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Heavy Burdens of Family Caregivers Caring for Persons with Severe Mental Disorders

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Abstract

Family caregivers who live with and care for individuals with severe mental disorders face serious issues. This study aimed to investigate the burdens of these family caregivers. This descriptive phenomenological study involved 15 family caregivers who looked after persons with mental disorders in Malang City, Indonesia; the participants were selected using a purposive sampling technique. Data were gathered using individual in-depth interviews and observations, and then analyzed inductively. Based on the findings, the burdens of family caregivers can be grouped into four main themes: 1) families encountered challenges and stigma in caring for persons with severe mental disorders, 2) there was a lack of support from the community and healthcare providers, 3) family caregivers reported experiencing various negative emotions and interpreting negative implications from their caregiving experiences, and 4) family caregivers employed coping strategies to alleviate their burdens. The researchers conclude that family caregivers experience complex burdens when caring for persons with severe mental disorders; hence, family caregivers need the support of healthcare personnel and community presence in situations of caring for persons with chronic mental disorders.

Keywords: burden of disease, caregiver, family, Indonesia, severe mental disorders

Abstrak

Beban Berat Caregiver Keluarga dalam Merawat Orang dengan Gangguan Jiwa Berat. Caregiver *keluarga yang hidup bersama orang dengan gangguan jiwa berat menghadapi masalah yang serius. Penelitian ini bertujuan untuk mengetahui secara mendalam beban para* caregiver *keluarga. Penelitian fenomenologi deskriptif ini melibatkan 15* caregiver *keluarga yang merawat orang dengan gangguan jiwa di Kota Malang, Indonesia; partisipan dipilih dengan teknik* purposive sampling. *Pengumpulan data menggunakan metode wawancara mendalam secara individual dan observasi, serta selanjutnya dianalisis secara induktif. Hasil penelitian menunjukkan bahwa beban* caregiver *keluarga dapat dikelompokkan ke dalam empat tema utama: 1) keluarga menghadapi tantangan dan stigma dalam merawat orang dengan gangguan jiwa berat, 2) kurangnya dukungan masyarakat dan penyedia layanan kesehatan keluarga, 3)* caregiver *keluarga mengalami berbagai perasaan negatif dan memaknai secara negatif pengalamannya, dan 4)* caregiver *keluarga menggunakan strategi koping untuk meringankan beban keluarga. Peneliti menyimpulkan bahwa* caregiver *keluarga mengalami beban yang kompleks saat merawat orang dengan gangguan jiwa berat; oleh karena itu,* caregiver *keluarga sangat membutuhkan dukungan dari tenaga kesehatan dan kehadiran masyarakat sekitar dalam situasi menghadapi situasi perawatan kronis bagi orang-orang dengan gangguan jiwa berat.*

Kata Kunci: *beban penyakit,* caregiver, *gangguan jiwa berat, Indonesia, keluarga*

Introduction

Various studies have highlighted the magnitude of severe mental disorders worldwide. The World Health Organization (WHO) (2020) reported that mental health problems rose by 13% in the decade ending in 2017. Meanwhile, the number of persons with severe mental disorders (PSMD) in Indonesia, where this study was conducted, is also increasing. The prevalence of PSMD in the Indonesian population was 1.7 per thousand people in 2013 (Ministry of Health of the Republic of Indonesia, 2013), which increased to 6.7 per thousand people in 2018 (Ministry of Health of the Republic of Indonesia, 2018). Certainly, this high number translates to a burden for their families, the community, and the country in taking care of PSMD. The Institute for Health Metrics and Evaluation (IHME) (2018) claimed that severe mental disorders contributed to an increase in the years lived with disability (YLD) metric in 2017, while the WHO (2020) stated that mental health problems were one of five causes of rising YLD.

Various treatment options are available for PSMD, but not all recover optimally. Therefore, this situation generates many problems for families and communities. PSMD generates a huge burden for their families (WHO, 2020) because PSMD suffer from various disorders that may affect an array of mental functions. Gupta et al. (2014) mentioned that some mental function problems of PSMD included blunting effects, such as limited facial expressions, vocal intonations, and gestures; a lack of expression; reduced fluency or content of speech and reduced verbal response (alogia); emotional and social withdrawal and a lack of intimacy or relationships (asociality); the inability to feel happy (anhedonia); and reduced personal interest and desire in activities (avolition). These complex problems of PSMD can cause them to be unproductive for long periods and depend on their families, on which they pose a great burden. As a consequence, families can experience embarrassment, annoyance, awkwardness, discomfort, agitation, or frustration (Wankiiri et al., 2013). It is intuitively evident that these great burdens have the potential to reduce families' motivation to care for PSMD.

Previous studies have shown that the burdens of family caregivers caring for PSMD can be highly complex. Asher et al. (2015) revealed that families living with PSMD experienced conflict, difficulty in participating in work and community life, and stigma (e.g., being laughed at and gossiped about, losing friends, and being mistrusted in the workplace or other settings). Yin et al. (2014) found that family caregivers experienced considerable stigma related to social support, patients' educational levels, kinship, and regional or local factors, such as sociocultural conditions. Furthermore, families felt compelled to shoulder an overwhelming burden. Their obligation to care for individuals with PSMD became excessively demanding. Additionally, they grappled with the anguish stemming from disrupted relationships and endured societal stigma and distress (Wirsén et al., 2020). However, prior research delineates these phenomena solely within particular locales in distinct countries, each with differing mental health care systems and diverse sociocultural contexts.

Hence, there is a pressing need for a comprehensive descriptive phenomenological study to delve into the burdens faced by family caregivers of PSMD in Indonesia. Indonesia presents a unique landscape in terms of its mental healthcare system compared to the settings explored in prior research. Notably, Indonesia's mental healthcare infrastructure lags behind other countries in the Asia-Pacific region, characterized by limited funding and technical resources hindering the full implementation of mental health initiatives (Ng, 2018). Most mental health services in Indonesia are provided in tertiary settings, mainly public psychiatric hospitals. However, such hospitals are not evenly distributed in Indonesia (Praharso et al., 2020). Based on our observations, the community mental healthcare system in which the study was conducted has not developed optimally, and as might be expected, this situation has influenced the quality of the community mental healthcare delivery system. In this regard, Samartzis and Talias (2019) stated that the high burden of family caregivers caring for PSMD can be influenced by the quality of the mental healthcare system.

Methods

Design. This qualitative study used a descriptive phenomenological design based on Husserlian phenomenology (Polit & Beck, 2018). This approach is used to formulate a detailed description of a phenomenon, describe the essential structure of the experience involved, and interpret the meaning of the experience according to the participants' perspectives and their impacts on behaviors and beliefs (Polit & Beck, 2018).

Setting and Participants. The participants in this study were 15 (fifteen) family caregivers caring for PSMD (e.g., schizophrenia) in Malang City, Indonesia. The participants were selected using a purposive sampling technique with the following inclusion criteria: 1) family caregivers involved in taking care of PSMD for at least one year, 2) families living together with PSMD, and 3) families willing to participate fully in this study. Recruitment of participants was stopped when data saturation was achieved, that is, when no new categories were identified. This occurred when the 11th participant was interviewed about coping strategies implemented by family caregivers to reduce their burdens. When data saturation was achieved, the researchers recruited four additional participants to confirm the data saturation.

Data Collection. Data collection was conducted by researchers from May to July 2018 through individual in-depth interviews and observations. The in-depth interviews were guided by the following research questions: 1) What challenges are faced by family caregivers in taking care of PSMD?; 2) How do family caregivers attempt to treat PSMD?; 3) How does the community behave toward PSMD and their family caregivers?; 4) How do healthcare providers support PSMD and their families?; 5) What is the meaning of caring for PSMD from the family caregivers' perspective?; and 6) What coping strategies are implemented by family caregivers to reduce their burdens?

Additional questions were asked to add clarity, depth, and quality to the information gathered during the interview and deeply probe the participants' answers. Interviews were conducted with family caregivers without the presence of PSMD. The researchers conducted data collection via the following steps: 1) The participants gave consent for their data to be used in the study by signing a consent sheet; 2) The aims, benefits, risks, processes, and other relevant information about the study were explained; 3) The researchers conducted face-to-face interviews with the participants in the latter's homes. Participants were interviewed for 1–2 hours using the locally spoken Javanese language. Throughout the interviews, besides documenting participants' verbal responses, the researchers also noted their non-verbal cues, recording them in field notes. Additionally, the researchers observed the conditions of both the individuals with PSMD and the environments in which they were cared for. Supplementary information was obtained from participants' neighbors or healthcare volunteers to corroborate their accounts.

The researchers also gathered socio-demographic information from participants, including sex, age, level of education, socio-economic status based on family occupation and income per month according to Statistics Indonesia (*Badan Pusat Statistik* [BPS]), family relations, duration of family experience in caring for PSMD, and major problems in connection with PSMD.

Data Analysis. Data were analyzed using thematic analysis according to the seven steps of Colaizzi's process: 1) listening to the audio recordings, writing transcripts, verifying and correcting inaccuracies; 2) identifying significant statements of participants in the transcripts; 3) formulating restatement of significant statements in general terms; 4) formulating derived meanings of the significant statements; 5) developing themes and organizing them into clusters and categories; 6) generating a detailed description of the experiences; and 7) describing the essential structure of participant's experiences (Polit & Beck, 2018). All researchers participated in interpreting themes based on the participants' statements.

Lincoln and Guba's criteria of trustworthiness, which include credibility, dependability, confirmability, transferability, and authenticity, were fulfilled in this study (Polit & Beck, 2018). To fulfill the credibility criterion, the researchers interviewed and observed participants, submitted notes from these interviews and observations for member checking, examined evidence several times, and explored the data in depth. To fulfill the dependability criterion, the researchers maintained an audit trail of process logs and peer debriefings with colleagues. To establish the confirmability criterion, the researchers kept detailed notes on all decisions and progress analysis. These notes were returned to participants for member checking and reviewed by two experts. The opinions of the experts were integrated into the findings and evaluated in the presentation of the final analysis. To fulfill the transferability criterion, the researchers gave a detailed description of the setting in which each interview was conducted and each participant in the study. Finally, to fulfill the authenticity criterion, the researchers presented the participants' experiences realistically.

Ethical Considerations. The study protocol and informed consent sheet were approved by the University Research Ethics Committee (No. LB.02.01/1.2/2224/2018). This study was also approved by the Malang City Government (No. 072/507.04.P/35.73.406/2018).

Results

Table 1 shows that the age of participants ranged from 32 to 69 years. Most participants had an education level equivalent to an elementary school level. Most were of lower socioeconomic status. Most families had been taking care of a person with a severe mental disorder for more than 10 years. Furthermore, the most frequent major problems of the PSMD were aggressive behavior and hallucination.

Thematic analysis identified four themes regarding the burdens of family caregivers caring for PSMD. Details are presented in Table 2.

Theme 1: The Families Faced Challenges and Stigma in Caring for PSMD. The families faced many challenges and stigma associated with mental illnesses. This theme was developed from the following four subthemes:

The families invested much effort in treating the PSMD. The families' challenges in treating the PSMD included investing much effort in obtaining treatment for them, including referring them to priests, traditional healers, or shamans. When the condition of PSMD did not improve, their families referred them to primary healthcare centers, general hospitals, or mental health hospitals. This is exemplified by the following participant's statement:

> *"We went to an alternative therapist; we took him to a 'Kyai' (an Islamic priest). But for now, they need medicines only from Public Health Services."* (P1)

The families had to fulfill the psychological needs of the PSMD. The families' challenges in caring for the PSMD included fulfilling the latter's psychological needs, such as remaining patient, paying more attention, and fulfilling all of their requests. As one participant said,

> *"We attempted to persuade him when we requested him to take a bath; we had to give him a cigarette first. We had to be calm, not angry; we had to be patient."* (P14)

The families had to fulfill the physical needs of the PSMD. The families' challenges in caring for the PSMD included fulfilling the physical needs of the PSMD, such as providing and preparing food, water, clothes, bathing, sanitation, and addressing other physical needs. As one participant stated:

> *"We built a toilet in his room so our son could take a bath by himself. Besides this, we prepared his food and [made him wear] clothes. We gave him meals three times a day. We prepared a chamber pot and cleaned up his feces."* (P3)

The families faced stigma from the people around them. Another burden in caring for PSMD for families was facing stigma from the people around them. People isolated and avoided them. According to one participant:

> *"People ridiculed him; as his parent, sometimes, I wanted to die. Oftentimes, people said that my son was an abnormal person."* (P1)

Theme 2: Lack of Community and Healthcare Provider Support for Family Caregivers. Most family caregivers encountered a lack of support from the community and healthcare providers in facing chronic care situations. This theme was generated from the following two subthemes:

Lack of community support. The family caregivers experienced a lack of community support. Few people supported family caregivers in facing severe care situations. Only some neighbors understood the condition of the PSMD. Several people avoided interacting with the PSMD, as is evident from the following statement by a family member:

> *"Only several people feel pity ... only some neighbors understood and realized our situation. Several people avoided interacting with my son; they felt afraid."* (P15)

Table 1. Characteristics of Participants

	Sex	Age (years)	Level of Education	Socio-economic status	Family relation	Years of caring experience	Major problems of PSMD
P1	Female	33	Elementary School	Middle	Sister	25	Aggressive behavior
P2	Female	54	Elementary School	Middle	Mother	25	Aggressive behavior
P3	Male	63	Elementary School	Lower	Father	16	Social isolation
P4	Female	57	Elementary School	Lower	Mother	14	Delusion of control
P5	Female	65	Elementary School	Lower	Mother	13	Aggressive behavior
P6	Male	32	Elementary School	Lower	Brother	3	Aggressive behavior
P7	Male	55	Elementary School	Lower	Husband	20	Social isolation
P8	Male	45	Senior High School	Lower	Son	28	Social isolation
P9	Female	60	Elementary School	Lower	Mother	18	Hallucination
P10	Male	65	Junior high School	Lower	Father	18	Hallucination
P11	Female	69	Elementary School	Lower	Mother	25	Hallucination
P12	Male	50	Senior High School	Lower	Brother	25	Hallucination
P13	Female	53	Elementary School	Lower	Wife	28	Aggressive behavior
P14	Female	56	Elementary School	Lower	Wife	5	Aggressive behavior
P15	Female	32	Senior High School	Lower	Daughter	5	Aggressive behavior

Table 2. Thematic Analysis of Findings

Themes	Subthemes	Keywords of the participants' statements
The families faced challenges and stigma in caring for PSMD.	The families invested much effort in obtaining treatment for the PSMD.	We brought him to an alternative therapist. We referred him to a traditional healer. We referred her to a shaman. We referred him to the hospital.
	The families had to fulfill PSMD's psychological needs	We tried to persuade him. We had to be calm. We should not be angry. We had to be patient. We should understand him. The family should pay attention. The family should do their best.
	The families had to fulfill PSMD's physical needs.	Building a special toilet. Preparing foods. Preparing clothes. Preparing a chamber pot. Cleaning feces.
	The families witnessed the PSMD facing stigma from people around.	The people ridiculed him. People oftentimes said "abnormal." My neighbors lack understanding. People avoided him.
Lack of community & healthcare provider support for family caregivers	Lack of community support	Only several people felt pity. Only several neighbors realized. Only some neighbors understood us. Several people avoided him.
	Healthcare providers did not support the PSMD optimally	In the hospital, my son almost died. Healthcare providers never visit here. My son never gets treatment from a primary health center.
Family caregivers experienced various negative feelings and inferred negative meanings in caring for the PSMD	The families experienced negative feelings.	It is hard. Feeling tired. Feeling sad. Feeling up and down. Feeling desperate. Feeling angry. Feeling bored. Feeling embarrassed.
	The families inferred negative meanings from their experiences	We have committed a lot of sins. He was under the influence of witchcraft. An evil spirit possessed my son. Black magic is involved. He is under the control of magic power.
Families coping strategies to reduce their burdens	Maladaptive coping	We brought him to a shaman. We never give him medicine. We secluded him. We restrained him.
	Adaptive coping	It is a test from God. We still have an optimistic feeling. It is a training of patience. It is a fate from God. We return to "almighty God."

Healthcare providers did not support PSMD optimally. Some of the families felt that healthcare providers had not optimally supported PSMD in the community. There were some PSMD who never received medication or healthcare services during the period that they suffered from mental illness, and families complained that the hospitals had not treated them well. A participant said:

> *"Healthcare personnel from the public health center never visit here, so my family [member] never gets medicines. In the hospital, my husband almost died; we requested to be picked up from the hospital. He went back home in bad condition: he was very thin, with only skin and bones left."* (P10)

Theme 3: Family Caregivers Experienced Various Negative Feelings and Inferred Negative Meanings from Caring for PSMD. Various negative feelings and meanings were expressed by family caregivers regarding caring for PSMD. This theme was developed from the following subthemes:

The families experienced negative feelings. Some of the families experienced negative feelings when caring for PSMD, such as feeling tired, bored, sad, etc. A participant said:

> *"My feelings [fluctuate]; sometimes, I despair... It is a long journey; there are many bad feelings, such as despair, anger, boredom, and tiredness; maybe anyone else would also feel the same."* (P4)

The families inferred negative meanings from their experiences. Several family caregivers inferred negative meanings associated with their experiences in caring for PSMD, including believing that they were suffering because they had committed a lot of sins or that the PSMD was under the spell of witchcraft or influenced by black magic. Two participants said:

> *"Maybe he is under [the spell of] witchcraft because his father married again."* (P9)

> *"My husband had [been under the influence of] black magic... sometimes he was good, and sometimes he was bad; he was powerlessly in control of this magic power."* (P11)

Theme 4: Family Caregivers Employed Coping Strategies to Reduce Their Burdens. There were two types of coping strategies employed by family caregivers to reduce their burdens. This theme was developed from two subthemes:

Maladaptive coping strategies. Some of the family caregivers demonstrated maladaptive coping strategies, such as referring the PSMD to traditional healers or religious leaders. Most families did not provide medicine and secluded or restrained the individual. As one participant said:

> *"We went to an alternative therapist; we took him to a 'Kyai' (an Islamic priest). We also secluded or restrained him, like in jail, because we were afraid my brother would run away."* (P1)

Adaptive coping strategies. As a positive response, some of the family caregivers showed adaptive coping strategies to reduce their burdens by viewing their problem as a test from God, feeling optimistic, and believing that their family members with mental disorders would be able to recover. Some also viewed their experience as training in maintaining patience or as a fate sent from God, while others surrendered their problems to "almighty God." In addition, some attempted to seek help from other family members and neighbors. These findings are exemplified in the following participant's statement:

> *"This is my test to serve my parents. I do not complain, feel bored, or feel burdened; I think it must be treated by love... I return it to almighty God."* (P7)

Discussion

The current study found that family caregivers caring for PSMD had complicated burdens. This finding is congruent with the study by Fekadu et al. (2019), who revealed that the multidimensional impacts on family caregivers included physical health problems (e.g., sleeplessness, headache, and extreme tiredness), psychological difficulties (e.g., depression), and socioeconomic problems (e.g., reduced likelihood of marrying, a higher divorce rate, and greater food insecurity). Ntsayagae et al. (2019) reported that family caregivers experienced the burden of the responsibility of caregiving, emotional effects, the hardship of administering support needs, and changed perspectives. Additionally, Akbari et al. (2018) discovered that family caregivers reported lacking support for their own needs, receiving no assistance when they experienced burnout, experiencing low levels of social support, and bearing the burden of care alone. Wirsén et al. (2020) found that family caregivers were burdened by their family members' illnesses, disrupted relationships, distress, and social stigma. Yu et al. (2017) stated that the most significant burden on families was the financial burden. Similarly, Chen et al. (2019) found that family caregivers experienced the imposition of a heavy financial burden in caring for family members. This burden has reportedly increased for families dealing with low incomes or unemployment, making it difficult for them to meet basic daily needs, such as clothing and food. In addition, Rezaei et al. (2020) found that caregivers faced interpersonal problems, role conflicts, stress, and constant anxiety in life.

The current study also found that families faced social stigma, resulting in isolation and avoidance. Yin et al. (2014) found that families with a member with a serious mental disorder faced stigma and discriminatory experiences in daily life related to social support, kinship, the educational level of the person with the disorder, and regional factors. Furthermore, Akbari et al. (2018), Lautenbach et al. (2012), and Wirsén et al. (2020) reported that family caregivers experienced high levels of social stigma, which significantly contributed to reducing families' participation in social interactions. Ngubane et al. (2019) found that families living with PSMD were rejected and segregated from society, discriminated against at work, and experienced discriminatory professional attitudes and seclusion.

The findings of this research revealed a lack of community support in terms of understanding chronic care situations. Few individuals felt empathy, understanding, insight, or acceptance toward individuals with PSMD; thus, their integration into social activities was hindered. This absence of community support places the responsibility on families to facilitate the reintegration of PSMD into mainstream society. This finding is congruent with the study by Lautenbach et al. (2012), who revealed that families with children with mental illnesses experienced a lack of acceptance and support from the community. Moreover, Clibbens et al. (2019) found that caregivers struggled to cope with their emotional conflicts and people's behavior toward them. In this regard, prior research has posited that the community can play a greater role. Chen et al. (2019) stated that health education and mutual support groups can be organized by the community, thereby creating opportunities for family caregivers to communicate with others, to increase their own knowledge, and to alleviate the psychological pressure on themselves.

The study found that some families felt that healthcare providers had not optimally handled PSMD, resulting in ineffective treatments arranged by families for PSMD that tended toward maltreatment. Families failed to provide regular medication, and most tried to obtain treatment for PSMD via traditional or alternative therapists. Similarly, Knaak et al. (2017) found that healthcare providers tend to take a pessimistic view of reality and the possibility of recovery; this attitude, which was found to be caused by the inadequate skills and training of healthcare providers, was a potential source of stigma and a barrier to the recovery of mentally ill people. This perspective results in anxiety or fear and a desire for social distancing toward mentally ill people. Clibbens et al. (2019) asserted that family caregivers need professional continuity across service transitions and that there is a requirement for delivering training to family caregivers concerning information sharing and a clearer understanding of the barriers to the implementation of family and other interventions to address family caregivers' emotional needs.

This study's findings show that most of the family caregivers experienced negative feelings and inferred negative meanings from their experiences in caring for PSMD. Most earlier studies have also similarly reported that family caregivers experienced negative feelings and inferred negative meanings. Chang et al. (2018) found that the experience of family caregivers with PSMD included encountering sorrow, conversing with sorrow, and living with sorrow. The study showed that the coping strategies of family caregivers to reduce their burdens were of two types: maladaptive and adaptive. Similarly, Rahmani et al. (2019) found that family caregivers of PSMD used more maladaptive coping strategies, including avoidance, coercion, and resignation. Adaptive coping strategies used by family caregivers include gathering information, seeking social support, and trying to implement problem-solving approaches are adaptive (Pompeo et al., 2016).

Limitation. The researchers were unable to observe the family caregivers' experiences of caring for PSMD for a whole day and were therefore unable to comprehend the lived situation in detail. However, to address this limitation, the researchers obtained additional information to confirm other lived experiences of participants, in particular, from their neighbors and health field volunteers around the participants.

Conclusion

This study found that the burdens of family caregivers caring for PSMD in Indonesia are highly complex and include four themes: 1) the families faced many challenges and stigma associated with mental illness, 2) there was a lack of community and healthcare provider support for family caregivers, 3) the family caregivers experienced various negative feelings and inferred negative meanings while caring for PSMD, and 4) the family caregivers employed coping strategies to reduce their burden. These findings suggest a growing need to strengthen mental health services in Indonesia. Families need healthcare personnel to train and educate them on caring for PSMD. This would help reduce caregivers' burdens and the social stigma related to mental illness. PSMD need to be treated with respect and dignity so they may eventually be reintegrated into mainstream society. Finally, there is a need to enhance community empowerment and participation in this context, and the quality of community mental health services must be re-evaluated.

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