

Stigma in Collective Culture: A Qualitative Study of the Role of the Family in Mental Disorder Treatment Decisions in Bandung

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Abstract. Social stigma against mental disorders in collective cultures is still a major obstacle in accessing mental health services. This research aims to understand the role of the family in making decisions regarding the treatment of mental disorders in the city of Bandung. Using a qualitative approach with a case study method, data collection was carried out through in-depth interviews with three families who had members with mental disorders. Thematic analysis revealed that social stigma caused families to delay or even refuse treatment due to concerns about social image and societal pressure. Collective culture reinforces this attitude, with families prioritizing social harmony over individual medical needs. This research also found that families were able to overcome stigma by seeking social adjustment strategies, such as getting literacy support about mental health from closed communities or using a scientific approach in dealing with mental illness. The collective culture within families in the city of Bandung is a barrier to medical treatment but at the same time it is a driver and strengthener of togetherness in facing stigma. This study highlights the need for culture-based interventions to increase mental health awareness and reduce social stigma in collective societies.

Keywords: collectivist culture, family resistance, family support, mental health treatment, social stigma

1. INTRODUCTION

Mental disorders are a global health problem that continues to increase, with impacts that are not only limited to the individuals who experience them but also extend to their social environment, including families and society as a whole. According to the World Health Organization (WHO) report, mental disorders are the main cause of disability throughout the world, with prevalence continuing to increase in various countries, including Indonesia.

“...Globally, over 70% of persons with mental illnesses do not have access to treatment, and much of this is attributed to stigma (5 – 7) There is high social vulnerability and marginalization linked to mental illnesses (8- 9). Such social vulnerabilities can make life complex for individuals with mental illnesses, diagnosed or otherwise, as well as their immediate families, especially in situations where lack of access to mental healthcare services makes families struggle to meet basic health needs while searching for treatment for their loved ones (10- 11).”¹

Data on the distribution of the prevalence of mental health problems in the population aged >15 in West Java in 2023 will be the highest, namely 4.4%. Despite these high numbers, access to mental health services in Indonesia still faces various challenges, especially those

¹ Adu, J. (2024). Negotiating familial mental illness stigma: the role of family members of persons living with mental illnesses. Plos One, 19(9), e0311170. <https://doi.org/10.1371/journal.pone.0311170>

originating from the strong social stigma towards mental disorders. Stigma in collective cultures causes family members to be reluctant to seek professional help because they are embarrassed and worried that they will be viewed negatively by society. The collective culture emphasizes family harmony and a good image in society. As a result, many families delay treatment decisions or hide their family members' mental disorders, which ultimately worsens the sufferer's condition. *"Many families delay treatment decisions or hide their family members' mental disorders, which ultimately worsens the sufferer's condition"*².

On the other hand, there are also families who actively seek treatment and use certain methods to deal with social stigma.

As one of the metropolitan cities in Indonesia, Bandung provides an interesting context for understanding this phenomenon. The Human Development Index (HDI) of Bandung City in 2024 is 83.75. This figure increased by 0.46 points (0.55%) compared to the previous year, 83.29. HDI is an indicator that measures people's quality of life. HDI is calculated based on three dimensions, namely: Long and healthy life, Knowledge, and Decent living standards. In 2024, Bandung City's HDI is higher than DKI Jakarta's HDI which is 83.08. Social interactions in the city of Bandung reflect the differences between traditional standards, in this case collective culture, and modern views of life in dealing with mental disorders due to the city's unique and diverse characteristics.

*"However, research that specifically examines these dynamics is still limited, especially in the context of Indonesian collective culture. An in-depth understanding of the factors that motivate or hinder families' decisions to seek treatment is critical, in order to design more effective interventions to reduce stigma and increase access to mental health services. 2) Mental illness in family and friends may be more obvious to lower status individuals because they are more likely to have untreated mental illnesses and may exhibit more symptoms, making low status people more aware of their contact with people who are mentally ill. 3) Low status individuals may be more likely to know about their family and friends' mental health problems as a result of their collectivist culture. People from low socioeconomic status backgrounds are more likely to perform prosocial behaviors (Piff et al 2010), experience more compassion for others, and are more attuned to and impacted by the distress of others (Stellar et al 2012). If, as these studies suggest, collectivism is stronger among lower status individuals, then they would be more likely to know about and empathize with their family and friends' mental..."*³

² Hajizadeh, A., Amini, H., Heydari, M., & Rajabi, F. (2024). How to combat stigma surrounding mental health disorders: A scoping review of the experiences of different stakeholders. *BMC Psychiatry*, 24, Article number: 782. <https://doi.org/10.1186/s12888-024-07234-5>

³ Billings, K. (2020). stigma in class: mental illness, social status, and tokenism in elite college culture. *Sociological Perspectives*, 64(2), 238-257. <https://doi.org/10.1177/0731121420921878>

This research was conducted to examine how families in Bandung who live in a collective culture face the negative stigma and reality of mental disorders in their families? How do families make decisions to initiate, delay and/or refuse treatment for mental disorders in their family? It is important to understand this process in order to make better plans to reduce stigma and increase access to mental health services in Indonesia.

2. RESEARCH METHODS

This research applies a qualitative approach using case studies to explore family experiences in making decisions regarding the treatment of mental disorders in the city of Bandung. The case study method was chosen because it provides a good opportunity for researchers to understand the phenomenon in its context by considering the social, cultural and emotional factors that influence family decisions. This approach focuses on an in-depth understanding of how families deal with social stigma and how collective culture influences their strategies for seeking or delaying treatment for family members with mental disorders.

Research Type

There are multiple primary phases that comprise the research process:

1. Participant identification and recruitment Families with relatives who suffer from mental illnesses make up the participants. Community networks, mental health organizations, and suggestions from medical experts were used to determine the research criteria. By taking into account the ethical guidelines for qualitative research, such as participant consent and privacy protection, the participants' willingness is verified.
2. Information Gathering In-depth interviews with family members who participate in treatment decision-making, accompany patients' family members while they receive treatment, and bear or manage treatment expenditures were used to gather data. Semi-structured interviews were employed to provide for flexibility in examining participants' experiences while maintaining focus on the study's goals. Interview questions cover family experiences in facing stigma, factors influencing treatment decisions, and strategies used to cope with or adapt to social pressures.
3. Recording and Documentation of Data Interviews are recorded with the participants' consent to ensure data accuracy. Field notes were also made to capture the social and emotional context during the interview.

4. Data Analysis Techniques

The data obtained were analyzed using a thematic approach that allows for the identification of patterns of meaning and main themes in family experiences.

5. Transcription and Familiarization of Data

All interview recordings are transcribed verbatim to ensure the accuracy of interpretation. The researcher reads the transcripts repeatedly to understand the emerging patterns of meaning.

6. Codification and Identification

The data themes are coded openly to identify initial categories relevant to family experiences. These categories are then grouped into main themes that reflect patterns in family decisions regarding the treatment of mental disorders.

7. Interpretation and Contextualization

The themes generated are interpreted within the context of social stigma theory and collective culture. The results of the analysis are linked with existing literature to understand the contribution of these findings to previous research.

8. Validation of Findings

The source triangulation technique was carried out by comparing perspectives from various family members as well as other sources, such as field notes, to enhance the validity of the research results. Member checking was conducted by confirming the main findings with participants to ensure the accuracy of the interpretation.

Place and Time of Research

The research was conducted in the city of Bandung in December 2024- January 2025.

Population and Sample

The population studied was families who had family members with mental disorders in the city of Bandung. The sample consists of three families with family members who experience mental disorders, covering a variety of social and economic backgrounds to gain a broader perspective. This sample selection aims to capture differences in family experiences in dealing with stigma and making decisions regarding treatment.

3. RESEARCH RESULT

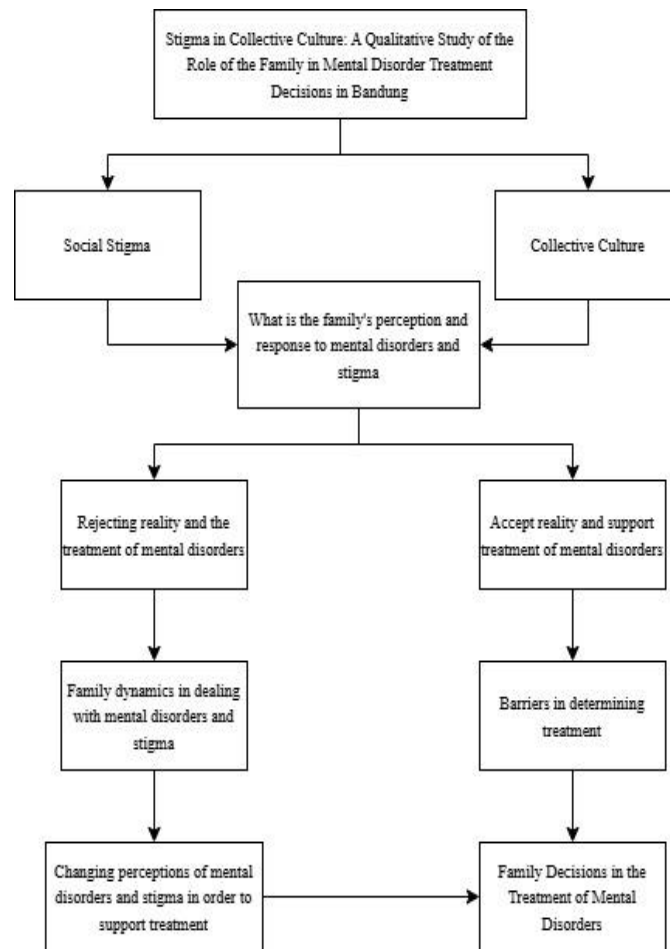


Figure 1: Result from Research on Stigma in Collective Culture

Results from research that have been coded into multiple categories are shown in Figure 1. From the findings of interviews and data analysis in this research, main themes and connected between issues were found. In order to answer the research questions, this image analyzes the interview results and highlights the connections and patterns that occur about perceptions, social stigma, collective culture, and the role of the family in making decisions about mental health treatment. Interviews with three Bandung families dealing with mental illnesses led to this key breakthrough

Discussion

1. How do families in Bandung who live in a collective culture face stigma and mental disorders in their families.

Social Stigma

Stigma is a negative label aimed at certain people or groups. Prejudice can arise based on certain characteristics or traits, such as skin color, cultural background, disability, or mental illness. Stigmatization is a negative label that people give to certain individuals or groups. This

stigma often causes people with mental illness to delay seeking help or not seek help at all. All families in the research sample felt that social stigma was the biggest factor influencing their decision to seek treatment. This is related to fear of society's negative view of their family. Even though all families are aware of the gravity of the situation they are facing, agreement in decision making for the extended family is difficult to achieve. These findings are in line with the results of research conducted by Tien,C among Hispanics: *“This research has shown the harm stigma does to Hispanic adolescents' mental health because of destructive cultural, religious, and societal values held by those in this community⁴.”*

This finding is also in line with the results of SLR research conducted among Americans:

“Stigma is integral to understanding mental health disparities among racial and ethnic minority groups in the United States. We conducted a systematic review to identify empirical studies on cultural aspects of mental illness stigma (public, structural, affiliative, self) among three racial and ethnic minority groups (Asian Americans, Black Americans, Latinx Americans) from 1990 to 2019, yielding 97 articles. In comparison studies (N = 25), racial and ethnic minority groups often expressed greater public and/or self-stigma than White American groups. In within-group studies (N = 65; Asian American, n = 21; Black American, n = 18; Latinx American; n = 26), which were primarily qualitative (73%), four major cultural themes emerged: 1) service barriers including access and quality (structural stigma); 2) family experiences including concealment for family's sake, fear of being a burden, and stigma extending to family (affiliative stigma); 3) lack of knowledge about mental illness and specific cultural beliefs (public stigma); and 4) negative emotional responses and coping (self-stigma). These findings confirmed stigma has both similar and unique cultural aspects across groups. Despite this, few studies tested stigma reduction interventions (N = 7). These cultural insights can inform contextual change at the health systems and community levels to reduce stigma, and empowerment at the interpersonal and individual levels to resist stigma.”⁵

⁴ Tien, C. (2023). How the stigma of mental health harms hispanic adolescents. Uc Merced Undergraduate Research Journal, 15(1). <https://doi.org/10.5070/m415160868>

⁵ Misra, S., Jackson, V., Chong, J., Choe, K., Tay, C., Wong, J., ... & Yang, L. (2021). Systematic review of cultural aspects of stigma and mental illness among racial and ethnic minority groups in the united states: implications for interventions. American Journal of Community psychology, 68(3-4), 486-512. <https://doi.org/10.1002/ajcp.12516>

The Role of Collective Culture

In collective communities, family decisions are often influenced by values that promote social harmony, reduce stigma, and greatly influence families' views and reactions to mental disorders, thus hindering access to mental health services. All families interviewed tended to hide their mental health problems for fear of being seen as bad by society. This shows that a culturally appropriate approach is needed to increase mental health awareness in society. This is in line with research on mental health stigma in collectivist cultural societies in Tunisia:

“Survey results show that 77% of respondents completely agreed or somewhat agreed that they would like to learn more about mental health. This study also found that 68% of the sample reported a lack of accessibility to mental healthcare services resulting in 49% reporting their preference to search their symptoms on the internet instead of informing someone. Throughout the interviews phase, the main factors identified to have a crucial impact on young adults' choice to openly communicate feelings and thoughts with each other and to seek professional help are: culture, gender roles, sexual orientation, and family approval. Conclusion: This study suggests a great desire among young adults to learn more about mental health, and highlights the cultural complexities regarding mental health stigmatization in Tunisia. It also highlights the need for culturally relevant approaches raising awareness about mental health.”⁶

Need for Medical Treatment vs. Social Stigma

Although medical needs are the main consideration, family decisions are also influenced by social factors such as maintaining the family's image and avoiding stigma from society. Differences in society's perspective on the importance of treating physical illnesses rather than mental illnesses were also found in a study of stigma among the Pakistani population:

““In some cultures, psychological problems and treatment are mostly not considered as important as medical illnesses. This is generally because of people's attitudes toward mental disorders and psychotherapeutic interventions. The current study involved 2702 Muslims from Pakistan. The study measured attitudes towards mental health through different dimensions. These mainly included attitudes toward mental health, attitudes towards mental disorders,

⁶ Eddahiri, S. and Johnson, K. (2021). mental health literacy, stigma, and access to services among young adults in tunisia. The Columbia University Journal of Global health, 10(2). <https://doi.org/10.52214/thecejgh.v10i2.7093>

attitudes towards medical illnesses, attitudes towards mentally disturbed, attitudes towards seeking psychological help for self, attitudes towards seeking psychological help for families, attitudes towards seeking psychological help for children, and attitudes towards seeking psychological help for friends. The understudied population had positive attitudes toward mental health and psychotherapy. A significant difference was found between people's attitudes towards medical illnesses and mental disorders. Attitudes based on gender, age, education, marriage, profession, and income were also significantly different. The findings of this study lead mental health practitioners and policymakers to modify their strategies for encouraging more clientele to the existing mental health facilities.”⁷

Barriers to Treatment

The biggest obstacles faced are social stigma and family agreement in carrying out treatment, including determining the health facility for treatment, accompanying the sufferer's family, treatment costs, readiness to face extended family and the community. Lack of family knowledge and literacy in society regarding the management of mental illness is also a major obstacle. As a result, almost all families find it difficult to accept reality because they are afraid of negative judgment from the extended family and society. This is in line with the results of research on stigma in mental health in Singapore:

“... Other possible barriers to successfully engaging the family in treatment are the lack of understanding of mental illness and the family's role in recovery, (52) as well as the stigma associated with mental illness. (54,56) For some families, their unwillingness to engage could be related to prior negative experiences when working with service providers. Poor rapport with service providers, including feeling patronised and not understood, has also been stated as a reason for their lack of motivation for further engagement. Other possible barriers to successfully engaging the family in treatment are the lack of understanding of mental illness and the family's role in recovery, (52) as well as the stigma associated with mental illness. (54,56) For some families, their unwillingness to engage could be related to prior negative experiences when working with service providers. Poor rapport with service providers, including feeling patronised and not understood, has also been stated as a reason for their lack of motivation for further engagement....”⁸

⁷ Husain, W. and Riasat, A. (2022). Attitudes toward mental health and psychotherapy in a collectivistic muslim culture: variations by gender, age, education, marriage, profession, and income. *Journal of Internal medicine Science & Art*, 3, 28-35. <https://doi.org/10.36013/jimsa.v3i1.101>

⁸ Ong, H., Fernandez, P., & Lim, H. (2021). family engagement as part of managing patients with mental illness in primary care. *Singapore Medical Journal*, 62(5), 213-219. <https://doi.org/10.11622/smedj.2021057>

2. How families make decisions to start, delay and/or refuse treatment for mental disorders in their family

The Role of the Family in Treatment Decision Making

In all families interviewed, the decision to seek treatment was dominated by the family member who had the greatest financial power and knowledge. However, this support and responsiveness to medical needs is not immediately approved by the extended family. The gap in knowledge and understanding of the importance of managing mental illness is not evenly distributed among family members. Mental health is not considered as important as physical health. Even though there is an initial fear of stigma, literacy towards individuals within the extended family can gradually change the family's view of the stigma of mental illness. This is in line with the results of research on families of schizophrenia sufferers:

“Family-centered care requires empathy, understanding, respect, and empowerment to choose, control decisions, and empower in the treatment of schizophrenia. This study concludes the importance of family involvement in the treatment of schizophrenia from the start. Health care providers help families through the admissions process.”⁹

The Impact of Stigma on Family Dynamics

Social stigma causes tension in family relationships, communication with other extended families becomes more closed, more distant and avoids interactions with outsiders, avoids neighbors' curiosity by lying about the whereabouts and condition of the sufferer's family members. However, families' views on mental disorders and their treatment change over time, both due to direct experience and new knowledge gained. The moment of change is marked by when the family begins to be more open to seeking information and taking action to obtain alternative treatment besides medical treatment.

Experience of Delaying Treatment

All families who were interviewed admitted that social stigma caused them to postpone treatment for some time before they finally decided to take the sufferer's family member to a health facility. Postponement is done because of shame and fear of public judgment. The decision for treatment was made because of pressure from the family who thought that the sufferer's family members showed a worse condition and also because of pressure from the

⁹ Iswanti, D., Nursalam, N., Fitryasari, R., Mendrofa, F., & Hani, U. (2023). Including families in schizophrenia treatment: a systematic review. *International Journal of Public Health Science (Ijphs)*, 12(3), 1155. <https://doi.org/10.11591/ijphs.v12i3.22462>

family who were sympathetic and had more in-depth knowledge about mental health. This is in line with the results of research on families of people with mental disorders among Hispanics: *"Among Hispanics, stigma has been found to be negatively associated with the desire to engage in mental health care, management of depression symptoms, disclosure of mental illness to family and friends, and adherence to antidepressant medications."*¹⁰

Changes in Family Views of Mental Disorders

The family's perspective on mental illness and their support for treatment, may change over time as a result of their own experiences or as they become enlightened through new knowledge. The moment of change occurs when a family member becomes more willing to seek treatment despite the stigma. Changes in the family's view of mental illness and treatment support can also change over time as a result of their own experience of witnessing the sufferer's experience as new knowledge for themselves.

Changes in perspective also occur, especially when family members share similar experiences with other family members in the community, so that family members become more willing to be involved in treatment even though stigma still exists.

Mental Health Literacy is very effective in dealing with the negative stigma of society. Most of the participants' family members do not understand what is meant by Mental Health. Definition of mental health according to Law Number 18 of 2014 concerning Mental Health. "Mental Health is a condition where an individual can develop physically, mentally, spiritually and socially so that the individual is aware of his own abilities, can cope with stress, can work productively and is able to contribute to his community."¹¹

Hope for Reducing Stigma and Strengthening Support for Suffering Families

All families hope that there will be literacy support about mental disorders to reduce stigma in society and provide greater support to families who face these problems. Mental Health Literacy helps individuals and families to recognize, prevent and overcome symptoms of mental disorders both in themselves and in other individuals. Mental Health Literacy understands individuals so they are able to provide First Aid for Mental Disorders, self-help strategies for mild mental disorders, and the help and treatment options available at health facilities for serious mental disorders. With mental health literacy, it is hoped that it can open up good and correct understanding among families regarding mental disorders and give

¹⁰ Eghaneyan, B. and Murphy, E. (2020). Measuring mental illness stigma among hispanics: a systematic review.. stigma and health, 5(3), 351-363. <https://doi.org/10.1037/sah0000207>

¹¹<https://bpsdm.esdm.go.id/posts/2023/06/23/pentingnya-literasi-informasi-terkait-kesehatan-mental-bagi-masyarakat/2721#:~:text=Dengan%20literasi%20Kesehatan%20mental%20ini,gangguan%20Kesehatan%20mental%20dan%20mengurangi>

strength to families in facing negative stigma, the most important thing is the formation of strong support in the extended family for family members suffering from mental health disorders.

Good literacy creates the correct view that mental health is as important as physical health. This research is in line with what was found in the following research:

“A significant difference was found between people's attitudes towards medical illnesses and mental disorders. Attitudes based on gender, age, education, marriage, profession, and income were also significantly different. The findings of this study lead mental health practitioners and policymakers to modify their strategies for encouraging more clientele to the existing mental health facilities.”¹²

4. CONCLUSIONS

The results of this study indicate that social stigma has a significant impact on family decisions in seeking treatment for family members with mental disorders. In collectivist cultures, social pressure to maintain the family's image is a major factor inhibiting access to mental health services. Many families choose to hide the condition, delay treatment, or seek alternative solutions that do not involve medical intervention. However, there are also families who have succeeded in overcoming stigma through various adaptation strategies, including community support, religious approaches, and increasing mental health literacy. This study confirms that treatment decisions are influenced not only by medical factors, but also by cultural values and the social structure of society.

The three informant families ultimately decided to carry out medical treatment on their family members who suffered from mental disorders. Treatment is not carried out quickly and in a short time, but requires time for all members of the extended family to reach a mutual agreement. Achieving the same knowledge and awareness in the extended family takes time as the sufferer's health level decreases. This is detrimental to sufferers, but on the other hand, collective culture is a driver and strengthener of togetherness apart from being a barrier treatment.

¹² Husain, W. and Riasat, A. (2022). Attitudes toward mental health and psychotherapy in a collectivistic muslim culture: variations by gender, age, education, marriage, profession, and income. Journal of Internal medicine Science & Art, 3, 28-35. <https://doi.org/10.36013/jimsa.v3i1.101>

Recommendations

Previous research that examined the theme of mental illness stigma was mostly carried out using a quantitative approach to record attitudes and perceptions statistically. However, qualitative approaches that explore families' subjective experiences in facing stigma from the perspective of Indonesia's collective culture are still limited. This study can be expanded more comprehensively from the perspective of Indonesian Communication Science. Furthermore, literature discussing the role of the family in treating mental disorders generally comes from the context of individualistic societies in Western countries, and there is still little research on the collectivist cultural context of Indonesia.

Suggestion

1. Increase mental health literacy:

The government through health institutions must develop educational programs aimed at families and communities to increase understanding of mental illness and the importance of medical care.

2. Culture-based approach:

Stigma reduction interventions should be adapted to local cultural norms and involve community and religious leaders in mental health education campaigns.

3. Community Support:

Establishing support groups for families with loved ones living with mental illness can help reduce stigma and increase access to mental health services.

4. Accessibility of mental health services:

The government must improve accessibility to mental health services, including cost, location and affordability for families from different economic backgrounds.

5. Family Approach to Treatment:

Treatment and rehabilitation programs for mentally ill patients must involve family members in the healing process through appropriate guidance and support. With these steps, it is hoped that the stigma around mental disorders can be reduced, so that more individuals can receive the treatment they need without facing significant social barriers.

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