



Family Burden of Schizophrenic Individuals in Asia: Review

Sheilla Varadhila Peristiano^{1,2} Subandi², Muhana Sofiati Utami²

¹ *Mercu Buana University of Yogyakarta, Yogyakarta, Indonesia*

² *Gadjah Mada University, Yogyakarta, Indonesia*

Corresponding Author: Sheilla Varadhila Peristiano, sheilla@mercubuana-yogya.ac.id

ARTICLE INFO

Submitted: May 13th, 2022

Accepted: July 24th, 2022

Published: September

15th, 2022

KEYWORDS

responsibility, burden,
family, schizophrenic.

ABSTRACT

This review aims to understand the evidence of factors and impacts on the family burden in caretaking families of schizophrenic individuals in Asia. The family burden is a problem commonly found in many families worldwide, especially those of schizophrenic individuals among family members. Schizophrenic individuals portray specific and severe symptoms, having a particular impact on the caretaking family. Responsibility for taking care of the schizophrenic individual makes the family feel either a subjective or objective burden. As a global issue, the family burden is closely related to the cultural context of each country. Values passed on for generations certainly influence individuals' attitudes and behaviour, including dealing with family burdens. The current review uses the scoping review step to discover psychological models in the family burden of caretaking families of schizophrenic individuals and is limited to Asia only. The inclusion criteria using the Populations, Concept, and Context (PCC framework). Populations for this review are families with schizophrenic family members, the Concept is the family burden or caregiver burden, and the Context is narrowed down to Asian countries. The exclusion criteria are the caregiver of individuals with mental illness, living in countries outside Asia, focusing on relapse models in non-family member schizophrenic individuals, speaking languages other than English and Bahasa Indonesia, and articles issued outside 2000 - 2020. There are five steps of methods in the current scoping review: (1) identifying the research question by PCC, (2) identifying the evidence, (3) study selection, "charting the data" (extracting the evidence), (4) data synthesis based on critical issues narratively, and (5) collating, summarizing and reporting the results. The results showed that the family's experience while caring for the schizophrenic individual is related to the family burden. The family burden is physical, psychological, emotional, social experiences, and financial problems that the family goes through because of their responsibility in caring for the schizophrenic individual.

INTRODUCTION

Schizophrenia is a psychotic disorder with hallucination as its specific symptom. Uhlhass and Mishara (Arksey & O'Malley, 2005) stated hallucination as a particular symptom of schizophrenia. Hallucination emerged as an impact of existing disorder in the cognitive or thinking process, which disturbed the affective process and triggered behaviour inconsistency. Maramis (Bademli, Lök, & Kılıç, 2018) explained that schizophrenic individuals showed disorder in cognitive processes through misperception and disturbance in the affective process. Therefore, schizophrenic individuals need proper

pharmacotherapy and psychotherapy treatments to de-escalate the symptoms. De-escalation of the symptoms is indeed a sign of recovery.

Recovery for schizophrenic individuals is influenced by treatments, caretaking, and family members' guidance (Durand & Barlow, 2006) This affirms that the caretaking family plays an essential role in recovering schizophrenic individuals. Such roles and responsibilities bring about subjective and objective burdens (Huang, Lam, Plummer, & Cross, 2021) The subjective burden includes emotional reactions of the family, such as amoral, negative perception, anxiety, dan depression. The objective burden includes physical activities impacting the family's behaviour and social life. Huang et al. (Jalaluddin, 2005) added that family burden triggered psychological attributes, such as feeling stressed, isolated, fatigued, and worried.

Recovery for schizophrenic individuals is seen not only from symptoms of de-escalation but also from the family condition (Janardhana, Raghevendra, Naidu, Prasanna, & Chenappa, 2018) Letting schizophrenic individuals participate in daily activities and social relationships can signify a low family burden. On the other hand, productive and social behaviour that schizophrenic individuals show also leads to recovery. The family that feels less burdened helps schizophrenic individuals to recover.

The burden is described as a physical, psychological, emotional, social and financial experience of caring for sick family members, either mental or physical illness (Roy et al., 2016)The importance of this research is due to the family burdens related to some psychological condition models, which can be concluded as the impact of family involvement in taking care of schizophrenic individuals. However, the family burden also plays a role in the recovery of schizophrenic individuals.

The family burden became a global issue closely related to the cultural context of each country. Some previous research showed a relationship between culture and family burden. Wai and Chan (Leff & Vaughn, 1984) conducted literature reviews that concluded that family burden was a global issue influenced by each country's culture. The family burden is perceived differently in each country, depending on the local socio-cultural context. Social norms, especially empathy, are dominant in the life principles of Asian countries, making individuals hold their parts and responsibilities in keeping a well-balanced social life with other people. This also means that families of schizophrenic individuals have the role and responsibility to practice kindness and empathy in taking care of schizophrenic individuals.

Taking care of schizophrenic individuals may bring about a specific family burden, yet there are local cultural norms that direct the role and responsibilities of the caretakers to remain kind and empathetic are the issues of this review. Further comprehension is needed to discuss family burdens related to cultural Context. Therefore, this scoping review helps discover research mind-map related to family burden in taking care of schizophrenic individuals from Asia's local cultural Context. In order to map previous research on this topic, researchers need to conduct such reviews to understand more about the factors and impacts of family burden in caretaking families of schizophrenic individuals in Asia.

Some previous systematic reviews on the family burden in families of schizophrenic individuals have been conducted globally. This affirms that further discussion on family burden is essential, especially in determining and mapping related psychological models. Parija et al. (Maramis & Maramis, 2009) explained that there might be some burden that the family experienced while taking care of a schizophrenic family member, and this burden impacted the family's emotional expression (Munn et al., 2018) Most families experiencing family burden showed passive, submissive behaviours toward schizophrenic individuals (Nevid, Rathus, & Greene, 2005) Those passive, submissive behaviours were related to the research culture in Turkey. Passive, submissive behaviours are thought to be a sign of respect toward other people.

Having a schizophrenic individual among family members means having more responsibilities at hand. These responsibilities are influenced by family dynamics and expectations from the local culture. For instance, for Taiwanese ethnicity and empathy are essential. Therefore, when families give up taking care of the schizophrenic individual, the country will blame them (Parija et al., 2016)This encourages

families to give their best to help the recovery of a schizophrenic family member. As Wai and Chan (Puspitasari, 2017) mentioned previously, the family burden in the caretaking family of schizophrenic individuals is perceived differently according to the cultural context of where the families reside. In China, the family burden is a stigma and closely related to the lack of rehabilitation and health service due to families' financial difficulties. In Asian countries, social norms such as empathy and respecting others are essential in their way of life, making them hold tight to their role and responsibilities in keeping well-balanced relationships with other people, including those with psychological issues.

Differences in culture and norms result in differences in perceiving family burden. That is why it is essential to map succeeding psychological models related to family burden without putting aside the Cultural Context of the country, as for this review, Asian countries. Mapping psychological models are based on family burden factors and impacts on caretaking families of schizophrenic individuals. This review establishes the current understanding of the factors and impacts influencing family burden in caretaking families of schizophrenic individuals.

LITERATURE REVIEW

Schizophrenia and the schizophrenic family

(Popay et al., 2006) explain that schizophrenia is a persistent psychotic disorder that includes disturbances in behaviour, emotions, and perceptions. The same opinion by Durand and David (Rafiyah, 2011) explains that schizophrenia is a violent psychotic disorder that can involve typical disturbances in thinking (Sczufca & Kuipers, 1996) perception (Sczufca & Kuipers, 1998) speech, emotions, and behaviour. (David, 2004) Nevid, Rathus, and Greene (Uhlhaas & Mishara, 2007) direct the notion of schizophrenia disorder as a disturbance in cognitive function (thoughts) that results in damage to affective functions (Chan, 2011) and behaviour.

Individuals with schizophrenia are at high risk not because of their psychosis but because of demoralization. Many acute and more dramatic symptoms go away with time, but chronic schizophrenia requires protection or spends years in a mental hospital. Involvement with the law for minor offences is expected (Young, Murata, McPherson, Jacob, & Vandyk, 2019) and is often associated with drug abuse. A small proportion of individuals with schizophrenia become dementia, and their overall life expectancy is shortened mainly due to accidents, suicide, and the inability to care for themselves (Cerqueira & Oliveira, 2002) This causes conflict in the family, especially among the parents of schizophrenic individuals. Family members can react negatively to other family members who have schizophrenia by showing a confused, angry, do not understand, hostile, overprotective attitude. If the schizophrenic family does not support it by showing excessively expressed emotions (EE), for example, schizophrenic individuals are often scolded or restrained by excessive rules, then the likelihood of schizophrenic relapse will also be greater (Leff, 2014).

Schizophrenic family issues

The family has an essential and functional role in treating and recovering individuals with schizophrenia. The existence of functional and role demands makes the family feel burdened by the condition of individuals with schizophrenia. Families who live side by side dealing with individuals with schizophrenia feel a burden. The family burden arises because of the role and responsibility of a family for schizophrenic individuals. The obligation to carry out family roles and functions raises psychological burdens (subjective and objective) that affect family attributes, including not providing support, not providing treatment, feeling depressed, tired, isolated, and worried about the future (Huang et al., 2021). The role of the family is huge in the recovery process of individuals with schizophrenia, starting from providing knowledge, attention, support, and preparing for roles in society, as well as modifying the environment.

Four situations experienced by families during coexistence with schizophrenic individuals are described, among others 1) as obligations, 2) functioning functionally, 3) having many challenges, and 4) living under pressure (Huang et al., 2021). This shows that when families deal with individuals with schizophrenia, they experience a psychological burden described by living conditions under pressure. Pressure is defined as a burden on the family.

The family burden causes various family psychological conditions in dealing with schizophrenic individuals in various family actions or behaviours that do not lead to recovery. Psychological or behavioural conditions that arise because of the burden, among others, make the family not know the condition and treatment of individuals with schizophrenia, negative perceptions, displaying high EE (Emotional Expression), lack of empathy, and do not support individuals with schizophrenia. The burden experienced by the family affects the EE of families who have schizophrenic family members (Sczufca & Kuipers, 1996; 1998; Thara et al., 1998).

METHODOLOGY

This scoping review uses existing literature to comprehend family burden factors and impacts in taking care of schizophrenic individuals in Asian countries. Scoping review has research questions with a broader range of sciences and data tracking, depending on the chosen issue and main topic. The current scoping review uses methods from (Arskey & O'MalleyO'Malley, 2005) with a methodology consisting of five steps: 1) identifying research questions and inclusion-exclusion criteria, 2) searching and identifying any relevant studies and evidence, 3) screening those studies or evidence, selecting studies or evidence for more detailed analysis, and extracting the evidence, 4) mapping data based on previously determined vital concepts, and 5) concluding findings from chosen studies or evidence.

The first step in the current scoping review is defining questions to direct the review: "What are the factors and impacts of family burden in caretaking family of schizophrenic individuals in an Asian country?". **The second step** is consulting and discussing reference search with the reviewer team to determine search terms, identify relevant databases, and organise review protocol. The team chose a few terms extracted from the research question and expanded on these terms to put together a comprehensive search list. Review questions are constructed using PCC (Population, Concept, and Context) (Munn et al., 2018). Populations for this review are families with schizophrenic family members, the Concept is the family burden or caregiver burden, and the Context is narrowed down to Asian countries. Those search terms are "schizophrenia", "schizophrenia disorder", combined with "caregiver burden", "caregiver", "family" and "in Asia".

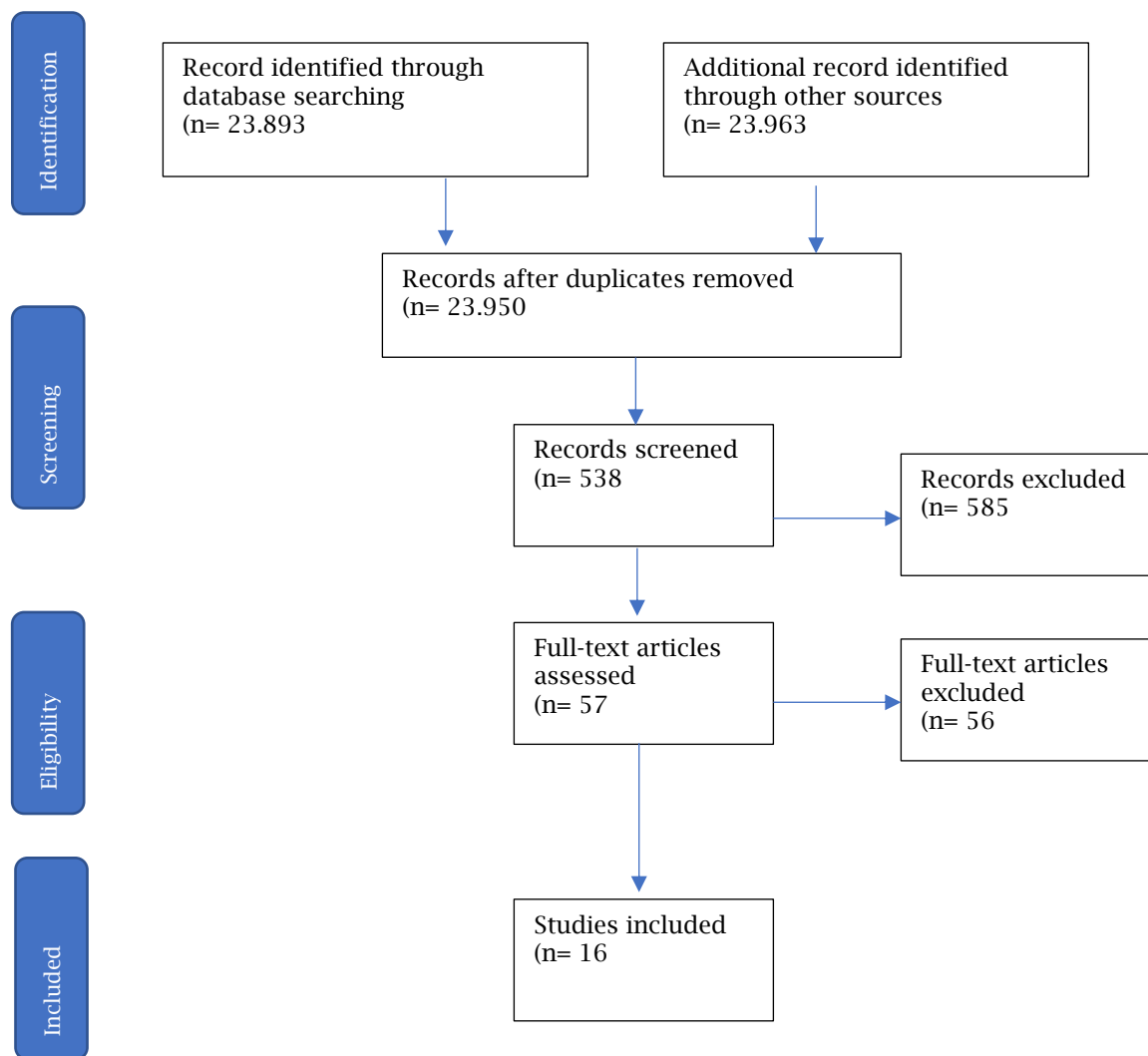
Inclusion and exclusion criteria are essential requirements to create a list in a scoping review and title screening, composing abstract and full-text later on. The title of this review is relevant to the issue chosen, which is a family burden or caregiver burden in the caretaking family of schizophrenic individuals. The abstract screening will be adjusted to specific criteria. Inclusion criteria are a family or caregiver of schizophrenic individuals, currently living in Asia, caregiver burden, orientation in the recovery of schizophrenic individuals, speaking both English and Bahasa Indonesia, quantitative and qualitative articles, and articles issued within 2000 - 2020. On the other hand, exclusion criteria are the caregiver of individuals with mental illness, living in countries outside Asia, focusing on relapse models in non-family member schizophrenic individuals, speaking languages other than English and Bahasa Indonesia, and articles issued outside 2000 - 2020.

The third step begins with the reviewer team independently screening all titles and abstracts of every study identified via an online literature search. The limitation is constructed based on the inclusion criteria mentioned earlier. This review only studies families or caregivers of schizophrenic individuals living in Asian countries, experiencing family burden and psychological models related to a family burden, and having an orientation in the recovery of schizophrenic individuals. The screening process uses reference manager software tools and Mendeley and Rayyan online review management tools. These tools

help the reviewer maintain and manage the screening flow and rules while also helping in resolving the conflicting literature reviewed by the team. If the studies match the chosen criteria, especially related to factors and impacts of caregiver burden, those studies are examined and extracted.

The fourth step is synthesizing the studies and sorting each study according to critical topics, leading to mapping those key topics. Key topics are adjusted to the factors and impacts of family burden. Afterwards, data are synthesized and sorted according to key topics that have been categorized to present a narrative (Arskey & O'MalleyO'Malley, 2005). Data synthesis will be using narrative synthesis, synthesizing findings from a few research articles using the textual approach to describe, review and explain article findings (Popay et al., 2006). Narrative synthesis consists of three steps: 1) developing a preliminary synthesis of findings of included studies, 2) Exploring relationships in the data 3) Assessing the robustness of the synthesis (Leamy et al., 2011). The primary purpose of this scoping review is to identify the breadth of literature in this area of study and whether there are any gaps in service identified within the subject matter.

The fifth step is concluding the findings from the whole study process. The conclusion will be presented narratively according to the critical issue and topics from the literature study. Findings may be in the form of concept mapping from several literature studies related to psychological models of family burden. The findings will be presented in tables or concept network maps to provide a visual representation.



RESULTS AND DISCUSSION

Result

Some of the themes found in the search related to the family burden of schizophrenia are the role and function of the family, various experiences, factors that influence the family burden, and the impact of the perceived burden.

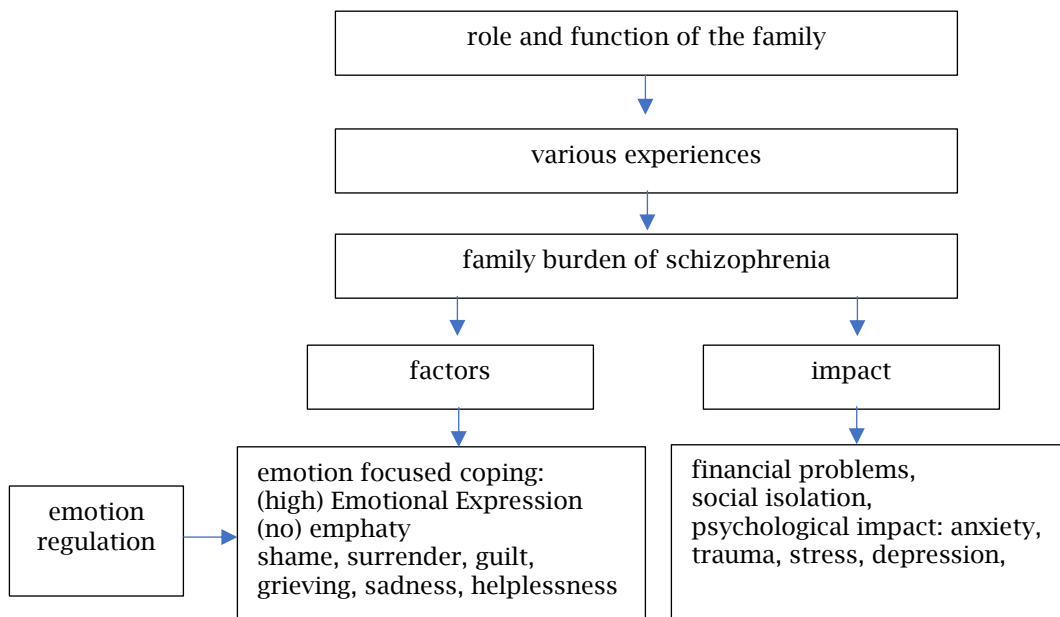
Family roles and functions include family responsibilities for the condition of schizophrenia. Family as the direct support or support (providing financing, attention, affection, security, sense of belonging); EE; prepare for roles in society; provide an explanation of the disorders & benefits of the drug; positive perception; know & support treatment; recognize, understand, adapt, care for, and modify the environment.

Experience during accompanying schizophrenia, among others, cognitively: namely in the form of negative perceptions, stigma on schizophrenia, pessimism, negative self-image, thinking of "losing" the previous schizophrenic individual. Affectively in the form of feelings of shame, surrender, guilt, grieving, sadness, helplessness, pain, depression, worry about the future, loneliness, frustration, overwhelmed, and suffering.

In the form of behaviour in self-harm, aggressive behaviour is not involved in therapy. Socially: namely withdrawing and avoiding. Other experiences related to financial experiences, decreased physical health, and family difficulties in accessing mental health.

Factors that affect the burdened family, among others, internally: maladaptive coping; emotion-focused (stress situations remain the same, high emotional expression, no empathy); avoidance behaviour skills (dishonest, avoid). Externally: demographic conditions of the family, duration of treatment of individuals with schizophrenia, the severity of schizophrenia, and local culture.

The impact is financial problems, social isolation, and a decrease in daily functions in life—psychological impact (in the form of anxiety, stress, trauma, depression).



Discussion

Experiences while working with people with schizophrenia are associated with a variety of responses to control, anger, and acting in people with schizophrenia or with social areas. In line with Zarit, Reever, and Beck-Peterson (1980), the family burden is an experience felt by the family in the form of

physical, intellectual, angry, social, and financial experiences because of the responsibility in dealing with the family body that is physically or psychologically ill.

All matters in the family as a form of responsibility to deal with people with schizophrenia. The urge, role, and responsibility to carry out their position and function as a family dealing with people with schizophrenia creates a burden (Huang et al., 2021). Family roles and functions include family responsibilities for the condition of schizophrenia. Family as the direct support or support (providing financing, attention, affection, security, sense of belonging); EE; prepare for roles in society; provide an explanation of the disorders & benefits of the drug; positive perception; know & support treatment; recognize, understand, adapt, care for, and modify the environment.

The impact while dealing with schizophrenia is financial problems, social isolation, and decreased daily functions in life—psychological impact (in the form of anxiety, stress, trauma, depression). Rafiyah and Sutharangsee (2011) defined burden as the negative effect of caring for people who face obstacles. The weight is in the form of what is felt by the family in its activities (objective burden) or feelings (individual or subjective weight) which relates full of emotions, physical health, social life, and financial status (Rafiyah & Sutharangsee, 2011). The objective burden is in the form of physical health facing depreciation. On the other hand, the individual subjective burden is from angry and irritated family responses.

Wai and Chan (2011) explain that Asian countries, dominated by social numbers by highlighting empathy as a principle of life, resulting in the people of that country having a position of responsibility, protecting balanced and good ties with others. The family has a number religiosity that is strong enough in itself as a result of this which makes the family remain relieved of what has to do with the situation of the schizophrenic person. Religiosity relates to family religious experience. Religious experience is a feeling factor in understanding religion, namely the feelings that lead to religion obtained by the action of (Jalaluddin, 2005).

CONCLUSION

The existence of living and dealing with individuals with schizophrenia is related to the demands and functions that must be carried out as a family. These demands, functions, and roles lead to a series of financial, physiological, and psychological experiences (in the form of cognitive, emotional, and social) during living with schizophrenia. This is interpreted as a family burden. Internally, the family burden is influenced by maladaptive coping and emotion-focused coping. Emotion-focused coping during dealing with schizophrenia includes escape avoidance, distancing, and self-blame.

Meanwhile, emotion-focused coping is influenced by the significant role of emotion regulation (reappraisal and suppression); it includes empathy (skills)-self-control, self-awareness, emotional expression, social support, and religiosity. Therefore, it is very related that when the family handles schizophrenia that arises as a family burden, this is influenced by how the regulation of family emotions as emotion-focused coping. Emotional regulation involves a series of empathy (skills)-self-control, self-awareness, and emotional expression influenced by religiosity and culture.

CONFLICT OF INTEREST

The authors declare that they have no conflict of interest.

ACKNOWLEDGMENT

Special thanks to Mrs. Ika Febrian as a supervisor in this paper publication. We also thank our university to support academic facilities. Last but not the least we would like to thanks our family and friends for the constant source of inspirations.

REFERENCES

- Arksey, Hilary, & O'Malley, Lisa. (2005). Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology*, 8(1), 19-32.
- Bademli, Kerime, Lök, Neslihan, & Kılıç, Ayten Kaya. (2018). The relationship between the burden of caregiving, submissive behaviors and depressive symptoms in primary caregivers of patients with schizophrenia. *Archives of Psychiatric Nursing*, 32(2), 229-234.
- Cerqueira, Ana Teresa de Abreu Ramos, & de Oliveira, Nair Isabel Lapenta. (2002). A Support Program for Caregivers: A Therapeutic and Preventive Action in the Health Care of the Elderly. *Psicologia Usp*, 13(1), 133-150.
- Chan, Sally Wai chi. (2011). Global perspective of burden of family caregivers for persons with schizophrenia. *Archives of Psychiatric Nursing*, 25(5), 339-349.
- David, A. Tomb. (2004). Buku Saku Psikiatri. *Buku Kedokteran EGC, Jakarta*.
- Durand, V. Mark, & Barlow, David H. (2006). Intisari psikologi abnormal. *Yogyakarta: Pustaka Pelajar*.
- Huang, Chongmei, Lam, Louisa, Plummer, Virginia, & Cross, Wendy M. (2021). Feeling responsible: Family caregivers' attitudes and experiences of shared decision-making regarding people diagnosed with schizophrenia: A qualitative study. *Patient Education and Counseling*, 104(7), 1553-1559.
- Jalaluddin, Psikologi Agama. (2005). *PT Raja Grafindo Persada*. Jakarta.
- Janardhana, N., Raghevendra, Guru, Naidu, D. M., Prasanna, Lakshmi, & Chenappa, Thippanna. (2018). Caregiver perspective and understanding on road to recovery. *Journal of Psychosocial Rehabilitation and Mental Health*, 5(1), 43-51.
- Leff, Julian, & Vaughn, Christine. (1984). *Expressed emotion in families: Its significance for mental illness*. Guilford press.
- Maramis, Willy F., & Maramis, Albert A. (2009). *Catatan ilmu kedokteran jiwa edisi 2*. airangga university Press.
- Munn, Zachary, Peters, Micah D. J., Stern, Cindy, Tufanaru, Catalin, McArthur, Alexa, & Aromataris, Edoardo. (2018). Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. *BMC Medical Research Methodology*, 18(1), 1-7.
- Nevid, J. S., Rathus, Spencer A., & Greene, B. (2005). Pengantar psikologi abnormal. *Jakarta: Penerbit Erlangga*.
- Parija, Seema, Yadav, Arun Kumar, Sreeraj, V. S., Patel, Ashok Kumar, Yadav, Jyoti, & Jain, Rakesh Kumar. (2016). Caregiver burden and expressed emotion in caregivers of patients with schizophrenia. *Journal of Psychosocial Rehabilitation and Mental Health*, 3(2), 83-87.
- Popay, Jennie, Roberts, Helen, Sowden, Amanda, Petticrew, Mark, Arai, Lisa, Rodgers, Mark, Britten, Nicky, Roen, Katrina, & Duffy, Steven. (2006). Guidance on the conduct of narrative synthesis in systematic reviews. *A Product from the ESRC Methods Programme Version*, 1(1), b92.
- Puspitasari, Emilia. (2017). Faktor Yang Mempengaruhi Kekambuhan Orang Dengan Gangguan Jiwa. *Jurnal Perawat Indonesia*, 1(2), 58-62.
- Rafiyah, Imas. (2011). Burden on family caregivers caring for patients with schizophrenia and its related factors. *Nurse Media Journal of Nursing*, 1(1), 29-41.
- Roy, Laurence, Crocker, Anne G., Nicholls, Tonia L., Latimer, Eric, Gozdzik, Agnes, O'Campo, Patricia, & Rae, Jennifer. (2016). Profiles of criminal justice system involvement of mentally ill homeless adults. *International Journal of Law and Psychiatry*, 45, 75-88.
- Scazufca, Marcia, & Kuipers, Elizabeth. (1996). Links between expressed emotion and burden of care in relatives of patients with schizophrenia. *The British Journal of Psychiatry*, 168(5), 580-587.
- Scazufca, Marcia, & Kuipers, Elizabeth. (1998). Stability of expressed emotion in relatives of those with schizophrenia and its relationship with burden of care and perception of patients' social functioning. *Psychological Medicine*, 28(2), 453-461.

- Uhlhaas, Peter J., & Mishara, Aaron L. (2007). Perceptual anomalies in schizophrenia: integrating phenomenology and cognitive neuroscience. *Schizophrenia Bulletin*, 33(1), 142-156.
- Young, Lisa, Murata, Lisa, McPherson, Christine, Jacob, Jean Daniel, & Vandyk, Amanda Digel. (2019). Exploring the experiences of parent caregivers of adult children with schizophrenia: A systematic review. *Archives of Psychiatric Nursing*, 33(1), 93-103.