The Effectiveness of Psychoeducation in Managing Caregiver Burden in Schizophrenia Caregivers

Laurentius Sandi Witarso[a], Sali Rahadi Asih[b], and Dharmayati Utoyo Lubis[c]

[a]*Faculty of Psychology, Universitas Indonesia, Depok, Indonesia;* [b]*Department of Clinical Psychology, Faculty of Psychology, Universitas Indonesia, Depok, Indonesia;* [c]*Department of Clinical Psychology, Faculty of Psychology, Universitas Indonesia, Depok, Indonesia*

*Corresponding author:
Sali Rahadi Asih
Department of Clinical Psychology
Faculty of Psychology, Universitas Indonesia
Jl. Lkr. Kampus Raya, Depok, Jawa Barat
Indonesia, 16424
Tel.: +62 217270004
Email address: sali.rahadi@ui.ac.id

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Abstract- People suffering from schizophrenia are limited in daily function and working ability, thus making them unproductive and requiring assistance to meet their daily needs. The assistance is usually provided by an informal caregiver. Living with a person with schizophrenia is very stressful and can lead to caregiver burden, a burden borne by the individual who helps family members with a chronic illness. Studies have found that families with low-income status tend to experience high caregiver burden because they lack sufficient resources such as money, knowledge, and skills. Psychoeducation is a way that can be used to mitigate the lack of knowledge and skills in the caregiver. However, there is a lack of documented intervention in managing caregiver burden, particularly for people on low incomes in Indonesia. This study aimed to employ psychoeducation for schizophrenia caregivers to help them manage their caregiver burden. This study consisted of three participants, all female (average age: 50 years old) with low-income status. Participants joined the intervention, which consisted of seven sessions, each of which lasted around 90 minutes. A pre-test, post-test, and a two weeks' follow-up test were administered. Quantitative data were obtained by using the Zarit Burden Interview, Hopkins Symptom Checklist-22, and a General Health Questionnaire, while qualitative data were obtained by interview and observation. Quantitative data indicated a decrease in caregiver burden and psychological distress at the conclusion of the intervention, compared to pre-intervention. Qualitative data showed that participants can better understand how to cope with patients, reduce stress, and take care of themselves at the end of the intervention.

Keywords: Psychoeducation, caregiver burden, schizophrenia, low-income, psychology

Introduction

People with Schizophrenia (PWS) are individuals who suffer mental disorders in thought, emotions, and behavior (Kring, Johnson, Davison, & Neale, 2010). They have symptoms such as delusions, hallucinations, a lack of interest in establishing social relationships and low motivation to carry out daily routine activities. Most importantly, they experience a decreased ability to understand reality. Data from the World Health Organization in 2010 show that more than 26 million people in the world experience schizophrenia (WHO, 2010). The symptoms of disturbances experienced by PWS make their role and job functions decrease so that they become unproductive (Jusuf, 2006). They need assistance to meet their daily needs. People who are able to take care of and fulfill the needs of people who are sick or unable to take care of themselves are termed caregivers (Kasuya, Polgar-Bailey, & Takeuchi, 2000). In some Asian countries, approximately 70% of individuals with mental disorders live with their families. Thus, the care is usually provided by a family member, usually known as an informal caregiver (Sethabouppha & Kane, 2005).

Great effort, energy and sympathy are needed in caring for people who experience chronic conditions to the extent that it can affect the life of the caregiver (Chan, 2011). According to Bever and Hampson (in Purba, Sutharangsee, & Chaowalit, 2016) some caregivers' tasks include assisting in daily activities, communicating with the unwell family member, administering medication, managing behavior problems and managing finances. In order to be able to assist, knowledge related to the person's medication, their personal habits, and their security are needed (Kosberg and Cairl, in Purba et al., 2016). The role of caregiver requires great effort because they interact directly with PWS every day and it can be a source of stress. If the stressor is not properly managed, the stress can lead to caregiver burden. Caregiver burden is the burden borne by individuals who provide assistance to family members who are elderly, have chronic illness or have limitations, in this case schizophrenia (Kasuya, Polgar-Bailey, & Takeuchi, 2000).

The caregiver burden arises from a multidimensional process caused by the accumulation of stress during the treatment process. Some levels of the process include the primary stressor, appraisal, the secondary stressor, and outcomes (Zarit, 2009). "Primary stressors" are a direct impact of patient care, "appraisal" refers to the caregiver's understanding of the stressors they experience, and "secondary stressors" denote other aspects, besides treating patients, which can become stressors. Outcomes denote a situation where all kinds of caregivers' stresses will accumulate and foreground the perceived burden and depression.

The burden experienced by the caregiver during the treatment can arise from the PWS and also stressors from the outside environment. Some PWS behaviors sometimes cannot be overcome, such as poor self-care, mood swings, and conflicts with the surrounding environment (Cheng & Chan, 2005). Stressors from the environment can take the form of stigmatization. This can result in loss of self-esteem companion, disunity in family relationships, social isolation, and feelings of shame (Subandi, 2008). The caregiver must strive to balance these aspects of the work, family and physical care of the PWS and their own health is often neglected. This is compounded by lack of support, both emotional and financial, that can have an impact on the worsening burden of caregivers.

Studies found that families with low-income status tend to experience high caregiver burden because they do not have sufficient resources such as financial aid, knowledge and skills. Andren and Elsmthal (2007) examined the relationship between income, subjective health and the caregiver's burden in people with dementia. The study showed that the situation of the low-income caregiver was associated with a higher degree of burden on the caregivers. Low income was a stressor that impacted while providing care for ill family members. Besides, they additionally had to sort out financial problems by finding a source of income. Some families who become caregivers usually do not have sufficient knowledge or abilities to be responsible for caring for their family members who suffer from mental disorders (Cheng & Chan, 2005). It is a barrier to the caregiver in providing quality care for patients. The lack of knowledge and skills in caring for patients has an impact on increasing the perceived caregiver burden. Sörensen, Pinquart, and Duberstein (2002) suggested that psychoeducation interventions have a positive and improved impact on all variables studied, especially for the caregiver burden.

Psychoeducation intervention is an approach to teach families about disorders, handling disorders, coping techniques, and utilizing available resources (Mericle, in Cheng & Chan, 2005). The focus of psyhoeducation is improving caregiver knowledge pertaining to the disorders, facilitating communication patterns, problem solving, developing coping strategies, and encouraging families to actively engage in social activities. Psychoeducation can mitigate the lack of knowledge and skills for caregiver.

However, there is a lack of documented intervention in managing caregiver burden, particularly with low-income people in Indonesia. Thus, this study aims to employ psychoeducation for schizophrenia caregivers in order to manage their caregiver burden. The researcher on this study used the Family Intervention and Support in Schizophrenia module from National Institute of Mental Health and Neurosciences ((NIMHANS), Bangalore), which includes assessment sessions, psychoeducation, basic interventions, assessment and management of difficult times, solving communication and emotional problems (Varghese, Shah, Kumar, Murali, & Paul, 2002) and the Powerful Tool for Caregivers (PTC), which covers self-care, identifying and reducing stress, communicating feelings, communicating in challenging situations, learning to identify emotions, and making decision in caregiving.

Methods

Participants

The criteria for participants in this research were: (1) participants were a companion of family members who had schizophrenia, (2) they had experienced burden, anxiety and depression in caring for family members who had schizophrenia, and (3) they showed their willingness to take part in the study by filling out the informed consent sheet provided by the researchers. The researchers used a non-random sampling technique in which the researchers did not know the population, individual probabilities could not be known, and the sampling method was based on the facilitation factors in getting participants (Gravetter & Forzano, 2009). The participants' demographic data are shown in the table below.

Table I. Demographic Data

Name	Yayah	Intan	Tri
Age	56 years old	39 years old	56 years old
Education	Elementary School	Junior High School	Junior High School
Occupation	Farmer	Merchant	Housewife
Duration of caregiving	18 years	4 years	35 years
Relationship	S	Wife	Mother

Patient	Randi, male, 40 years old	Joni, male, 37 years old	Fara, female, 35 years old
Salary (monthly)	Rp. 1.000,000,00	Rp. 700.000,00	Rp. 700.000,00
ZBI-pre-test	42	19	29
GHQ-12 pre-test	23	6	9
HSCL pre-test	2,48	2	2,36

Research Design

This study used pretest-posttest design in order to evaluate the effect of treatment by comparing measurement before and after the intervention (Gravetter & Forzano, 2003). Pre-test, post-test and a two weeks' follow-up test were administered. Quantitative data was obtained by using the Zarit Burden Interview (ZBI), the Hopkins Symptom Checklist-22 (HSCL-22), and the General Health Questionnaire-12 (GHQ-12) while qualitative data was obtained by interview and observation.

Measures

The ZBI is an instrument to measure the burden experienced by a schizophrenia caregiver. This instrument was developed by Zarit (2009) and consists of 22 items of self-report inventory. The items in the ZBI are grouped into three sections: personal strains, role strains, and guilt (Dumaria, 2016). The HSCL-22 is an instrument to measure psychological distress and anxiety in the caregivers of PWS. This instrument consists of 25 statements regarding the emergence and intensity of the symptoms of anxiety and depression felt by a given individual within the past week (Turnip & Hauff, 2007). The GHQ-12 is an instrument to measure the depression experienced by the caregiver. This instrument can identify psychiatric disorders in patients with basic health services (Primasari & Hidayat, 2016). The researcher also used interview guidelines from the Family Intervention and Support in Schizophrenia module of NIMHANS (2002). Interviews were conducted to find out the description of participants' identities, the background of PWS disturbances, family knowledge about disturbances, the perceived burden, the caregiver's needs related to PWS conditions, the social support they have, and the family's response to PWS conditions. After the intervention is complete, the question that will be given to the caregiver concerns the perceived changes after following the psychological intervention compared to the current perceived situation before following the psychological intervention.

Procedure

The researcher collaborated with Pusat Rehabilitasi Yakkum (an institution that provides assistance to people with mental disorders) and Godean Health Center to identify participants who fit the criteria, by going directly to the home of prospective participants. The researcher screened by giving participants a ZBI measuring instrument to examine the caregiver burden score they experienced. The researcher also used a Hopkins Symptom Checklist-12 (HSCL-12) and the General Health Questionnaire-25 (GHQ-25) measuring instruments as additional data to determine the anxiety and tendency to experience depression experienced by PWS caregivers.

From the results of the questionnaire, 8 respondents were found who classified as experiencing little or no burden (0-20), 3 respondents experienced mild/moderate burden (21-40), and 1 respondent experienced moderate/severe burden (41-60). Researchers chose participants who experienced little or no burden to mild/moderate burden. In the end, the researchers got 3 participants who would undertake to see the intervention process through to the end. A respondent who experienced moderate or severe burden did not want to take part in the intervention, because he often went out of town. Researchers also offered intervention for 9 participants who did not meet all the criteria. The three remaining participants willing to take part in the intervention process then signed the informed consent sheet provided by the researchers.

The researcher deployed modules according to NIMHANS and the PTC. The researcher carried out the intervention with a duration of 1 to 2 hours for each session. The following are intervention plans conducted by the researcher.

Table II. Intervention Planning

Session	**Topic**
Pre-session	Orientation, assessment, completion of questionnaire.
Session I (Psychoeducation)	Definition of schizophrenia, symptoms and causes, medications, drug side effects.
Session II (Self-care)	The importance of self-care, setting a goal and action plan.
Session III (Stress Management)	Identifying stress, taking action to manage stress.
Session IV (Family Communication)	The importance of communication, how to build supportive communication.
Session V (Conclusion)	Review, completion of questionnaire, conclusion.
Follow-up	Completion of questionnaire.

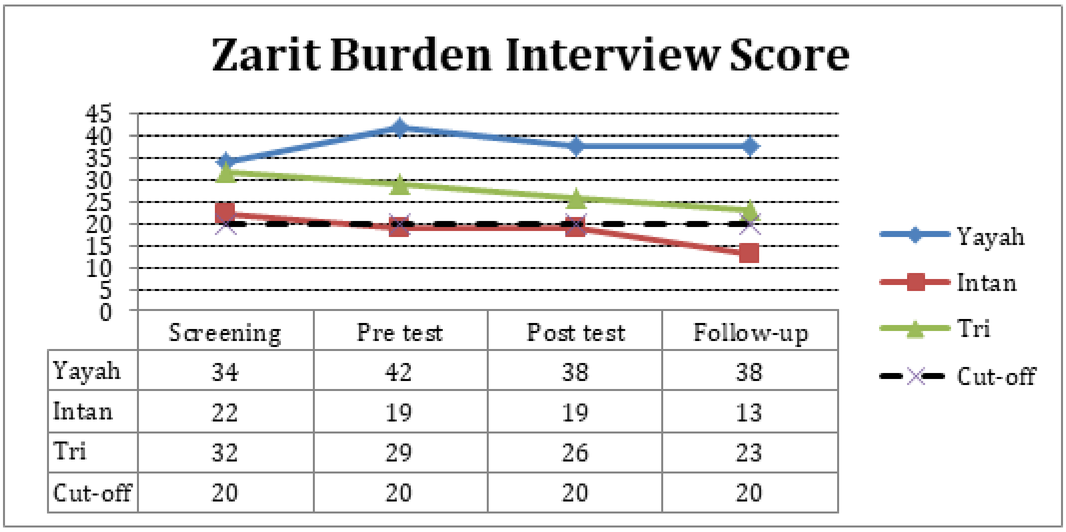
Data Analysis

The researcher compared the measurement of data before and after the intervention by using quantitative and qualitative methods in analyzing the data. Quantitative data were obtained from the ZBI measuring instrument, the Hopkins Symptom Checklist (HSCL-25), and the General Health Questionnaire (GHQ-12). The qualitative method was conducted by interviews to examine the changes experienced in the intervention process. The researcher repeated the questionnaires in the screening session, pre-test, post-test and follow-up, in order to examine the consistency of the research data.

Results

Quantitative Data

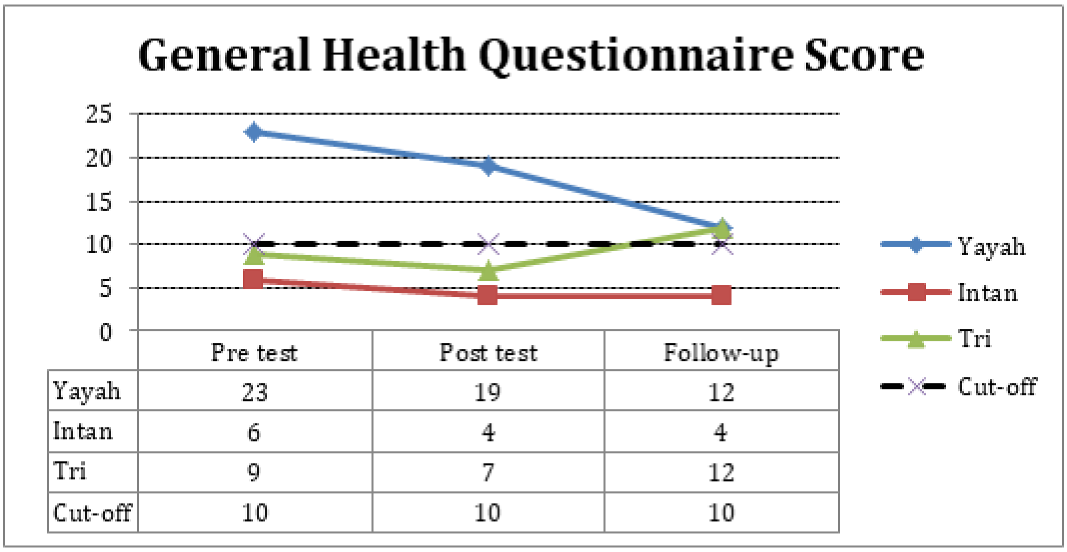
Table III. Zarit Burden Interview Score



	Screening	Pre test	Post test	Follow-up
Yayah	34	42	38	38
Intan	22	19	19	13
Tri	32	29	26	23
Cut-off	20	20	20	20

In the table above, it can be seen that there is a decrease in the caregiver burden score experienced by Intan and Tri. Intan had a lower score than before. Her score changed from low level to moderate to non-burdened to low level. Moreover, Tri experienced a decrease in her score, but she was still in the average or low-level categories. A different result appears on Yayah's ZBI score. According to alteration from screening to pre-test, there was an actual increase in the caregiver burden. This increase of scores also showed a change in the caregiver burden from low to average and average to high burden. Then, the score was less than before in post-test and still consistent until follow-up. It was classified as low to average burden.

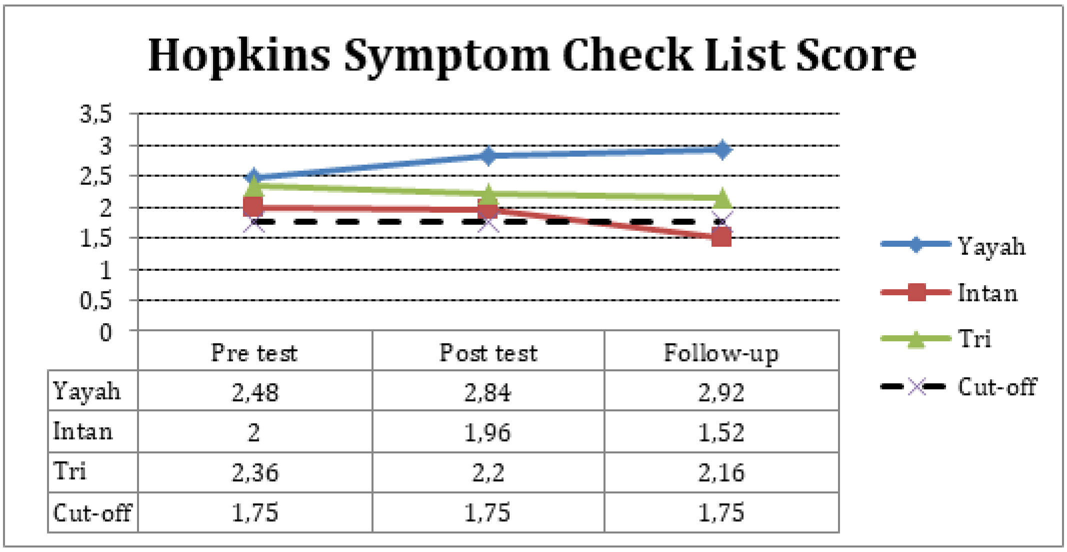
Table IV. General Health Questionnaire Score



	Pre test	Post test	Follow-up
Yayah	23	19	12
Intan	6	4	4
Tri	9	7	12
Cut-off	10	10	10

In general, it can be seen that there was a decrease in GHQ scores in Yayah and Intan. Although there was a score decrease in Yayah, according to the result, she still showed symptoms of depression until the follow-up session. In the intervention with Intan, the data from pre-test until follow-up showed no symptoms of depression. Inconsistent changes occurred with Tri. In the pre-test to post-test session there was a decrease in scores, but it increased at the follow-up session. Depression symptoms came up in the follow-up session.

Table V. Hopkins Symptom Check List Score



	Pre test	Post test	Follow-up
Yayah	2,48	2,84	2,92
Intan	2	1,96	1,52
Tri	2,36	2,2	2,16
Cut-off	1,75	1,75	1,75

According to this study, it can be seen that there is a decrease in psychological distress symptoms or anxiety in Intan and Tri. Until the follow-up session, Intan experienced a decrease but showed psychological distress symptoms or anxiety. Tri also showed a decrease in score, but still showed psychological distress symptoms or anxiety. Different results were shown in Yayah's case. She actually experienced an increase in HSCL score from the pre-test session to the follow-up.

Qualitative Data

Yayah	Intan	Tri
Yayah seemed happier than before after she got some materials from psychoeducation. Besides, she also understands more after researchers gave her psychoeducation materials. She began to gain more knowledge on how to treat PWS. So far she had applied the material, such as giving appropriate and routine medicine in accordance with the schedule.	She felt calmer in overcoming her anxiety when going through a stressful situation. This also makes her a more patient and encouraging companion to her husband. He can also get more knowledge to accompany and take care for her husband. She felt that her husband was getting better. In the past few days, her husband was able to carry out activities as usual, such as working as a builder, helping her to sell at the market, and also helping to raise their children. So far, the material he has tried to apply centers on managing stress and self-care.	The changes experienced by Tri during intervention were increasing knowledge and being more patient with her PWS. However, she felt that her family member was still in an unstable condition. The PWS still cries for no reason. She still confused to calm down this condition. Many things she had gained during the intervention. She can take care of herself more, take care of the PWS, teach the PWS how to take a bath, clean the bed and other activities related to patient self-care. The aspects she has applied are self-care, stress management, and family communication.

Discussion and Conclusion

The PWS’s condition will affect the burden experienced by participants. This can be inferred from the severity of the disorder experienced by the PWS. The more severe the patient's disorder, the greater the burden the caregiver will feel. This is based on the limitations of patients in carrying out their daily activities and their limited interaction with others. The conditions which were experienced by Fara as the PWS, greatly affect the burden experienced by her family. At home, she rarely interacts and does not do much activity. The thing that has become a family concern, and could become a burden, is the aggressive behavior exhibited by Fara.

The coping skill affects the burden experienced by the companion (Rafiyah, 2011). A caregiver with poor coping skills will experience difficulties in the care process. Based on this study, according to this finding, Intan and Yayah have good coping skills, unlike the coping abilities possessed by Tri. If the patient relapses and cannot control her anger, Tri locks Fara's room door and leave her inside. She rarely talks about problems she experienced with others. This also illustrates the caregiver's understanding of the stressors she experienced. Coping that focuses on problems (problem-focused) is effective when the patient's condition is still open to change. On the other hand, coping that focuses on emotions (emotional-focused-coping) is more effective when the patient's condition is chronic and difficult to change (Ostman & Hansson, 2001).

Some of the material provided by researchers on this intervention is new and there is reinforcement for participants. Some participants seemed to have scant knowledge about schizophrenia. They did not even know the name of the disorder experienced by their family member. The things they did know were only about symptoms such as frequent anger and hallucinations.

All participants also agreed that drugs were the most important factor in the recovery process of patients. Researchers also looked at several techniques to reduce stress, which were actually new to the participants. One of those techniques was a relaxation technique using controlled breathing. Other materials such as self-care and communication in the family are the materials they have used every day. Researchers provided reinforcement so that they could maintain their behavior better.

The researcher saw that the participants in this study applied a ngemong pattern in treating their family member. Ngemong refers to a way to treat children until they feel peaceful (Subandi, 2008). This basic principle also applies when someone treats someone whose behavior is similar to a child. There are three aspects of ngemong, which are showing a tolerant and non-critical attitude, not being demanding, and meeting the needs of PWS. According to Subandi (2008), the main points in ngemong are tolerance and positive acceptance of aggressive and impulsive behavior. This study also found that all participants had a ngemong attitude toward PWS.

The results showed that this intervention is sufficient to reduce the level of burden experienced by the companions of PWS which could be demonstrated quantitatively from the scores on ZBI. This also showed that participants were able to manage the caregiver burden they have. Changes in ZBI score were seen in the data from Tri and Intan, but not in Yayah. Tri and Intan tended to experience a decrease in ZBI. According to data on Yayah, the score remained the same even during the pre-test session. In the GHQ result, there was a change in Yayah and Intan’s score but not with Tri. This was because she was still feeling confused about how to deal with a recurrence that had not healed in Fara. It made her score show symptoms of depression.

According to the result of the HSCL, there was a decrease in psychological distress symptoms in Intan and Tri but not in Yayah. Actually, Yayah showed an increase in psychological distress symptoms or anxiety. Researchers cannot find a definite cause of Yayah experiencing an increase in psychological distress symptoms or anxiety. The observations and qualitative results showed that she seemed happy and did not complain much about the stress she experienced. According to the quantitative measurement results, this study illustrates that educational background influences the results of questionnaire scores. Scores obtained from quantitative data on the three participants cannot be used as a benchmark for the condition of the caregiver burden, psychological distress symptoms, or anxiety and depression symptoms. The level of education influences the way a person approaches each question in the questionnaire.

According to the qualitative assessment, all participants could gain benefits from the interventions provided by the researcher. All participants could understand better how to deal with patients who are less controlled, have problem-solving strategies to avoid stress, and know how to take care of themselves as outside part beside their task to accompany patients. With materials from the intervention, the caregiver could apply the new insights in their daily lives. The success of this intervention in reducing the burden was also influenced by the willingness and openness of the participants to talk about their problems.

Based on the experience of doing this research, it is clear that a psychologist needs to be highly flexible. All the participants in this study were housewives with Javanese culture, had education below high school level and also low-income status. The researchers did not initially establish these conditions of the participants in the field; they were established after the selection process.

Before they were selected, researchers had prepared a module design based on the literature study that had been carried out. However, the module was not properly targeted, where it is given to participants of this study. Some obstacles experienced by researchers were that participants experienced difficulties in understanding the questionnaire given by researchers; participants were also unfamiliar with some terms used to understand schizophrenia and also too many written explanations were used.

The flexibility of a psychologist when conducting an intervention is needed in these conditions, so that the purpose of the intervention that has been set at the beginning can properly align with the target. The intended flexibility can be in the form of adjusting the module or questionnaire according to the conditions of the participants. The materials in the module could use more visuals as opposed to text, making it easier for them to understand the material. Measurement of data using questionnaires could be replaced with qualitative measurements. The researchers can give them open questionnaires to get more in-depth qualitative data. In this study, what has been adjusted by the researchers, is a way of delivering the material of the modules using the Javanese language so that it helps participants understand the material. In addition, the use of language in accordance with the conditions of the participants can, according to researchers, improve the rapport between researchers and participants. The impact will also make it easier for researchers to provide material to participants.

Limitation & Future Research

There were some limitations in this intervention and these can be developed in future research. First, the time gap between sessions was inconsistent. At first, the researchers set a gap of five days between sessions, but because it had to be adjusted to the conditions of participants and researchers, there were several inter-session time intervals that were more than five days. Second, the time between sessions was too short. This affected the understanding and application of material provided by researcher to participants. Third, the time period for follow-up is too short, taking place only about two weeks after the material was completed. There will be more visible effectiveness of the intervention if follow-up is done over a longer period. Fourth, the number of participants in this study was too small, only three people, so the results of this study cannot be generalized to the general population. Fifth, researchers need to evaluate qualitative methods in more depth as these methods can be very useful because their use enriches research findings beyond using quantitative data. Sixth, in this study, researchers did not use statistical analysis to measure the comparison of questionnaire scores to the participants, so the changing results could not be concluded at the level of its significance.

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