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Identifying Strategies to Cope with Mental Illness-related Stigma of Family Caregiver Living with Mental Illness in Pamekasan, Indonesia: A Qualitative Study

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Abstract. The social stigma that experienced by people with mental illness has negative consequences both for the patients and their family members. The stigma causes psychological stress, such as depression, frustration, and anxiety for the family. The study aimed to explore the family members' efforts to cope with mental illness stigma in social encounters. This study was qualitative. Eleven families were living with mental illness who were experiencing stigma, and data were collected mainly through in-depth interviews. The results of this study reported that families were using different coping strategies to counter the stigma. They used Problem-focused coping and emotional focused dealing. Adaptive coping strategies used by families of people with mental illness can help to reduce psychological stress. In contrast, coping strategies that tend to be maladaptive can increase the occurrence of psychological stress. Families of people with mental illness that affected by stigma must get psychological therapy to improve the quality of life, and to reduce the negative impact of the stigma itself

Keyword: Life experience, stigma, coping strategy

INTRODUCTION

The existence of people with mental illness often created a burden on the family. Lack of knowledge about mental illness significantly impacted family burden became. The aggressiveness of people with mental illness worsens the social stigma, and increases discrimination against people with mental disorders (1).

In 2015, World health organization revealed that the number of mental disorders increase, the prevalence in the world reaches 516 million people. One from three Southeast

Asian residents has experienced mental, emotional disturbances. The results of the Basic Health Research of Indonesia in 2018, showed that the prevalence of severe mental disorders such as schizophrenia increased in 2013. It was about 1.7% of the Indonesian population or around 4,250,000 people, in 2018 to 7 per 1000 people, or approximately 18,550 .000.

Studies have conducted and reported in the field of the experiences of stigma among psychiatric patients and their families (2–4). Others said the experience of stigma in Alzheimer patients and their families (5,6).

Social stigma is associated as a source of shame that is pinned to individuals with mental disturbances by society. Families with kinship relationships with people with mental disorders can also experience stigma and eventually experience higher depression (7). Families that are experiencing shame will limit the relationship between their friends and family so that the social support received by the family will be low (7). Under such conditions, families need to adopt adaptive coping strategies to deal with the stress-related stigma

OBJECTIVE

This study aimed to explore family members' efforts to cope with mental illness stigma in social encounters.

METHOD

This study was a qualitative study with a phenomenological approach. The participants in this study were family members of people with mental illness who are experiencing stigma. We recruited 11 participants using the purposive sampling technique. All participants were required to sign the informed consent and receive the information regarding the purpose and procedure of the study. The data were collected mainly through in-depth interviews. This study was granted ethical approval by the Ethical Committee of Health Research in the Faculty of Nursing, Universitas Airlangga No. 1533-KEPK.

The participants of this study were 11 family members (Table 1). The inclusion criteria for the participants were family members who treat people with mental illness with *pasung* for at least six months, age > 20 years, and can talk about the experiences. Purposeful sampling was used to select participants with the above criteria from Pamekasan district health office.

RESULTS

Characteristic of respondents

Descriptive statistics of the characteristics of participants are shown in Table 1. This study followed 11 family members as primary caregivers of people with mental illness (8 females and three males), aged within the range of 42 years 80 years old. The educational level of participants varies from unschooled to university. Most of the participants (7 people) are working, as a civil-government, self-employed, laborer, farming, while 4 people are not working. The relationship between participants with the patients are parents (4 mothers and 1 father), 5 siblings, and 1 child

Table 1. Characteristic of respondents

Characteristic	n	%
Gender		
Male	3	27%
Female	8	73%
Age		
36 – 45 years	2	18%
46 – 55 years	5	46%
56 – 65 years	0	0%
>65 years	4	36%
Occupational status		
No work	4	36%
Self-employment	3	27%
Laborer	1	9%
Civil-government	1	9%
Farming	2	18%
Educational level		
No	4	36%
Elementary school	1	9%
Middle school	1	9%
High school	3	27%
Bachelor	2	19%
Relationship with patient		
Mother	4	36%
Father	1	9%
Siblings	5	46%
Child	1	9%

Coping Strategy

Two themes were abstracted from the family members' experiences related to the coping strategy of family living with mental illness who was experiencing stigma. The themes are problem-focused coping and emotion-focused coping (Table 2). The details of each theme are described

Table 2. Identified coping strategy themes and an exemplary significant statement from family members

Theme	Subtheme	Significant Statement
Problem-focused coping	Confronting coping	"I was immediately angry and said something harsh to those who were mocking me" (P3)
	Seeking social support	"I just keep silent. After arriving at home, I told my husband what just happened. Then, he told me to be patient" (P1) (P4) (P7)
	Planful problem solving	"I took my son to the alternative treatment, I hope they stop insulting me if my son get cured" (P2) (P5)
Emotion-focused coping	Escape-avoidance	"When I was invited to come to my neighbor's house, I did not come, I'd better avoid them, so they would not insult me" (P3) (P8) (P7) (P6)
	Positive reappraisal	"I surrender to God, what happened in my life has been written by God" (P4) (P10) (P11) (P5)
		"There must be a lesson to what happen to my family" (P9) and me

Problem Focused on coping

Problem-focused coping is classified into three kinds: confrontative coping, seeking social support, and planning problem-solving. The family adopted the confrontative coping

because they felt anger toward other's insults and ridicule. Families were used in aggressive ways to solve the problems they face. Seeking social support was done by the family to talk to someone who could do something concrete about the problem. Planful problem solving was adopted by family members to deliberate problem-focused efforts to alter the situation. The issue focused coping was selected by participants to solve the problem. Participants tend to use this form of coping if they sure they still control the problem. The following is a planful problem-solving quote by the family.

> *"Once, my grandson's friend visited my house. Then I told him not to let his friends know about his uncle's mental illness" (P5)*

Emotion-Focused on coping

The emotion-focused coping adopted by participants is classified into two kinds; they are escape-avoidance and positive reappraisal. Escape avoidance was taken by participants to avoid others, so they don't experience unpleasant behavior. Positive reappraisal was adopted by participants to create a positive meaning by focusing on a religious tone. Participants tend to use emotion-focused coping if they were not sure of managing the problem. So, what they can do were regulate their emotion, avoid the crowd, and pray to God. The following is a positive reappraisal quote by the family.

> *"I surrender to God, what happened in my life has been written by God" (P4)*

DISCUSSION

Stigma and discrimination against people with mental health problems are a global public health issue [8–10]. They can have substantial negative impacts on all aspects of a person's life, from employment and housing to social and family life (7,11). Some Study has documented that stigmatization of individuals with mental illness has significant impacts on their mental health and well-being (1). Not only the patients, but other studies also documented that their family can be stigmatized as well only (12–14). Studies that focus on family experiences with stigma reveal that experiences of social discrimination and rejection and blame for their relatives' illnesses are common, often leading to feelings of shame and contamination (15,16). To reduce the negative impact of stigma, family members adopted various coping strategies (17). Lazarus and Folkman (17) defined coping as "continually changing cognitive and behavioral efforts to manage specific external and internal demands that are appraised as taxing or exceeding the resources of the person.

This study documented that coping strategies adopted by the family are classified into two kinds: problem-focused coping and emotion-focused coping. Problem-focused coping is coping that leads to efforts to solve the issues. At the same time, emotion-focused coping is dealing that aims to modify the function of emotions without directly changing the stressor.

In problem-focused coping, there were three kinds of coping, confrontative coping, seeking social support, and planful problem-solving. Some families that adopted planful problem solving; they use this kind of dealing with altering the situation. Participants reported that they try to hide their sick relatives from others. This coping strategy is similar to that found in another study (18). In their report on being an immediate family member of PWMI (people with mental illness) found that co-residence reinforced feelings of shame, embarrassment, social exclusion, rejection by friends and acquaintances, concealment, and the need of getting away from home and the stigmatized situation.

Participants also reported that they sometimes adopted confrontative coping. When participants were experiencing unpleasant action from others, they spontaneously scold them. They felt anger and made some aggressive efforts to alter the situation. This result similar to Abojabel's study (5) and Paul's (8), where the results of their research prove that some of the stereotypes they perceive to be associated with them by others trigger feelings of anger and hatred.

Emotion-focused coping is classified into two kinds, they are escape avoidance and positive reappraisal. In this Study, Participants were using escape avoidance to avoid others, so they don't experience unpleasant behavior. Participants reported that they choose to prevent meet and make conversation with others. They were afraid that others would humiliate them. This founding is adapt to form Lazarus and Folkman's theory (17). This theory explained that escape avoidance was a behavioral effort to escape or avoid unpleasant moments.

Participants have reported another result that they pray to God and hope there will be a "miracle," so their sick relatives would accept in community. This result is consistent with the finding in the study of wong (19) about stigma in families of individuals in the early stages of psychotic illness: family stigma and early psychosis. In this study, families endorsed that both talking and a belief in God and prayer can help someone get better, and this finding is similar to positive reappraisal (20).

CONCLUSION

Problem-focused coping and emotion-focused coping were two kinds of coping strategies found in family members with mental illness stigma in social encounters. The limitation of this study is that the coping strategy was evaluated only in those families who had sought treatment and obtained care for family members, so further research is needed.

REFERENCES

[1] Larson JE, Ed D, Corrigan P, Psy D. The Stigma of Families with Mental Illness. 2008;(April):87–91.

[2] Koschorke M, Padmavati R, Kumar S, Cohen A, Weiss HA, Chatterjee S, et al. Social Science & Medicine Experiences of stigma and discrimination of people with schizophrenia in India. Soc Sci Med [Internet]. Elsevier Ltd; 2014;123:149–59. Available from: http://dx.doi.org/10.1016/j.socscimed.2014.10.035

[3] 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;

[4] Sanden RLM, Bos AER, Stutterheim SE, Pryor JB, Kok G. Stigma by Association Among Family Members of People with a Mental Illness : A Qualitative Analysis. 2015;417(November 2014):400–17.

[5] Abojabel H, Werner P. Exploring family stigma among caregivers of persons with Alzheimer ' s disease : The experiences of Israeli-Arab caregivers. 2016;

[6] Mukherjee A, Lahiri S, Mukherjee A, Choudhury S, Sinha R. Study on Defense Mechanisms to Cope With Stress Due to Stigma Among People Living With HIV / AIDS Reported in Eastern India : A Single-Center Experience. 2017;

[7] Magana S, Garcia J, Hernandez M, Cortez R. Psychological Distress Among Latino Family Caregivers of Adults With Schizophrenia: The Roles of Burden and Stigma. 2007;58(3).

[8] 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.

[9] 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.
[10] 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
[11] 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
[12] Management B. Psychological distress, perceived stigma, and coping among caregivers of patients with schizophrenia. 2016;211–8.
[13] Maiocco S, Shelley E, Salmond S, Jewell ST, Caldwell B, Lieggi M, et al. living with schizophrenia : a systematic review protocol. 2017;1575–84.
[14] 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.
[15] 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).
[16] 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.
[17] Lazarus RS, Folkman S. Transactional theory, and research on emotions and coping. 1987;1(March):141–69.
[18] Sanden RLM Van Der, Pryor JB, Stutterheim SE. Stigma by association and family burden among family members of people with mental illness : the mediating role of coping. Soc Psychiatry Psychiatr Epidemiol. Springer Berlin Heidelberg; 2016;
[19] Wong C, Davidson L, Anglin D, Link B, Gerson R, Mcglashan T, et al. illness : family stigma, and early psychosis. 2009;3(2):108–15.
[20] Pescosolido BA, Medina TR, Martin JK, Long JS. The " Backbone " of Stigma : Identifying the Global Core of Public Prejudice Associated With Mental Illness. 2013;103(5):853–60.