



Systematic Review

Family Burden for the Caregivers of People with Mental Disorders: A Systematic Review**Aplonia Nenobais, Atika Jatimi and Muh Jufriyanto**

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ABSTRACT

Introduction: The main caregivers of people with mental disorders are their family members. Families as the caregivers of people with mental disorders is associated with a significant burden. This systematic review aims to identify and summarize the main focus based on the scientific evidence about family burden as the caregivers of people with mental disorders.

Methods: The databases used were Scopus, Science Direct and Sage Journal with the keywords 'burden', 'family', 'caregiver', 'mental', 'health', 'illness', 'disorder' and they were limited to 2014 – 2018 from within nursing and health science journals. One hundred and four full text articles were reviewed. The 14 articles that fulfilled the inclusion criteria were analyzed using narrative synthesis followed the Joanna Briggs Methodology model for the Qualitative Systematic Review to find the main themes of each article.

Results: Seven main themes were found to be related to family burden as the caregivers of a family member with mental disorders. The 7 themes were knowledge, emotional burden, physical burden, medication, financial burden, social burden, health services and government support.

Conclusion: The findings suggest that the family burden on the caregivers was diverse and that this has an effect on the ability of the family to care for patients with mental disorders. Family burden has become an important indicator for the provision of mental health services.

ARTICLE HISTORY

Received: Dec 26, 2019

Accepted: Dec 31, 2019

KEYWORDS

family burden; caregivers; mental disorder

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Cite this as: Nenobais,A., Jatimi, A., & Jufriyanto, M. (2019). Family Burden for the Caregivers of People with Mental Disorders: A Systematic Review. *Jurnal Ners*, 14(3si), 26-34.
doi:[http://dx.doi.org/10.20473/jn.v14i13\(si\).16971](http://dx.doi.org/10.20473/jn.v14i13(si).16971)

INTRODUCTION

Family members are the main caregivers of people with mental illness. Family plays an important role in caring for people with mental disorders such as monitoring their mental state and treatment, accompanying them to a hospital or clinic, offering emotional support and helping them with their finances. The family also plays a significant role in making sure that the patient adheres to the treatment while tolerating changes in patient behavior such as aggressiveness (Venkatesh, Andrews, Parsekar, Singh, & Menon, 2016). People with chronic mental disorders generally live with their families (Bademli, Lök, & Kılıç, 2017). The patients' families are the major source of support and caregiving for psychiatry

patients and most of the patients live with their families. Being a caregiver is something that cannot be chosen or planned, so the caregivers are required to be able to adapt to these situations. This situation causes the other family members to experience the feeling of being burdened (Kizilirmak & Küçük, 2016). Caring for people with mental disorders with other routine activities makes the family members as caregivers experience negative experiences and consequently this leads to substantial stress or burden. Constant stress or burden has a negative effect on the physical, psychological and social health of the caregivers, and the caregivers must adjust to the situation (Venkatesh et al., 2016).

Studies on caregivers living with mental illness patients have found that they experience high levels

of burden. Caregiver burden, especially tension, is associated with the caregivers' use of maladaptive coping strategies, poor quality of life and higher levels of psychological morbidity (Bademli et al., 2017). Family burden is also related to tradition and culture (Von Kardorff, Soltaninejad, Kamali, & Eslami Shahrababaki, 2016). In addition, stigma and discrimination against mental health problems not only affects people with mental disorders but it also burdens the family (Varghese, Pereira, Naik, Balaji, & Patel, 2017).

The purpose of this study was to explore and summarize the caregivers' burdens when related to people with mental disorders. The specific research question was: 'Based on qualitative research literature, how does the family as the caregivers of people with mental disorders describe their burden?'

MATERIALS AND METHODS

This systematic review is a narrative synthesis following the Joanna Briggs Methodology (JBI) model for Qualitative Systematic Review (The Joanna Briggs Institute, 2014). Qualitative Evidence Synthesis (QES) integrates the findings from qualitative studies by finding existing themes. The JBI methodology allows the researchers to answer a specific research question through reviewing the evidence in a systematic manner.

The databases used were Scopus, Science Direct and Sage Journal with the keywords "burden, family, caregiver, mental, health, illness and disorder". Furthermore, the inclusion and exclusion criteria were determined to find eligible articles. The inclusion criteria were that they had to be qualitative or mixed methods studies with a standalone qualitative piece, full text articles published in English and within the last five years (2014 – November 2018). The exclusion criteria were that the caregivers were not family members, that the articles were without direct quotes, that the articles were published in any other language and outside of the last five years or they were not available online. Unpublished or grey literature, abstracts, theses, dissertations, books and conference summaries were excluded. See on Figure 1.

After searching the literature with the keywords, we found 382 articles in the Scopus database, 435 articles in Science Direct and 403 articles in Sage Journal. In total, 585 potential articles met the criteria, 336 articles were similar, and 249 articles matched the criteria. After selecting the abstracts, 145 articles were deemed to be irrelevant and inaccessible. Finally, 104 full articles were selected, 89 were excluded and the remaining 14 articles fulfilled the inclusion criteria.

Extracting and synthesizing the data from the selected study used a summary table containing the data of the author, the year of publication, country, purpose, the method of data collection and the method of the data analysis. The results of the study

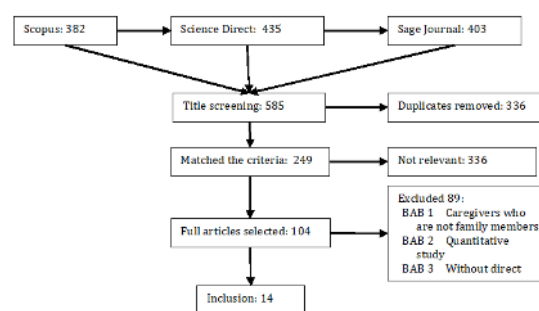


Figure 1. Search tree diagram

were then synthesized by categorizing each theme that was found.

RESULTS

According to the review of the selected studies, seven main themes were found to be related to family burden as the caregivers of the family member with a mental disorder. The seven themes were knowledge, emotional burden, physical burden, medication, financial burden, social burden, health services and government support.

Insufficient knowledge

Insufficient knowledge about the treatment of people with mental disorders makes the family as the caregivers always wonder when the patients will recover and they were confused about the patients' constantly changing behavior (Fitryasari et al., 2018; Krupchanka et al., 2018). The majority of the caregivers did not have enough information about the disease or the treatment (Von Kardorff et al., 2016).

When I faced this illness, I did not know about the illness. I did not know what I should do. I did not know what schizophrenia is about (Von Kardorff et al., 2016).

...but even when he recovered, he relapsed again, our family does not understand this disease (Schizophrenia) (Fitryasari et al., 2018)

...He (first-born son) decided that schizophrenia is infectious. So, he is careful and does not keep in touch with X at all (Krupchanka et al., 2018).

In addition, a lack of information is caused by the absence of information from the nurses and doctors about the disease (Ebrahimi et al., 2018; Von Kardorff et al., 2016).

No one has ever spoken to me about my daughter's illness or explained anything to me yet. I don't understand what is going on. They (health care team) are always too busy to give me an opportunity to share my problems with them (Ebrahimi et al., 2018).

Emotional burden

An emotional burden is felt by almost all family members such as sadness and shame due to the uncontrolled patient behavior, fearing that the patients can be harmful to the environment and

worrying about the future of the patients. This can make the emotional burden of the family increase (Fitryasari et al., 2018; Krupchanka et al., 2018; Tlhowe et al., 2017).

...I'm afraid he will hit me or damage the house ...when he relapses ... He can go out without wearing clothes, go anywhere ... as his mother, I am very ashamed ...I feel annoyed almost every day, and when I can't stand it, I hit her (patient) (Fitryasari et al., 2018). My sister was

undressing in the street and this was really embarrassing, I could not even walk freely at the mall (Tlhowe et al., 2017)

I feel anxious now when I am talking about that because they started avoiding me because they were afraid (Krupchanka et al., 2018).

Emotional burdens also make the family blame themselves, lose hope and worry about the future (Fitryasari et al., 2018; Krupchanka et al., 2018). The caregivers also think that the patients can only

Table 1. Joanna Briggs Institute- check list for qualitative research

Criteria		Dicé, Federico, & Zoena (2017)	Fitryasari, Yusuf, Nursalam, Tristiana, & Nihayati (2018)	Hernandez and Barrio (2015)	Krupchanka et al. (2018)
1	Is there congruity between the stated philosophical perspective and research methodology?	Yes	Yes	Yes	Yes
2	Is there congruity between the research methodology and the research question or objectives?	Yes	Yes	Yes	Yes
3	Is there congruity between the research methodology and the methods used to collect data?	Unclear	Yes	Yes	Yes
4	Is there congruity between the research methodology and representation and analysis of data?	Yes	Yes	Yes	Yes
5	Is there congruity between the research methodology and interpretation result?	Yes	Yes	Yes	Yes
6	Is there a statement locating the researcher culturally or theoretically?	Yes	Yes	Yes	Yes
7	Is the influence of the researcher on the research, and vice-versa, addressed?	Yes	Yes	Yes	Yes
8	Are participants, and their voices, adequately represented?	Yes	Yes	Yes	Yes
9	Is the research ethical according to current criteria or, for recent studies, is there evidence of ethical approval by an appropriate body?	Unclear	Yes	Yes	Yes
10	Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Yes	Unclear	Unclear	Unclear
Total		8	9	9	9

Criteria		Mccann, Bamberg, & Mccann (2015)	Radfar, Ahmadi, and Fallahi Khoshknab (2014)	Radfar et al. (2014)	Tristiana et al (2018)	Varghese, Pereira, Naik, Balaji, & Patel (2017)
1	Is there congruity between the stated philosophical perspective and research methodology?	Yes	Yes	Yes	Yes	Yes
2	Is there congruity between the research methodology and the research question or objectives?	Yes	Yes	Yes	Yes	Yes
3	Is there congruity between the research methodology and the methods used to collect data?	Yes	Yes	Yes	Yes	Yes
4	Is there congruity between the research methodology and representation and analysis of data?	Yes	Yes	Yes	Yes	Yes
5	Is there congruity between the research methodology and interpretation result?	Yes	Yes	Yes	Yes	Yes
6	Is there a statement locating the researcher culturally or theoretically?	Unclear	Unclear	Yes	Yes	Yes
7	Is the influence of the researcher on the research, and vice-versa, addressed?	Yes	Yes	Unclear	Unclear	Yes
8	Are participants, and their voices, adequately represented?	Yes	Yes	Yes	Yes	Yes
9	Is the research ethical according to current criteria or, for recent studies, is there evidence of ethical approval by an appropriate body?	Yes	Yes	Yes	Yes	Unclear
10	Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Yes	Yes	Yes	Yes	Yes
Total		9	9	9	9	9

Table 1. Joanna Briggs Institute- check list for qualitative research (Continue)

Criteria	Venkatesh et al (2016)	Von Kardorff, Soltaninejad, Kamali, & Eslami Shahrababaki (2016)	Ebrahimi et al (2018)	Gater et al. 2014)	Prevo et al. (2018)
1 Is there congruity between the stated philosophical perspective and research methodology?	Yes	Yes	Yes	Yes	Yes
2 Is there congruity between the research methodology and the research question or objectives?	Yes	Yes	Yes	Yes	Yes
3 Is there congruity between the research methodology and the methods used to collect data?	Yes	Yes	Yes	Yes	Yes
4 Is there congruity between the research methodology and representation and analysis of data?	Unclear	Yes	Yes	Yes	Yes
5 Is there congruity between the research methodology and interpretation result?	Yes	Yes	Yes	Yes	Yes
6 Is there a statement locating the researcher culturally or theoretically?	Yes	Yes	Unclear	Yes	Yes
7 Is the influence of the researcher on the research, and vice-versa, addressed?	Unclear	Yes	Yes	Unclear	Yes
8 Are participants, and their voices, adequately represented?	Yes	Yes	Unclear	Yes	Yes
9 Is the research ethical according to current criteria or, for recent studies, is there evidence of ethical approval by an appropriate body?	No	No	Yes	Yes	Unclear
10 Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Yes	No	Yes	Yes	No
total	7	9	8	9	8

depend on them (Dicé et al., 2017; Von Kardorff et al., 2016). Concern about the patients' current and future condition is because the family feels powerless to control the future, even though they know that they have to consider the patients as people who have the right to live as they wish. The families are still worried about the inability of the patients to have normal lives (Gater et al., 2014; Radfar et al., 2014).

I will not be here forever (Krupchanka et al., 2018)

Every moment, I can't escape thinking of him ... his future, his fate ... (Fitryasari et al., 2018).

...he always needs somebody to help him, to care for him, and to give him affection, warmth, attention. Because if he's left alone even 5-10 minutes, he panics, freaks out... (Dicé et al., 2017)

I can't go anywhere. I can't go on a trip. I must always accompany her and look after her. Whenever I go out, I have to come back early (Von Kardorff et al., 2016).

The family expressed their concern about the future of their members with mental disorders. The families also felt worried about who will take care of the patients if they died (Radfar et al., 2014).

What if I die! Who will take care of her? I worry about compliance with the medication. I worry about her ability to be independent in future... (Radfar et al., 2014).

Concerned about them being raped, the family members had to take their female members with mental disorders with them whenever they left home. In addition, cognitive problems and social interaction

problems cause abuse. This is considered to be contrary to religious and cultural doctrine (Radfar et al., 2014).

She went to the park. Instead of sitting on the bench, she laid on the grass. This is not a good behavior for a girl (Radfar et al., 2014).

For a spouse, being depressed because of changes in the relationship made the partner feel like a widow (Mccann et al., 2015).

I have depression. I don't want to admit it to myself that I was depressed and I was eating like a 'horse' (eating excessively). I put on a lot of weight, because I just sat in front of the TV, eating. Leaving my husband depresses me more because he is mentally and physically ill and he doesn't respond (to me) anymore (Mccann et al., 2015).

Treatment burden

They also feel burdened because of the long lasting treatment (Dicé et al., 2017) and because of the difficulty in managing the treatment according to time and the patient's condition (Von Kardorff et al., 2016)

He doesn't take his drugs on time or puts it under his tongue and then throws it out. I have big problems with medication adherence with my patient (Von Kardorff et al., 2016).

The treatment of mental patients is often late due to stigma in society. Families are habitually in denial of having a family member who is mentally ill (Venkatesh et al., 2016).

Table 2. Study characteristics (Country, title & purpose)

Author (year)	Country	Title	Purpose
Dicé, Federico, & Zoena (2017)	Italy	Loneliness and Family Burden: An Exploratory Investigation on the Emotional Experiences of Caregivers of Patients with Severe Mental Illness	To conduct a descriptive investigation into the needs of the caregivers of patients with severe mental illness (SMI) referring to a mental health service
Fitryasari et al. (2018)	Indonesia	Family members' perspective of family Resilience's risk factors in taking care of schizophrenia patients Rizki	Conducted to illustrate the risk factors of family resilience when taking care of patients with schizophrenia.
Hernandez and Barrio (2015)	Amerika Serikat	Perceptions of Subjective Burden Among Latino Families Caring for a Loved One with Schizophrenia	To explore the perceptions of subjective burden among Latino family members providing care for a loved one with schizophrenia
Krupchanka et al. (2018)	Republik Ceko	Experience of stigma and discrimination in families of persons with schizophrenia in the Czech Republic	Explores the practice of stigma and discrimination in families with schizophrenia
Mccann, Bamberg, & Mccann (2015)	Australia	Family carers' experience of caring for an older parent with severe and persistent mental illness	To understand the lived experience of the primary caregivers of older people with severe and persistent mental illness, and to explore what, if anything, helps to sustain them in their caring role.
Radfar, Ahmadi, & Fallahi Khoshknab (2014)	Iran	Turbulent life: the experiences of the family members of patients suffering from depression	To explore and describe the experiences of the family members of patients suffering from depression on the impact of provision of care to the patients.
Tlhowe, du Plessis, & Koen (2017)	South Africa	Strengths of families to limit relapse in mentally ill family members	To explore and describe the strengths of family members in assisting mental health care users to limit relapses
Tristiana, Yusuf, Fitryasari, Wahyuni, & Nihayati (2018)	Indonesia	Perceived barriers on mental health services by the family of patients with mental illness	To identify the perceived barriers on mental health services by families whose members suffers from mental illness.
Varghese, Pereira, Naik, Balaji, & Patel (2017)	India	Experiences of stigma and discrimination faced by family caregivers of people with schizophrenia in India	To describe the experiences of stigma and discrimination of people living with schizophrenia (PLS) in three sites in India and to identify factors influencing negative discrimination
Venkatesh, Andrews, Parsekar, Singh, & Menon (2016)	India	Stigma and mental health- caregivers' perspective: A qualitative analysis	To understand the perception of caregivers of mentally ill patients
Von Kardorff, Soltaninejad, Kamali, & Eslami Shahrababaki (2016)	Jerman	Family caregiver burden in mental illnesses: The case of affective disorders and schizophrenia – a qualitative exploratory study	To explore the specific burdens experienced by caregivers of patients with schizophrenia and affective disorders.
Ebrahimi et al (2018)	Iran	Barriers to Family Caregivers' Coping With Patients With Severe Mental Illness in Iran	To explore the barriers to coping with people who have severe mental illness as perceived by their family caregivers.
Gater et al. (2014)	Amerika Serikat	"Sometimes It's Difficult to Have a Normal Life": Results from a Qualitative Study Exploring Caregiver Burden in Schizophrenia	To investigate the subjective experiences of caregivers of people with schizophrenia as a means of understanding "caregiver burden" in this population
Prevo et al. (2018)	Belanda	Exploring Informal Caregivers' Views on Their Perceived Burden	To explore information about relationship factors, positive effects of caregiving, and coping strategies as factors influencing the physical or mental burden that caregivers perceive

Physical burden

A physical burden is also experienced by the family due to more time needing to be devoted to taking care of the patients. They do not have time to rest and there is a lack of social interactions (Fitryasari et al. 2018; Tristiana et al. 2018). The caregivers also feel very tired, lose energy and often have sleeping disorders (Von Kardorff et al., 2016). Chest pain and increased blood pressure are also felt by the caregivers (Hernandez & Barrio, 2015). Having the responsibilities associated with being caregivers,

they often suffer from chronic physical and mental fatigue (Prevo et al., 2018; Radfar et al., 2014).

I have been affected by thousands of somatic pains, such as backache, headache, lumbar disc and leg pains (Von Kardorff et al., 2016).

High blood pressure...at times I feel a pain in my chest. I know that it is due to the sadness that I have, the pressure (Hernandez & Barrio, 2015). *I don't remember such a day as I'm tired today. I feel really tired* (Radfar et al., 2014).

I feel it in my body... bending, lifting and even moving are all becoming more difficult (Prevo et al., 2018).

Table 3. Study characteristics (design, data collection method & data analysis method)

Author (year)	Design	Data collection method	Data analysis method
Dicé, Federico, & Zoena (2017)	Phenomenological approach	Semi-structured interview	Thematic-categorical analysis
Fitryasari, Yusuf, Nursalam, Tristiana, & Nihayati (2018)	Phenomenological approach	Semi-structured interview	Thematic-categorical analysis
Hernandez & Barrio (2015)	Grounded theory approach (Glaser and Strauss 1967; Strauss and Corbin 1990)	Open-ended section of the Family Burden Interview Schedule (FBIS; Pai and Kapur 1981)	Data were sorted and coded using the qualitative software program ATLAS.ti, version 7
Krupchanka et al (2018)	Phenomenological approach Hermeneutics,	Semi-structured in-depth interviews	Thematic analysis
Mccann, Bamberg, & Mccann (2015)	phenomenology, and idiography (Smith et al. 2009).	Semi-structured, audio-recorded interviews were	Interview transcripts were analyzed in accordance with the IPA approach outlined by Smith and Osborn (2008).
Radfar, Ahmadi, & Fallahi Khoshknab (2014)	Phenomenological approach	Unstructured interviews	content analysis approach
Tlhowe, du Plessis, & Koen (2017)	Phenomenological design	Unstructured interviews	Thematic analysis
Tristiana, Yusuf, Fitryasari, Wahyuni, & Nihayati (2018)	Phenomenological design	Semi-structured in-depth interviews.	Thematic analysis
Varghese, Pereira, Naik, Balaji, & Patel (2017)	Mixed methods	In-depth-interviews	Thematic analysis
Venkatesh, Andrews, Parsekar, Singh, & Menon (2016)	Phenomenological approach	In-depth interview	Manual thematic content analysis
Von Kardorff, Soltaninejad, Kamali, & Eslami Shahrababaki (2016)	Grounded theory	Semi-structured interviews	Deductive and inductive content analysis
Ebrahimi et al (2018)	Phenomenological approach	Semi-structured, in-depth interviews	Four step qualitative content analysis method; Graneheim and Lundman (2004)
Gater et al. (2014)	Grounded theory	Semi structured, qualitative interviews	Qualitative analysis software package (Atlas. Ti)
Prevo et al. (2018)	Phenomenological approach	Semi-structured interviews	Interpretative phenomenological analysis approach

Financial burden

The financial burden is also felt by the family. A lot of money is needed for medical expenses including education, regular visits to the health care centers, transportation costs to the hospitals, food, and for their daily needs (Fitryasari et al., 2018; Gater et al., 2014; Tristiana et al., 2018; Von Kardorff et al., 2016).

We should sell our motorbikes, sometimes sell our bird collection ... Yes, for treatment for him (patient), his meals and daily needs ... (Fitryasari et al., 2018).

I've spent a lot for the travel costs ... (Tristiana et al., 2018).

Well, financially, because, um, sometimes we need people to, uh, to stay with her, to watch her, you know, medical bills for certain things at times (Gater et al., 2014).

Families need high financial support because the patients cannot live independently (Krupchanka et al., 2018).

The financial situation is not good. I would say that without the help of relatives, we could not live in... We know that many of our friends with mental disorders still live with their parents, they do not have enough money to become independent... (Krupchanka et al., 2018)

Social burden

Social burden as a stigma does not only come from the community but it can also come from the closest members of the family. They do not get support including visits from other family members, neighbors or relatives (Fitryasari et al., 2018; Tristiana et al., 2018; Von Kardorff et al., 2016). Stigma and discrimination are the heaviest burdens, so much so that they often trigger another family burden (financial, physical or emotional) (Krupchanka et al., 2018).

Mostly people do not want to go near us because of being scare or they are afraid of being beaten

...

The stigma experienced by the families is categorized into four types: labeling, stereotyping, separation and discrimination. Labeling hurts the family because the people with mental disorders are called "madman" and they cannot be cured. Stereotypes come from other people's opinion that the patients can hurt others. Separation is when the neighbors keep their distance from them. The families are discriminated against because they cannot join in with social activities due to unpredictable behavior of the patients (Fitryasari et al., 2018).

The neighbor sometimes calls him (patient) ... "madman" (labeling) (Fitryasari et al., 2018).

People often do verbal bullying with nicknames of crazy person or insane... (Tristiana et al., 2018).

His behavior is sometimes strange ... all day sitting on the edge of the trench in front of the house while daydreaming... When he relapses ... he will be dangerous, sometimes uncontrollable (stereotype) (Fitryasari et al., 2018).

Neighbors who do not dare come here (to the house)... afraid of him (separation) (Fitryasari et al., 2018).

We are rarely invited to public events, if invited, they (neighbor) always order us to come alone, and that my father (patient) should stay at home (discrimination) (Fitryasari et al., 2018).

Negative comments and actions from the public and their extended family as well as criticism and the beliefs about the cause of the disorder adds to the family burden (Dicé et al., 2017; Hernandez & Barrio, 2015; Prevo et al., 2018).

People hear schizophrenia is a mental illness, and run away. They just run away (Dicé et al., 2017)

The families as the caregivers also felt avoided by society. The families that have members with mental disorders felt separated from the community, with the patients unable to get the right treatment and at the right time. It is not as easy to visit a psychiatrist as it is to visit a cardiologist (Venkatesh et al., 2016).

...every person should have freedom to say boldly 'I am visiting a psychiatrist' like how they say, without any hesitation, that I am visiting a cardiologist (Venkatesh et al., 2016).

Health service and government support

Problems related to the health services and government support are strongly felt by the families including insurance, transportation and the distance to the health services (Ebrahimi et al., 2018; Krupchanka et al., 2018; Tristiana et al., 2018; Von Kardorff et al., 2016). Distant health care means that the families spend more money on transportation. The unavailability of medication and psychiatric help as well as mental health nurses in the Community Health Centers means that the family have to travel a considerable distance to the hospital (Tristiana et al., 2018).

I'm the one who should manage all of these. Who would help me out? The government doesn't help. The hospital doesn't care how to provide care for my husband. No help, no advice ... nothing ma'am, nothing. There is no support when we are in crisis. I perceive myself as being abandoned in the caregiving role (Ebrahimi et al., 2018).

We found it different between the health centre and mental health hospital; in the mental health hospital, there were examinations, hospitalization and treatment but not in the health centre; so there should be a referral to the mental health hospital... (Tristiana et al., 2018).

DISCUSSION

The lack of knowledge about the disorder and treatment has been illustrated in three of the studies reviewed. A lack of information about mental disorders makes the caregivers more anxious. Sufficient knowledge can reduce caregiver anxiety and emotional burden. The knowledge of patient care and treatment can improve family self-efficacy. Studies conducted by (Durmaz & Okanli, 2014) show that family burden decreases when family self-efficacy is improved.

The families of patients suffering from mental disorders have the symptoms of emotional burden. Financial problems, stigma, family support, governmental and society factors are closely related to the emotional burden of the family. This was confirmed by the quantitative study conducted by (Alzahrani, Fallata, Alabdulwahab, Alsafi, & Bashawri, 2017) which showed a feeling of tension, anxiety and rush experienced by the caregivers. The quantitative study by (Kizilirmak & Küçük, 2016) showed that 67.49% caregivers are at risk of experiencing depression and anxiety and that 43.3 % of caregivers are at a high risk of depression and anxiety. Emotional burdens such as being impatient, feeling guilty, feeling shameful and feeling sinful are also shown in the quantitative studies by (Alzahrani et al., 2017). The study conducted by (Zanetti et al., 2018) shows that an increase in family emotional expression increases the family burden significantly. They also have feelings of shame and low self-esteem. Most family caregivers are embarrassed because the community often looks down on and insults their family members who are suffering from a mental disorder (Azman, Jamir Singh, & Sulaiman, 2017).

The physical burden experienced by the caregivers is caused by the amount of time spent caring for the patient. The physical burden becomes higher when it is associated with the amount of time spent caring for the family members (Alzahrani et al., 2017). Other quantitative studies described that the time spent treating patients with mental disorders was between 4-8 hours a day (Mulud & McCarthy, 2017) and 16-17 hours a day (Zanetti et al., 2018). Other studies (Dicé et al., 2017) showed that the caregivers' burden increased if the intensity of contact with the patients increased. In addition, more time devoted to taking care of the patients reduces the social interactions of the caregivers (Mulud & McCarthy, 2017).

The financial burden described in 4 studies reviewed showed that financial burden is caused by the complete dependency of the patients on their caregivers. Many caregivers do not have a job because they have to take care of the patient. The loss of productivity caused by the patients with mental disorders has an impact on the financial burden of the family. The burden of caregivers who experience financial problems is higher than those who do not experience it (Kizilirmak & Küçük, 2016). The economic burden experienced by families was

claimed (Agboola, Esan, Afolabi, & Soyinka, 2018) in his study conducted in Nigeria. This indicates that the families are responsible for financing the care of people with mental disorders (68%) and that only 4% of respondents were financed by insurance. Finances are also needed to fulfill the patients' basic needs such as buying clothes and diapers for one's parents with mental disorders (Azman et al., 2017).

Social burden, in this case stigma and discrimination, is illustrated by all studies of the reviewed. Stigma is the social burden felt by families. Stigma damages family and community relations (Park & Seo, 2016). Stigma and discrimination are the heaviest burden that is faced by the families. It leads to an emotional and physical burden for the caregivers. Studies conducted (Chai, Mahadevan, Ng, Chan, & Md Dai, 2018) showed a significant relationship between stigma and depression in the caregivers. The study conducted by (Varghese et al., 2017) highlights the need for interventions that address the family needs such as providing knowledge about schizophrenia, which can affect the stigmatization process both positively and negatively. Educational interventions need to consider more specific contextual factors when choosing the anti-stigma messages that are to be delivered. This study shows that messages such as "recovery is possible" and "no one is blamed" might be more useful for reducing stigma than for focusing on bio-medical knowledge.

Problems related to government support and the availability of health services were revealed in 4 of the studies. The study concluded (Nurjannah, Mills, Park, & Usher, 2015) that institutional policies are important in the process of treating mental disorders. Legal rules are needed to protect the human rights of mental disorder caregivers.

LIMITATION

Some of the articles found were not relevant to the problem of family burden as caregivers because some of the journal articles that supported the review were inaccessible. In addition, the articles used only represent twelve countries with the largest number of participants in the qualitative study being 64 people.

CONCLUSION

The burden of the family as the caregivers of people with mental disorders is very diverse and it has an effect on the ability of the family to treat patients with mental disorders. Family burden has become an important indicator for the provision of mental health services. Cultural differences in each country affect the burden experience by each family as caregivers. Families need support when caring for patients. Families as caregivers need service and support for their own mental and physical health so then they are able to maintain their nurturing role.

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