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## Original Article

# Perceived barriers on mental health services by the family of patients with mental illness

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## ABSTRACT

**Background:** Various efforts have been made by the Indonesian government to improve mental health services. In 2014, the government established Law no 18, which is about mental health and the treatment of people with mental illness covered by the universal health coverage. However, many people still experience difficulty in accessing mental health services. In Indonesia, family plays the role of a caregiver to people with mental illness.

**Objective:** This study aims to identify the perceived barriers on mental health services by families whose members suffers from mental illness.

**Methods:** This study is a qualitative research study with a phenomenological approach. Sampling was conducted by purposive sampling with a sample size of 12 participants. Data were collected using semistructured in-depth interviews. Thematic analysis was performed using Colaizzi steps.

**Results:** The obtained results presented three themes. Theme 1, mental health service affordability; theme 2, mental health service availability; and theme 3, negative attitudes (stigma).

**Conclusion:** Families whose members suffered from mental illness still experienced barriers in relation to mental health services even with universal health coverage. Improved mental health services are related to the health insurance coverage, affordability, availability of mental health services and stigma reduction in the health professionals and wide community.

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## 1. Introduction

Universal health coverage aims to protect each individual to ensure that they get equal treatment in terms of getting access to health care. Universal health coverage is one of the World Health Organization (WHO) global priorities for their sustainable development goal (SDG) program [1]. The universal health coverage in Indonesia, also known as the National Health Insurance program, was initially conducted in early 2015. Indonesian Law No. 18 was established in 2014; this law provides support to health services for people with mental disorders. Various efforts have been made by the Indonesian government in dealing with issues related to mental disorders; these efforts include the following: 1) applying a comprehensive, integrated and sustainable mental health services in community; 2) providing facilities, infrastructure, and resources

required for mental health services in all regions of Indonesia, including drugs, medical devices, health professional and health workers and 3) actuating the community to implement preventive and promotive efforts, and also the early detection of mental disorders and implement rehabilitation and mental disorder reintegration into society [2]. However, many perceived barriers against people with mental disorders are mainly related to mental health services. People with mental disorders are often marginalised and discriminated, which is contrary to their healthy rights. A number of barriers, both at the social and organisational levels, have contributed in this regard; these barriers include comorbidity, stigma, difficulty in accessing mental health services and lack of resources in the mental health services in various countries [3]. Although various efforts have been made, Rusdi (2012) showed that 91.08% of respondents can not access the mental health services available in formal health care facilities [4].

The number of people with mental disorders in Indonesia is 1.7 per 1000 of the population, or approximately 400,000 people [2] at the time of data collection. This number shows high concern regarding mental disorders in Indonesia. The East Java Social

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Service stated that the number of people with mental disorders in East Java reaches 2369 people by 2016. This number increases by 750 compared with that in 2015 (1619). The number of people with mental disorders who are being restrained also increases; in East Java, the number of such people is 712, which is different from the data obtained from Menur Mental Health Hospital, which records about 1650 persons in the same region. Only two mental health hospitals are available in East Java. Therefore, in-patient rooms for people with mental disorders requiring hospitalisation are considerably limited. The treatment process should be focused on and within community settings by utilising first-level health centre services (*puskesmas*) in the area.

Changes in the national universal health coverage system has also resulted in changes to the treatment of people with mental disorders. An example of change is that related to the length of hospital stays (close to 2 weeks, with drugs that can be taken at home by the patient; these drugs are also limited to only two weeks, but their stocks are previously available for one month). Nevertheless, other people with mental disorders still receive no comprehensive mental health treatment. Comprehensive treatment should be received both in hospital and community settings. A barrier caused by an individual with a mental disorder is that they seek no treatment [5]. Perceived barriers can be obtained from both the patients and the involved healthcare professionals. Some of the barriers related to mental health care are the stigma [6], treatment cost, lack of knowledge, and isolation [7]. Other studies indicated that stigma is an insignificant barrier [8].

Mental disorders affect the person diagnosed and the family. The family must provide housing, income assistance, daily living assistance, emotional support, medications and hospitalisation [9,10]. Family plays an important role in caring for the family members suffering from a mental disorder, especially as a caregiver. The family is a support resource during patient recovery and rehabilitation; the support provided by the family can prevent relapse in people with mental illness. Mental illness exerts remarkable effects because of costly treatment, loss of productive time and issues related with legal jurisdiction (committing violence or injustice actions). Mental illness increases the psychological burden and the social and economic burden on the community and the potential number of physical diseases [11]. Mental health treatment should be carried out with attention to the service recipient aspects in order to identify the barriers in each aspect. Nursing care can also be provided comprehensively.

The present study explored the perceived barriers on mental health services from the patient's family perspective. The users of mental health services, namely, the patient and their family, were investigated. The perceived barrier of mental health services from the user's perspectives was expected to increase the mental health service details. Consequently, they can be administered significantly so as to reduce the recurrence rate and new severe mental illness case findings.

## 2. Method

This study aimed to explore the barriers experienced by the patient's family regarding mental health services. A qualitative method with a phenomenological approach was used.

### 2.1. Participants

The population included families whose family member are suffering from mental illness and who have been treated in Menur's Mental Health hospital in Surabaya. Sample was obtained by purposive sampling. The inclusion criteria were as follows: 1) outpatient mental disorder patients with family; 2) aged > 20 years; 3)

the family had been the patient's caregiver for at least 1 year and 4) can communicate well using Indonesian language (*bahasa*) or regional language (Java), which was understood by both the participants and researchers and subsequently translated into English language. The sample size was 12 participants.

### 2.2. Data collection

The interview guide was developed from the main requirements for health service and health service access of Penchansky and Thomas [12]. Prior to data collection, the researchers carried out interview guidance trial tests on two participants to validate the questions that were listed with the assistance of a supervisor involved in mental health nursing. The participants were recruited on the basis of ethical principles (confidentiality, beneficence and informed consent). The researcher established the trust in the researcher-participants relationship by conducting 2–3 meetings in a place that was agreed by both. Hence, the participants were relaxed during the interview process. The researcher also cross-checked and compared information with other family members to avoid the Hawthorne effect, which may result in minimal findings [13].

A total of 12 participants were included in this study. Questions to the participants were preceded by an opening question, namely, 'how long have you been caring for your family member who is suffering from a mental illness?' and 'explain to me your experience in the use of mental health services while caring for your family member with a mental health disorder.' Subsequent question explored the perceived barriers and family expectations in caring for family members (health facility, health professional, medication, treatment, universal health coverage, costs and policy). The researchers also made some observations in the form of written field notes after the interview process.

The interview process was carried out until no new themes and data were observed. Interviews were conducted in the room that was provided in the hospitals and recorded. Interview results were written as verbatim transcripts and constructed after each completed interview with one participant.

### 2.3. Data analysis

Data analysis was performed using Colaizzi steps [14], which starts with writing the interview in written form (verbatim). Afterward the verbatim transcript of all of the participants was read repeatedly to identify sentences or words with a particular meaning and provide them with a code based on the similarities and differences. The process also involved explaining the meaning of the significant sentences and collecting and organising the formulation of category descriptions into a collection of themes, which resulted in the validation theme. Categories and themes were extracted from the main idea of the statement and the sentence stated by the participants during the interview process. Data collection was conducted simultaneously with data analysis process until data saturation occurred.

### 2.4. Data validity

The researchers validated the data accuracy by performing two methods of data collection [15], namely, interviews and observations of the participants. Subsequently, they matched that data with the verbatim interpretation of the results among the three researchers. The researchers also returned the transcript of the interview to the participants to validate or clarify things that were not understood.

### 3. Results

This study included 12 participants (Table 1): eight women and four men aged 30–69 years old. The participant's job varied: three housewives, two civil servants, four self-employed, one retired, one person who was a scavenger and one person did not have a job. Most of the participants finished with a high school education level (seven), two participants completed undergraduate education, one person obtained a diploma, one person obtained a Master's degree and one completed secondary school education. Eleven of the participants were Javanese, and one participant was from the Ambon tribe. Eleven participants used Universal Health Coverage and one participant used private health insurance (public). The participants started being a caregiver for the mental health patients in the range of 1–20 years ago. Mothers and fathers with a caregiver role had the mean age (years) of 49.25 and 62, respectively, and their mean caregiving duration was 11.2 years. Sisters and brothers with caregiver roles showed a mean age of 41 and 39, respectively, with the mean caregiving duration of 3 years. Wife and husband with the caregiver role presented a mean age (years) of 38 and 69, respectively, with the mean caregiving duration of 3 years. Grandfather with average age of 67 years provided caregiving role for 2 years. Daughters with mean age of 43 years played caregiving role for 3 years.

The emerging theme was formulated on the basis of the participants' answers to the interview questions and the field notes during the interview process. This study obtained four themes that were explained in order to reflect the purpose of study.

#### 3.1. Mental health services affordability

With regard to the theme of mental health services affordability, distances, transportation means and cost categories were obtained.

Distance hindered the access to mental health services in terms of geographical affordability, as stated by the participants:

*'It is so far away; if I want to come here (psychiatric hospital), I must take a bus of about a 4–5 h drive' (P1);*

*'Hospital is only available here (Surabaya) ... In my district (rural area), there is no mental health hospital so I must come here and must take a long bus ride ...' (P6) (P7);*

*'The closest health centres (puskesmas) are almost 2 h away from my house ...' (P1)*

Other barriers related to mental health service affordability included transportation means, as stated by the participants:

*'To come here from my village is difficult in terms of transportation means ...' (P1)*

**Table 1**  
Demographic data of participants.

No. of participants	Gender	Relationship to patient	Education
1	Female	Mother	No education
2	Female	Mother	Senior high school
3	Male	father	Senior high school
4	Male	Husband	Master Degree
5	Male	Brother	Senior high school
6	Female	Sister	Diploma Degree
7	Male	Brother	Bachelor Degree
8	Female	Daughter	Senior high school
9	Female	Mother	Senior high school
10	Male	Grandfather	Junior high school
11	Female	Wife	Senior high school
12	Female	Mother	Senior high school

In terms of cost as a barrier, participants stated the following:

*'I've spent a lot for the travel costs ....' (P1) (P6)*

#### 3.2. Mental health services availability

With regard to mental health services availability, data collection obtained three categories: health professionals, medicine and the mental health hospital.

For health professionals category, participants stated the following:

*'There was no medical doctor with psychiatric specialization in health centre (puskesmas) (psychiatrists):' (P6)*

*'I'd like to see a psychologist but I do not know where to find it here ....' (P7)*

*'There is not a mental health nurse there, so I should brought him here (mental health hospital):' (P10)*

In the medicine category, participants stated the following:

*'Yaa that's ya ... several medicines were not on the list of insurance coverage ... finally, I have to buy my own.' (P4)*

*'Sometimes, the medicines are not available in the health centre; we have to wait long time to take medicines; sometimes, I have to wait for 2 weeks ....' (P1)*

*'The medicine counters for mental illness patients in health centre are opened on Thursday and Tuesday, that is, two days a week for a limited time of 4 h, which starts from 10 am to 14 pm, and long queued up; when it's closed, the worker asked us to come in the next day ...' (P1)*

In the mental health hospital category, participants stated the following:

*'We found it different between health centre and mental health hospital; in mental health hospital, there were examination, hospitalization and treatment but not in health centre; so it should be a referral to the mental health hospital ...' (P9)*

#### 3.3. Negative attitudes (stigma)

Three categories were obtained for the negative attitude: self, health professionals, and the community.

On the self category, participants stated the following:

*'Yeah, sometimes I feel afraid, because if relapse occurs, he often hit me, and I think that he is dangerous ....' (P11)*

*'I think that he is hard to be told, I say this, and he never likes what I've said ...' (P2)*

*'I ask to talk about something, but it has no connection with my speech (incoherent) .... I can't understand her answer.' (P9)*

*'I have been caring for her in a long time; it's difficult to take care of her and give advice; she is also difficult to be talked to ....' (P12)*

*'Um ... sometimes, I think it's useless to treat or care for him; now, he practically recovered and can be brought home and then he relapse again; he often has relapse ....' (P4) (P5)*

In terms of the health professionals category, participants stated the following:

*'I am just a poor person; sometimes, there is a health professional who looks down to us and speaks to us rudely. I know that not all health professionals are like that, but sometimes they do.'* (P1) (P9)

*'When hospitalized, it will need long duration; there is still no facility to care for basics human need, such as defecation and bathing, so we have to ask or hire other person to care for....'* (P4)

*'Sometimes, the information from nurses or doctors was less clear and less complete.'* (P4)

In the community category, the following statements were presented by the participants:

*'Everybody made a distance from us; no one wants to be close with us.'* (P5)

*'Most people consider us as danger because he acts violently, such as hitting, destroying plants, and talking rudely.'* (P1) (P6)

*'Mostly people do not want to go near us because of scare or afraid to be beaten ....'* (P2)

*'People often do verbal bullying with nicknames of crazy person or insane ....'* (P1) (P2)

#### 4. Discussion

With regard to mental health service affordability, the distance of mental health service hospital was limited and considerably far for some people. Transportation difficulties were also a challenge in reaching health service, especially for participants from rural areas. The transportation costs that must be spent to reach health services were also perceived as barriers by the participants. Five of the participants were from rural areas that were distant from Surabaya. Seven of the participants who lived in Surabaya indicated no barriers related to mental health service affordability. Data were consistent with those of Syed et al. (2014), who stated that rural and urban areas differ in terms of transportation, transportation options, transit cost and availability and distance from the mental health service [16]. Differences in the level of ease of geographical access to the mental health services resulted the difference in additional costs for transportation to the destination place. Barriers related to costs according to four of the participants were in accordance with those of Jack and Uys study regarding financial barriers [17]. Patients' families were familiar with the heavy burden of long-term care and the transportation costs mainly by the families from rural area. Under Law No. 18, Indonesia's free restraint program in 2017 is a government program related to mental health. The program involves all aspects of society, including the head of the village, subdistrict head police and health workers. Village mental health programs should be reactivated to improve the mental illness case findings and the mental health services in the area.

In terms of mental health services and health facility availability categories, some of the participants explained that no psychiatrists, psychologists and nurses with mental health training were available in the health centre. The participants stated that in their home rural area, no health professional with psychiatric speciality was available. The national ratio of the health professionals who work in Indonesia exceeds the ratio recommended by the WHO, which is one physician per 1000 of the population [18]. The number of

health professional workers in Indonesia is increasing in terms of quantity and quality, but the level of the equitable distribution of health professional workers (not limited to general health practitioners and physicians with special expertise) is still lacking. The inequitable distribution of health profession workers with specialised skills results in barriers to accessing mental health services. Other studies also reported unequal distribution of health profession workers, especially when related to the region's policies about the minimal number of health professional workers [19], low salary, lack of facilities and future uncertainty [20]. The uneven distribution of health professional workers is an important issue because it relates to community needs, particularly care in remote areas. Data from the Ministry of Health in Indonesia consists of 87 regions in the 27 provinces (out of a total of 33 provinces) that are lacking in terms of health services [20]. This issue can be addressed by providing health professional workers with adequate skills through training related to the early detection of mental illness, the investigation of people with mental disorders and psychiatric problems and the treatment of people with mental illness. The government also plays an important role related to policies in the region or districts about mental health and the mental health program's sustainability.

Participants also indicated barriers related to the limited medicine for people with mental illness. Some of the participants stated that the medicine stocks for people with mental illness in health centres were low, and the operational hours of taking and providing medicine were limited that is, 4 h (two days a week from 10:00 a.m. to 14:00 p.m.). The medication of people with mental illness is not sold freely in drugstores or pharmacies. Thus, the lack of medication for patients or the family interferes with the prescribed compliance suggested for medication. In addition, we obtained data stating that the number of drugs in health centres for mental illness patients is limited [21,22]. Patients reported a reduced drug stock allocation of only two weeks (the patients can previously access a one-month stock allocation of medicines). Consequently, mental illness patients therefore need to come to the health centre every two weeks [23–25]. Barriers in the schedule and limited operational hours were also observed by Langholz.

Langholz further determined barriers to drug access. Several people are forced to change medication because the medicine is not covered by insurance or universal health coverage. The same case was also expressed by four of the participants who stated that some medications must be purchased at their own expense because they are not covered by the universal health coverage. This observation suggested that although some medical costs can be covered with the insurance, the mental health patients' families and still suffer from other costs associated with the treatment of mental illness, such as transportation. This problem can result in the decreased patient care management [26]. The drug and medicine supplication process is changed in the health facilities by using an e-catalogue and e-purchasing, which exhibit both advantages and disadvantages. One disadvantages is that if the medicines stock is insufficient or not ordered by the e-catalogue or e-purchased previously, then a considerable amount of time is needed to obtain the medicine required for the first time. Patients treatment is not only about taking of medicine. Mental illness problems also include psychosocial disorders. Consequently, treatments also include psychosocial interventions, such as psychotherapy and counseling. The skills of health professional workers in psychological interventions for people with mental illness should be enhanced. Furthermore, family involvement in the treatment of their family member should be increased. Hence, health professional workers should improve their family knowledge and skills.

Other barriers were the negative attitude (stigma) towards people with mental illness. Two participants perceived that the

treatment of their family member who was suffering from a mental illness was ineffective or that no change was observed in the patients after treatment. Consequently, the family or patients decided not to continue the treatment because they considered the mental disorder treatment a failure. Such situation occurs because the stigma can affect someone's behaviour. Several examples of negative perception (stigma) by the community were also stated by five participants. Two participants stated that they suffered from negative experience with their health care workers. Previous study [27,28] results showed that the health workers' attitude showed no difference from that of general society with regard to the associated stigma towards patients with mental illness. Hansson et al. stated that the health professional workers' attitude towards people with mental illness is the most pronounced negative attitude compared with those in other in-patient wards. Research findings [29] also showed that a negative experience with the provider will cause the user to stop the treatment that they are receiving or select another health service for the care of people with mental illness. Stigma in Indonesia is still a considerable problem, which extends towards the families of people with mental illness [30]. Some efforts related to stigma reduction in health care workers, families and the community should be further made. Family knowledge about mental illness should be improved, and positive information about mental illness patients should be provided intensively.

## 5. Conclusion

The present results indicated that the families of people with mental disorders encounter barriers associated with mental health services. Mental health services are centralised in major cities, and the mental health services in rural areas are minimal. To obtain an effective mental health service and reach all places, a government policy related to the equitable distribution of health personnel with special skills and mental health facilities is needed.

## 6. Ethical clearance

This study received a certificate of ethical clearance from Menur Surabaya Hospital No. 423.4/6787/305/2016.

## 7. Study limitation

The interview guidance was developed by the researcher using the access concept developed by Penchansky and Thomas [30] who analysed the five access dimensions: availability, accessibility, affordability, accommodation and acceptability. The interview guide showed limitations. This guide was not tested by experts in a clinical setting (the interview guidance was tested by our supervisor). The sample was selected without any inclusion criteria related with the mental disorder patient, such as illness duration, age, disease severity and origin of the participants (rural and urban). The study cannot investigate family burden because the barrier may differ among participants who come from rural and urban areas.

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