but what can I do? I just accept it as God's will." (P10)*

Anger

Some participants responded to the stigma with anger. While they understood that society lacked awareness of their situation, feelings of anger and hatred still arose due to the stigma they experienced. Participants revealed that even though they tried to accept their circumstances, feelings of anger were difficult to avoid. Below are some statements from participants:

> *"I feel angry, but I suppress it." (P3)*
> *"Yes, but what else can I do? It's natural to feel angry. My child gets mocked, and I'm sometimes treated poorly. I hate it at times." (P7)*
> *"People only know how to blame. Do they think I asked for my child to be sick? It makes me angry." (P11)*

Shame

Shame was also a strong emotional reaction among participants. They felt ashamed of society's perceptions of their family for having a member with mental disorders. This shame led them to avoid social interactions and prefer to stay away from social gatherings. Here are some participant statements about their feelings of shame:

> *"I feel ashamed, sir. If I could choose, I would rather my sibling were dead." (P6)*
> *"When I meet people, I just want to hide." (P8)*
> *"I feel ashamed, yes, because of my sibling, because of the insults from the neighbours." (P9)*

Guilty

Some participants felt that the stigma they experienced was a result of their own past mistakes. This guilt added to the psychological burden they felt while caring for their ill family member. They believed that their suffering was a punishment or consequence of their previous actions. The following quotes illustrate the guilt experienced by participants:

> *"I feel like this happened because of my own mistakes in the past. I once did something wrong. Maybe this is Allah's way of repaying me." (P10)*
> *"I feel guilty, sometimes I feel useless as a sibling." (P2)*

Discussion

The findings of this study revealed that the psychological response expressed by participants primarily involves emotional responses. This theme focuses on how participants react to the stigma they experience and feel, as well as how they live their lives under such stigma. Participants emotionally reacted to the stigma they faced, leading to feelings of sadness, frustration, anger, and guilt (Paul, 2017). These feelings were experienced by most participants. This subtheme is divided into several categories: sadness, anger, shame, and guilt.

Several participants expressed sadness due to the way others treated the patient and themselves. The study found that participants' sadness arose when they encountered stigma and were treated differently by others. Participants also disclosed that they felt others perceived the entire family as being "contaminated" by the mental illness experienced by the patient, which deepened their sadness (Huggett, 2018).

Another category within the emotional subtheme is anger. Participants revealed that the stigma they experienced triggered feelings of anger and hatred. While they acknowledged that others were not entirely to blame, they struggled to suppress their feelings of anger and resentment (Clement, 2015).

Participants also expressed shame as an emotional reaction. They felt ashamed of the patient's condition and embarrassed when publicly humiliated. Moreover, some participants disclosed feelings of guilt regarding their family member's illness. Certain participants believed that the stigma they and their families experienced was a consequence of their own past mistakes (Catthoor, 2015).

A study by Abojabel and Werner (2016) also highlighted that stereotypes directed at families can provoke feelings of anger and hatred. Similarly, Sanden et al. (2015) found that parents and spouses often experienced stigma in the form of exclusion, blame, and negative treatment, resulting in feelings of shame, guilt, and, at times, helplessness. Ling et al. (2018) further supported this by stating that families with members suffering from mental disorders often feel guilty and ashamed of their ill family member's presence.

Stigma refers to negative perceptions attached to an individual's existence, manifested in the form of discrimination, stereotypes, and labeling. Four emotional reactions to stigma were identified in this study: anger, sadness, shame, and guilt. Each emotional reaction represents participants' expressions of their feelings toward the stigma they experienced. Emotional responses play a significant role in participants' lives, as emotions reflect human expressions in social interactions (Lam, 2010).

Emotions also function as a learning process that can be either positive or negative and continues to develop. Effective management of emotional responses enables individuals to regulate negative or harmful emotional expressions. Proper emotional management can lead to constructive actions in addressing the stigma experienced by participants.

Conclusion

This study concludes that family caregivers of individuals with mental illness face significant psychological distress due to stigma, primarily manifesting as sadness, anger, shame, and guilt. These emotional responses stem from discrimination, stereotyping, and societal labeling. Effective emotional management is crucial in helping caregivers cope and respond constructively to stigma. The findings emphasize the need for supportive interventions to enhance caregivers' emotional resilience and overall well-being.

Conflict of interest

The authors have no employment, financial, non-financial, or other competing interests to declare. The researchers stated that there is no conflict of interest related to the implementation and publication of the results of this research. The entire research process, from planning, data collection, analysis, to report preparation, was carried out independently without any influence or pressure from any third party. A commitment to research ethics is upheld throughout the research process, ensuring transparency, accuracy and honesty in reporting results. Respondents' participation was voluntary with informed consent, and their confidentiality and privacy were maintained in accordance with applicable research ethics standards. With this statement, researchers hope that the research results can be trusted and used as a valid reference for the development of science and health practices related to ethnomedicine and reproductive health.

References

1. Abojabel H, Werner P. Exploring family stigma among caregivers of persons with Alzheimer ' s disease : The experiences of Israeli-Arab caregivers. 2016;
2. Ae-ngibise KA, Christian V, Doku K, Poku K, Owusu-agyei S, Ayuurebobi K, et al. The experience of caregivers of people living with serious mental disorders: a study from rural Ghana. 2017;9716(February).
3. Angermeyer M.C., Schulze B. Reinforcing stereotypes: how the focus on forensic cases in news reporting may influence public attitudes towards the mentally ill. Int. J. Law Psychiatr. 2001;24(4–5):469–486. doi: 10.1016/S0277-9536(02)00028-X
4. Alasmee, N., and A. Hasan. 2020. "Primary Caregivers Experience of Anti-Psychotic Medication: A Qualitative Study." Archives of Psychiatric Nursing 34, no. 6: 520–528. https://doi.org/10.1016/j.apnu.2020.09.002.
5. ARMAIJN, L. (2019). Persepsi Penderita Kusta Terhadap Stigma Kusta Di Kota Ternate. Kieraha Medical Journal, 1(2), 31–37. https://doi.org/10.33387/kmj.v1i2.1705
6. Al-Sawafi, A., K. Lovell, L. Renwick, and N. Husain. 2021. "Exploring the Experience of Relatives Living With Individuals Diagnosed With Schizophrenia in Oman: A Qualitative Study." Journal of Psychiatric and Mental Health Nursing 28, no. 6: 1029–1040. https://doi.org/10.1111/jpm.12786.
7. Bachtiar A., Windarwati H.D., Keliat B.A., Ismail R.I., Ati N.A.L., Sulaksono A.D., et al. The fight against stigma: multilevel stigma interventions in schizophrenia patients. J. Publ. Heal. Res. 2020;9(4):1883. doi: 10.4081/jphr.2020.1883.
8. Catthoor K, Schrijvers D, Hutsebaut J, Feenstra D, Persoons P, De Hert M, et al. Associative stigma in family members of psychotic patients in Flanders: an exploratory study. World J Psychiatry. 2015;5(1):118–25.
9. Clement S, Schauman O, Graham T, Maggioni F, Evans-Lacko S, Bezborodovs N, et al. What is the impact of mental health-related stigma on help-seeking? A systematic review of quantitative and qualitative studies. Psychol Med. 2015;45(1):11–27.
10. Corrigan PW, Watson AC, Miller FE. Blame, shame, and contamination: The impact of mental illness and drug dependence stigma on family members. J Fam Psychol. 2006;20(2):239–46.
11. Darban, F., R. Mehdipour- Rabori, J. Farokhzadian, E. Nouhi, and S. Sabzevari. 2021. "Family Achievements in Struggling With Schizophrenia: Life Experiences in a Qualitative Content Analysis Study in Iran." BMC Psychiatry 21, no. 1: 7. https://doi.org/10.1186/s12888-020-03025-w.

12. Deshpande, S., S. Dewani, S. N. Sirkhot, and D. Veerkar. 2018. “Insights Into Psychosocial Problems of Primary Caretakers of Patients With Schizophrenia in India. Annals of Indian.” Psychiatry 2, no. 2: 130. https://doi.org/10.4103/aip.aip_25_18.
13. Dijkxhoorn, M. A., A. Padmakar, J. F. G. Bunders, and B. J. Regeer. 2022. “Stigma, Lost Opportunities, and Growth: Understanding Experiences of Caregivers of Persons With Mental Illness in Tamil Nadu, India.” Transcultural Psychiatry 60, no. 2: 255–271. https://doi.org/10.1177/13634615211059692.
14. Fung KM, Tsang HW, Chan F. Self-stigma, stages of change and psychosocial treatment adherence among Chinese people with schizophrenia: a path analysis. Soc Psychiatry Psychiatr Epidemiol. 2010;45(5):561–8.
15. Fitryasari, R., A. Yusuf, T. Nursalam, and H. E. Nihayati. 2018. “Family members' Perspective of Family Resilience's Risk Factors in Taking Care of Schizophrenia Patients.” International Journal of Nursing Sciences 5, no. 3: 255–261. https://doi.org/10.1016/j.ijnss.2018.06.002.
16. Goh, Y. S. 2024. “The Landscape of Mental Health Care Landscape in Asia: Issues and Challenges.” Jurnal Ners 19, no. 3: 273–274. https://doi.org/10.20473/jn.v19i3.62529.
17. Goh, Y. S., Q. Y. Ow Yong, V. C. K. Ng, et al. 2024. “Caregivers' Experiences in Helping Individuals With Severe and Enduring Mental Health Challenges Integrate Into the Community: A Qualitative Descriptive Study in Singapore.” Journal of Psychiatric and Mental Health Nursing 20: 13071. https://doi.org/10.1111/jpm.13071.
18. Huggett C, Birtel D, Awenat YF, Fleming P, Wilkes S, Williams S, et al. A qualitative study : experiences of stigma by people with mental health problems. 2018;1–18.
19. Lam CS, Tsang HWH, Corrigan PW, Lee Y-T, Angell B, Shi K, et al. Chinese lay theory and mental illness stigma: implications for research and practices. J Rehabil. 2010;76:35–40.
20. Lasalvia A, Zoppei S, Van Bortel T, Bonetto C, Cristofalo D, Wahlbeck K, et al. Global pattern of experienced and anticipated discrimination reported by people with major depressive disorder: a cross-sectional survey. Lancet. 2013;381(9860):55–62.
21. Ling Y, Wong I, Kong D, Tu L, Frasso R. “ My bitterness is deeper than the ocean ”: understanding internalized stigma from the perspectives of persons with schizophrenia and their family caregivers. Int J Ment Health Syst [Internet]. BioMed Central; 2018;1–15. Available from: https://doi.org/10.1186/s13033-018-0192-4
22. Linden M., Kavanagh R. Attitudes of qualified vs. student mental health nurses towards an individual diagnosed with schizophrenia. J. Adv. Nurs. 2012;68(6):1359–1368. doi: 10.1111/j.1365-2648.2011.05848.x.
23. Maiocco S, Shelley E, Salmond S, Jewell ST, Caldwell B, Lieggi M, et al. living with schizophrenia : a systematic review protocol. 2017;1575–84.
24. Mukherjee A, Lahiry S, Mukherjee A, Choudhury S, Sinha R. Study on Defense Mechanisms to Cope With cejiyStress Due to Stigma Among People Living With HIV / AIDS Reported in Eastern India : A Single Center Experience. 2017;
25. Paul S, Nadkarni V V. A qualitative study on family acceptance, stigma and discrimination of persons with schizophrenia in an Indian metropolis. Int Soc Work. 2017;60(1):84–99.
26. Phillips MR, Zhang J, Shi Q, Song Z, Ding Z, Pang S, et al. Prevalence, treatment, and associated disability of mental disorders in four provinces in China during 2001–05: an epidemiological survey. Lancet. 2009;373(9680):2041–53.
27. Ran MS, Zhang TM, Wong IY, Yang X, Liu CC, Liu B, et al. Internalized stigma in people with severe mental illness in rural China. Int J Soc psychiatry. 2018;64(1):9–16.

28. Rezayat F, Mohammadi E, Fallahi-khoshknab M, Sharifi V. Experience and the meaning of stigma in patients with schizophrenia spectrum disorders and their families: A qualitative study. Japan J Nurs Sci. 2018;
29. Tanaka C, Teresa M, Tuliao R, Tanaka E, Yamashita T, Matsuo H. A qualitative study on the stigma experienced by people with mental health problems and epilepsy in the Philippines. BMC Psychiatry; 2018;1–13.
30. Walker L. 'There's no pill to help you deal with the guilt and shame': Contemporary experiences of HIV in the United Kingdom. Heal An Interdiscip J Soc Study Heal Illn Med [Internet]. 2017;(1998):136345931773943. Available from: http://journals.sagepub.com/doi/10.1177/1363459317739436
31. Yang LH. Application of mental illness stigma theory to Chinese societies: synthesis and new directions. Singapore Med J. 2007;48(11):977–85.