

## Article

# The effectiveness of nursing psychoeducation toward family burden and quality life on caregiver of people with schizophrenia in the community

Suharsono,<sup>1</sup> Noor Faidah,<sup>2</sup> Moh Hanafi<sup>1</sup>

<sup>1</sup>Health Polytechnic Semarang, Central Java, Indonesia; <sup>2</sup>Institute of Technology and Health Cendekia Utama Kudus, Central Java, Indonesia

## Abstract

**Introduction:** The caregivers of people with schizophrenia have problems that include high family, burden and low quality of life at home. Therefore, this study aims to determine the effectiveness of nursing psychoeducation on family, burdens and quality of life in caregivers of schizophrenia patients in the community.

**Design and Methods:** This study used a pre-test and post-test group control design and repeated measurement with a total of 100 respondents. The treatment group was given weekly nursing psychoeducation for seven sessions. Also, the general linear model (GLM) was used to analyze the result.

**Results:** This study showed that before the intervention of nursing psychoeducation, the average family burden was 49.02 and 46.28 in the treatment and control groups, respectively. This decreased to 38.24 and 37.56 in the first and fourth weeks of post treatment. Meanwhile, the control group was 44.86 in the first week and 45.62 in the fourth. The psychoeducation had an effect on decreasing the family burden with a p value < 0.001. Moreover, this study showed that before the intervention of nursing psychoeducation, the average caregiver quality of life was 75.72 and 74.24 in the treatment. After treatment, it increased to 91.22 in the first week after intervention and 92.54 in the fourth week of post-intervention. Therefore, the intervention effectively improved the caregiver quality of life with p < 0.001

**Conclusions:** Nursing psychoeducation can effectively reduce family burdens and improve the quality of life for caregivers.

## Introduction

Schizophrenia is a chronic mental disorder that requires long-term care and treatment. The prevalence of this disease in the Indonesian population is 6.7% and the provinces with the highest cases include Bali with 11.1%, followed by Yogyakarta Special Region with 10.4%, West Nusa Tenggara with 9.6%, South Sulawesi 8.8%, West Sumatra 9.1%, Central Java and Aceh 8.7%.<sup>1</sup> Patients with schizophrenia who have been discharged

from the hospital and live with their families often relapse with behavioral and emotional disturbances caused by low medication adherence, lack of family support or interpersonal relationships, and stressful life events.<sup>2</sup> A study stated that 52% of patients experienced a relapse once a year after being discharged from the hospital.<sup>3</sup> The factors that contributed to this relapse include an unsupportive family environment, feelings of inferiority and worthlessness, side effects of drugs that patients often experience and joblessness. Therefore, the family as a caregiver is important in order to get a clear understanding of caring for these patients at home. Mental disorders need continuous services because the impact is not only felt by people with this condition but also by their families.<sup>3</sup> These disorders cause susceptibility to psychosocial problems caregivers, including feelings of worry and guilt. In addition, the psychological burden experienced by the family and the stigma in society often make them vulnerable to mental disorders.<sup>4</sup> The family is the center of nursing services because it is a source of fulfillment for individual needs. All dysfunctions that occur in the family will have an impact on one or more members or the whole.<sup>4</sup> The family is also a system, therefore, a disturbance in one of its members will definitely affect the whole system.

The paradigm shift in mental health services that focuses on the community (deinstitutionalization) has resulted in the family playing an important role in providing the care that patients need at home.<sup>5</sup> In addition, there has been a change in the focus of management from biological symptoms and their pathological implications to specific interventions addressing the spectrum of sequelae, biological, psychological, social, and cultural consequences of severe mental disorders.<sup>6</sup> The success of hospital care might be less than optimal when it is not followed up with nursing home care because it can result in the patient being hospitalized again (relapse).

Families play an important role in handling and preventing the recurrence of mental patients.<sup>7</sup> They are also very important in dealing with mental disorders in the community. This is because health workers are limited and patients live with their families, therefore, it is easier for them to be independent. Furthermore, the sources of support are more, varied as the costs are cheaper, and

### Significance for public health

*Patients with schizophrenia who are discharged from the hospital and live with their families often relapse with behavioral and emotional disturbances. This situation is caused by low medication adherence, lack of family support or interpersonal relationships, and stressful life events. Families as caregivers for schizophrenic patients are at the risk of having a lower quality of life due to mental and physical health problems, as well as high family burdens. Therefore, this condition needs modalities therapy to improve the knowledge and skill of these individuals. One of the treatments is nursing psychoeducation. Nurses in the community play an important role in psychoeducational, program because they have frequent contact with caregivers who care for schizophrenic patients. This study showed the effectiveness of nursing psychoeducation on family, burdens and quality of life among caregivers of schizophrenia patients in the community.*

patients are easier to adapt and require long treatment to overcome psychological symptoms.<sup>4</sup> This condition requires the participation of the community and family in improving mental health efforts. However, the families face challenges while caring for patients at home. This is due to the condition and behavior of patients, which can be a burden.

The concept of burden describes the negative impact of mental illness/disorder on the family. The burden in caring for schizophrenic patients can be divided into objective and subjective, where the former include practical problems and those related to having relatives with patients, such as loss of income and disruption of routine household activities. Meanwhile, subjective burdens include psychological and emotional impacts such as feelings of sadness and worries about relatives.<sup>8</sup> Based on previous studies, families with relatives suffering from schizophrenia experienced a very high burden as a consequence of treatment, hence, it can negatively affect all areas of their lives.<sup>9</sup> It was also revealed that schizophrenia is a severe mental illness, which places a heavy burden on the family as caregiver.<sup>10</sup> In addition, caregivers experience much physical, emotional and financial stress due to the patient's abnormal behavior, as well as social and occupational dysfunction. This burden is mainly felt by the closest relatives, such as the family as caregivers who live together, interact regularly, and assist patients with daily activities.<sup>11</sup> Caregiver burden as a psychological condition that arises is a combination of physical work, emotions, social pressures, and financial restrictions which are consequences of caring for patients.<sup>9</sup> A study showed that family members who lived with patients or spent many time with sick relatives felt more burdened and the level is usually associated with dysfunction or disability, the severity of negative and positive symptoms, and the duration of schizophrenia, the frequency of visits to the hospital, as well as the distance to the hospital from home.<sup>12</sup> A study explained that caregiver burden is used to describe the severe consequences of mental disorders for families as caregivers.<sup>13</sup> The family burden is not only the burden of care but others such as physical, psychological, social, and financial problems.<sup>14</sup>

The shift in the mental health care system from hospital-based to community-based care has caused families to take a greater role in caring for patients.<sup>14</sup> The family as a caregiver is at the forefront of caring for relatives with schizophrenia.<sup>15</sup> Changes in roles and responsibilities, high treatment costs, inappropriate behavior, shame, and negative stigma towards patients and their families can cause changes in family dynamics. This condition also affects health and become a burden on the family as a caregiver.<sup>16</sup> The schizophrenia symptoms cause the family to experience stress, frustration, and ineffective coping. Therefore, a coping strategy is needed to reduce the. Coping strategy is one of the factors that affect the caregivers' quality of life. The caregivers with effective coping strategies have a higher level of commitment in caring for schizophrenic patients and are able to reduce their psychological morbidity.<sup>17</sup>

Families as caregivers for these patients are at the risk of having a lower quality of life due to mental and physical health problems, as well as high burdens.<sup>18</sup> Several studies showed that these families have a lower quality of life compared to caregivers of patients with other psychiatric diagnoses or the general population.<sup>19</sup> The caregiver's quality of life has a direct impact on the patient's symptoms and indirectly on their quality of life. In addition, quality of life has been shown to be a predictor in the functional recovery of schizophrenic patients. Therefore, the quality of life for families as caregivers should be an important issue for health professionals and policy makers in considering or providing interventions to caregivers.<sup>20</sup>

Psychoeducation is one of the therapeutic modalities in mental

health nursing that provide ways to overcome psychosocial problems and offer skills to care for clients which are given by the therapist through family meeting sessions.<sup>21</sup> This intervention does not only provide training but also emotional reinforcement, psychological and social support to reduce feelings of anxiety. This is certainly very helpful in reducing the subjective and objective burden of the family.<sup>22</sup> Psychoeducation is an effective therapy and it saves costs when the intervention is carried out in groups, because in this way the therapist can work with various families at the same time.<sup>22</sup> A study was conducted to assess the efficacy of family psychoeducation programs in changing behavior and health perceptions in families with schizophrenia. It was further stated that family psychoeducation could change the relative's negative behavior towards schizophrenic patient. In addition, the study was conducted to assess the efficacy of the interventions on caregivers' quality of life. The results indicated that most caregivers experienced a significant increase in the overall quality of life scores as observed in the experimental group compared to the control. The study aims to test the efficacy of the psychoeducational intervention program (PIP) compared to standard care to reduce caregiver burden at post-intervention (4 months), and at follow-up (8 months). The results showed a change in scores since there was baseline on the Zarit Burden Interview (ZBI) and Involvement Evaluation Questionnaire (IEQ).<sup>23</sup>

Nurses play an important role in psychoeducational programs, because they have frequent contact with caregivers. The increasing involvement of mental nurses with the programs was demonstrated through the literature.<sup>24</sup> Therefore, they need to provide accurate information and skill to caregiver in order to enhance their knowledge and high skill in dealing with schizophrenic patient at home. Generally, this study aims investigate the effect of nursing psychoeducation on family burden, coping skills, and caregiver's quality of life of people with schizophrenia.

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## Design and methods

This is an experimental study with a pre-test and post-test control group design with repeated measurement. The population is a family with a schizophrenic patient in the mental health alert village area, the public health center, Magelang Regency. This study classified the respondents into the experimental and control groups, while an informed consent was signed. A paired simple randomization was applied, and the intervention group received the psychoeducational nursing intervention for 7 sessions per week while the control did not receive the intervention.

This study was conducted at the public health center in the working area of Magelang Regency, which has a community mental health program and developed a mental health alert village since January 2020. The data collection procedure was carried out through primary data which were obtained by filling in the provided instruments, including i) personal data questionnaire, ii) family burden with Zarit Burden Interview (ZBI), iii) quality of life with WHOQOL-BREF. The secondary data were obtained from the results of the patient's medical records and the results of family interviews. The data collection procedure was follows: i) Patient data were recorded and traced by the mental health coordinator nurse to ensure the eligibility of the caregivers. This is in line with the criteria, and the doctor or person in charge of mental health at the puskesmas provided a letter of willingness when they agreed to be participants; ii) Caregivers who meet the requirements to become the participants were given an explanation of the objectives, and their willingness to participate in the entire process was confirmed; iii) After obtaining informed consent, an invitation was

given to come to the nearest public health center at a predetermined time where the data collection process and implementation of all nursing psychoeducation sessions according to the schedule will be completed; iv) The filling of the informed consent and instruments was carried out by the subjects themselves; v) Personal data questionnaires and instruments to measure family burden and quality of life were completed and collected back by the study team to check the completeness; vi) Caregivers who completely filled out the instruments were given a transport fee of Rp. 50,000 as an expression of gratitude. Each session was divided into 4 stages, namely, pre-interaction, orientation, work, and termination. The topics in the seven session nursing psychoeducation were i) identification of family problems, ii) definition, response ranges and causes of schizophrenia, iii) symptoms and effects of schizophrenia, iv) how to care for the patient, v) management of relapse, vi) stress management, and vii) family burden management and family empowerment.

The obtained data were analyzed and univariate analysis was carried out by descriptive analysis to observe the characteristics of each variable studied. Furthermore, the general linear model statistical test was used to determine the effectiveness of nursing psychoeducation on family burden and quality of life.

## Results and discussions

The results indicated that majority of the caregiver's age group was more than 35 years while the gender was dominated by female in both treatment and control groups. Table 1 shows the educational level of most respondents was college graduates, with 21 people (42%) each in the treatment group and 24 (48%) in the control. Furthermore, high school education levels were 19 (38%) in the treatment group and 17 (34%) in the control. This result indicated that most of the caregivers were married with as many as 40 people

(80%) and 39 (78%) in the treatment and control groups, respectively. Meanwhile, the caregiver's job as a trader was 17 (34%) and 15 (30%) in the treatment and control groups, respectively. Majority of the respondents in the treatment group were life partners (husband/wife) as many as 21 (42%), while the control group was majorly parents with 23 people (46%). The duration of caring for family members was mostly more than 5 years by 26 (52%) and 33 (66%) in the treatment and control groups, respectively.

This study showed that there was a significant difference in mean before and after giving nursing psychoeducation. In the first week after intervention, there was a difference in the average burden of the family as a caregiver in the treatment and control groups with -6.62. Likewise, in the post test's 4th week, there was a decrease in the family burden score with a difference of -8.06 between the treatment and control groups. The results indicated that nursing psychoeducation had statistically and clinically significant effect in reducing the burden on families as caregivers for people with schizophrenia ( $p$  value  $<0.001$ ).

Furthermore, before the intervention, majority of the respondents from both treatment and control groups experienced a fairly high family burden in caring for their relatives suffering from schizophrenia. The control group had a mean family burden score of 46.1, while the treatment group had average score of 46.02. This occurs since schizophrenia is a severe mental disorder that causes a decrease in social function and has the potential to cause a long-term burden for the family as caregiver. The burden experienced by the caregivers includes meeting daily needs, finances, and loss of jobs.<sup>25,26</sup> This also occurs in Indonesian society where besides meeting the needs of relatives suffering from schizophrenia, families also feel subjective burdens such as shame, anxiety, guilt and stigma. The burden of families with schizophrenic patients has a high level of distress and difficulty, specifically during the early phase. The results are in accordance with previous studies which identified that the family burdens experienced by caregivers were both objective and subjective.<sup>27</sup> The objective burden includes the

**Table 1. The caregiver characteristics.**

Variables		Experimental group (n=50)		Control group (n=50)	
		f	%	F	%
Age (year)	<35	10	20	16	32
	>35	40	80	34	68
Sex	Male	23	46	21	42
	Female	27	54	29	58
Educational level	No Formal Education	1	2		
	Elementary School	6	12	7	14
	Junior High School	3	6	2	4
	Senior High School	19	38	17	34
	University	21	42	24	48
Marital status	Married	40	80	39	78
	Unmarried	6	12	9	18
	Widow	4	8	2	4
Occupation	No Job	4	8	2	4
	Civil Servant	15	30	12	24
	Police	2	4	1	2
	Trader	17	34	15	30
	Farmer	9	18	11	22
	Labor	3	6	9	18
Relationship with the patient	Parent	15	30	23	46
	Couple	21	42	12	24
	Sibling	3	6	10	20
	Child	11	22	5	10
Caring duration	< 5 years	24	48	17	34
	>5 years	26	52	33	66

cost of care, housing, food and transportation. This was also experienced by caregivers in this study who had to take patients to a health facility, prepare daily needs, control medication as well as monitor their behavior and emotions at home. While the subjective burden include worrying when patients experience a relapse and stigma from the community.

Most of the respondents cared for the patients at home for more than five years with 52% and 66% in the treatment and control groups, respectively. The results of the regression test showed there was no relationship between duration of care and family burden. This is contrary to a study which stated that there was a relationship between the duration of caring for clients with family burdens.<sup>27</sup> This difference could be as a result of Indonesian culture, the longer duration of caring for patients do not cause the perceived psychological burden or pressure to be greater. The family already has a close relationship or an attitude of helping and tends to be able to adapt.<sup>27</sup>

This study showed the burden on the family as a caregiver was not influenced by age. This is contrary to a literature which stated that family burden had a positive correlation with caregiver's age. It was stated that the older the age, the more the burden due to reduced physical abilities and concerns about who will be responsible for the patient after death. The difference in this study could be caused by Indonesian culture of helping each other, as families believe it is their responsibility when a member is sick.<sup>27</sup>

Studies in India and Chile on outpatient schizophrenic caregivers in hospitals stated that length of illness, levels of psychopathology and disability, frequency of relapse, positive symptoms and lack of social support were predictors of family care burden.<sup>28</sup> This burden was not only influenced by the condition of patients and the characteristics of the caregiver, but also by differences in mental health services in the health care system. The caregiver characteristics that affected the family burden were symptoms, male gender, joblessness, marital status, coping abilities, contact with patients and sufferers' parents. Therefore, sociocultural and ethnic characters have an important role in the perception of the family care burden.

Schizophrenia management in the community should not only be conducted for sufferers but should also focus on families as caregivers.<sup>29</sup> It can increase understanding in caring for patients at home, reduce the stress, improve coping and the quality of family life as caregivers. Caregivers need to access health services which are part of the schizophrenic management in the community set-

ting.

The results were supported by previous study conducted in Japan to provide psychoeducation for caregivers with schizophrenia in the community by visiting nurses.<sup>30</sup> The results showed that there was a significant reduction in family burden after home visits and psychoeducation.

Although psychoeducation effectively increased knowledge and positive coping with the patient's family, it was less useful in reducing psychological morbidity, care burden or emotional expression. Psychoeducation conducted in this study in the form of groups where participants could exchange experiences, increase knowledge and skills facilitated by health workers. This is in accordance with a previous study which stated that psychoeducation can increase caregiver's knowledge about psychosis<sup>31</sup>. Psychoeducation was recommended to be carried out as early as possible from the first contact of caregivers with severe mental disorders to health workers and on an ongoing basis.<sup>5</sup> This intervention could reduce the burden of family care because it could improve the life quality of patients and caregivers, and reduce the severity of symptoms.<sup>32</sup> In this study, psychoeducation was carried out in the form of groups for caregivers to interact with each other among participants or health workers and gain knowledge or skills regarding the definition, causes, symptoms, signs, care and treatment management, stress and family burden management, family empowerment as well as preventing recurrence. Families as caregivers need support for community-based mental health services. This is because patients living with their families need to get long-term care which will increase the burden of family life as caregivers, such as financial burdens, time devoted to caregiving, resulting in loss of job opportunities and reduced income. It takes a long time to manage stress while caring for patients, and the stress increases when families experience a relapse. In addition, caregivers are worried about the future of people with schizophrenia when the family as caregiver dies.

The majority experienced a burden as a result of the deteriorating condition of patients who require long-term care and decreased ability to interact with other people. Caregiver burden results in physical and mental health, social relationships, financial condition, psychological morbidity, less free time, workload, and caregiver burnout. In addition, their emotional problems, such as feelings of frustration, anger, shame, fear, sadness, and stress increases due to the patient's behavior, and the negative attitudes towards the patient. This study is in accordance with previous ones which

**Table 2. The effect of nursing psychoeducation on family burden.**

Family burden	Control group (n=50) Mean (s.d.)	Experimental group (n=50) mean (s.d.)	Mean difference	CI 95%	P value
Before Nursing psychoeducation	46.28 (9.40)	49.02 (12.16)	2.74	45.22	<0.001
Post test 1 <sup>st</sup> week	44.86 (6.20)	38.24 (9.88)	-6.62		
Post test 4 <sup>th</sup> week	45.62 (7.33)	37.56 (8.62)	-8.06		

**Table 3. The effect of nursing psychoeducation on quality of life.**

Family burden	Control group (n=50) Mean (s.d.)	Experimental group (n=50) mean (s.d.)	Mean difference	CI 95%	P value
Before Nursing psychoeducation	74.24 (9.59)	75.72 (2.53)	1.48	-1.30 – 4.26	<0.001
Post test 1 <sup>st</sup> week	79.44 (2.58)	91.22 (2.50)	11.78	10.77 – 12.79	
Post test 4 <sup>th</sup> week	74.00 (2.05)	92.54 (3.08)	18.54	17.50 – 19.58	

showed that there was a decrease in the family burden for the group receiving psychoeducation treatment compared to the control group.<sup>33</sup> This consistency occurs because psychoeducation serves to inform about illness and how to deal with it, provide emotional support to caregivers and implement coping strategies or stress management.<sup>34</sup> The family burden is very important and needs attention as it is the result of a chronic disease condition and considering that the patients live with their families. This burden occurs due to emotional reaction to illness suffered by relatives, the family's ability to cope with psychological problems of caring for people with schizophrenia, the stigma that arises as well as social withdrawal and family economic problems. The caregiver's burden is caused by the distress they experienced, disrupted routine activities as they need to care for and fulfill their daily integrity.<sup>25</sup> Nursing psychoeducation carried out in this study was a comprehensive technique which is a combination of a model that focuses on providing information to families about the disease and its management (information model), a model that focuses on skills in order to be treated effectively by the relatives (skill training model), and a model that involves families sharing feelings in a support group.<sup>21</sup> This intervention was carried out in groups for caregivers to interact with themselves and gain knowledge and skills in defining causes, response ranges, signs and symptoms, management of care for relatives at home, stress and family burden management as well as prevention of recurrence and empowerment of families as caregivers.

This study showed that there was a significant difference in mean before and after giving nursing psychoeducation. In the first week after the intervention, there was a difference in the average quality of family life as caregivers in the treatment and the control groups with 11.78. Likewise, in the post test's 4th week, there was an increase in the quality of life score with a difference of 18.54 between the treatment and the control groups. The results showed a p value of  $<0.001$ , which indicated that nursing psychoeducation had a significant effect in improving the life quality of caregiver for people with schizophrenia (Table 2). It was also revealed that prior to the implementation of the intervention, majority of the respondents, both the treatment and control groups, had poor quality of life in all areas including physical, psychological, social relationships, and environmental domains. The mean for quality of life in the treatment and control groups was 75.72 and 74.24, respectively. This could be due to socioeconomic conditions and caregiver's level of knowledge. This is in accordance with the study which stated that caregivers with lower economic status were associated with lower quality of life.<sup>18</sup> Individuals with better financial conditions could meet basic physical and psychosocial needs such as higher self-esteem in order to improve their quality of life.

The results indicated that age and relationship with the patient affect the caregiver's quality of life. The results are in accordance with the study that caregivers who were older had a significantly lower quality of life in the social and environmental domains.<sup>35</sup> Furthermore, elderly caregivers often have illnesses and declining physical health which could affect the physical domain on their quality of life.<sup>36</sup> Several studies in western countries showed that the life quality of caregivers increases with age, while it decreases with age in Asian countries. These results are consistent with a study which stated that parents a lower quality of life compared to other family members. This was contrary to a study which stated that age was not significantly related to the caregiver's quality of life.<sup>12</sup> This difference was possible due to cultural factors. Older caregivers could accept the patients with their condition.<sup>37</sup> In addition, the results were a small proportion of respondents who did not work (8%) in the treatment group and 4% in the control group and there was no relationship between family work and caregiver's

quality of life. These are consistent with a study that there was no significant relationship between work status and caregiver's quality of life.<sup>12</sup> However, in contrast to the results, several studies showed a relationship between the variables.<sup>35</sup> Caregivers who work will have better financial conditions to meet basic physical and psychosocial needs like higher self-esteem. In addition to having an income, caregivers can temporarily switch from caregiving tasks while working outside. Having a job will indirectly expand the social support network that plays an important role in reducing the burden on the caregivers. This difference could be caused by the culture of mutual assistance that is still developing in Indonesia. The study discovered that there was no decrease in the life quality of family caregivers of schizophrenia patients in Indonesia, even though they did not have a job. It is a common habit in the extended family and the surrounding environment to support each other, even financially. In addition, caregivers who are not working did not have to make adjustments between their work life and caring for their family members.<sup>18</sup>

This study showed that after the nursing psychoeducation was carried out, caregivers experienced an increase in the average quality of life score in the treatment group from 75.72 in the initial data to 91.22 in the 1<sup>st</sup> -week of post-measurement and 92.54 in the 4<sup>th</sup> week of post-nursing psychoeducational implementation. Therefore, there is a significant effect of the intervention on improving the quality of life with a p value of  $<0.001$  (Table 3). This is in accordance with a study which assessed the efficacy of family psychoeducational interventions on the schizophrenic patients and the caregiver's quality of life.<sup>35</sup> Most of the respondents are over 40 years, married, and male. The results showed family psychoeducation significantly improved the overall quality of life observed in the treatment group caregivers compared to those in the control. The similarity between these results could be due to nursing psychoeducation increasing knowledge and skills in caring for patients with schizophrenia at home, therefore, caregivers are able to use effective coping which can improve quality of life.

This study also showed that the quality of life in the physical domain experienced an increase after the intervention with a mean difference between the control and treatment groups of 3.72 in the first week after treatment and 4.46 in the fourth week. Study identifying the life quality of families who care for schizophrenic patients showed that the highest average WHOQOL-BREF score was recorded in the physical health domain.<sup>35</sup> This means the quality of life was higher in the physical health domain compared to others. These results were consistent with this study.<sup>35</sup> This is because caregivers tend to ignore physical limitations or complaints of pain, and feel that they get more physical strength when caring for relatives suffering from the disease.

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## Conclusions

There was a decrease in the mean score of caregiver burden in the group that received nursing psychoeducation compared to those who did not. This showed the effectiveness of the intervention towards family caregiver burden. Furthermore, there was an increase in the average quality of life score in the group that received the intervention compared to those who did not. Therefore, this study showed the effectiveness of nursing psychoeducation towards family quality of life.

Correspondence: Suharsono, Health Polytechnic Semarang, Central Java, Indonesia. Tel.: +6293365185.  
E-mail: suharsono.disi@gmail.com

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