

นิพนธ์ต้นฉบับ

The Relationships between Health Status, Perceived Control of Symptoms, Caregiver Burden, Perceived Social Support and Quality of Life among Family Caregivers of Patients with Schizophrenia in Indonesia

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ผู้ดูแลผู้ป่วยโรคจิตเภทในอินโดนีเซีย

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บทคัดย่อ

ที่มาของปัญหา

การดูแลผู้ป่วยจิตเภทนับว่าเป็นภาระหนักของสมาชิกในครอบครัว ซึ่งอาจมีผลกระทบต่อการรักษาที่ต่อเนื่องของผู้ป่วย ดังนั้น ญาติผู้ดูแลจึงควรได้รับความสนใจในฐานะที่มีบทบาทสำคัญในการดูแลผู้ป่วยจิตเภท และในอีกมุมมองหนึ่ง ภาระการดูแลผู้ป่วยอาจส่งผลให้ญาติผู้ดูแลมีความเครียดและมีผลกระทบต่อคุณภาพชีวิตทั้งของผู้ป่วยและญาติผู้ดูแล

วัตถุประสงค์

เพื่อศึกษาความสัมพันธ์ระหว่างภาวะสุขภาพ การรับรู้ความสามารถในการควบคุมอาการ ภาระการดูแล และการรับรู้การสนับสนุนทางสังคม กับคุณภาพชีวิตของญาติผู้ดูแลผู้ป่วยโรคจิตเภทในอินโดนีเซีย

วิธีการศึกษา

การศึกษาคั้งนี้เป็นการวิจัยเชิงพรรณนาแบบศึกษาความสัมพันธ์ระหว่างตัวแปร โดยเก็บรวบรวมในช่วง เดือนกรกฎาคม ถึง เดือนสิงหาคม พ.ศ. 2557 จากญาติผู้ดูแลผู้ป่วยโรคจิตเภทในอินโดนีเซีย จำนวน 137 คน วิเคราะห์ข้อมูลโดยใช้สถิติพรรณนา และหาค่าสัมประสิทธิ์สหสัมพันธ์ของเพียร์สัน

ผลการศึกษา

ผลการศึกษาพบว่าภาวะสุขภาพ การรับรู้ความสามารถในการควบคุมอาการ และการรับรู้การสนับสนุนทางสังคมมีความสัมพันธ์เชิงลบ ส่วนภาระการดูแลมีความสัมพันธ์เชิงบวก อย่างมีนัยสำคัญทางสถิติกับคุณภาพชีวิตของญาติผู้ดูแลผู้ป่วยโรคจิตเภท โดยการรับรู้การสนับสนุนทางสังคมเป็นตัวแปรที่มีขนาดของความสัมพันธ์มากที่สุดกับคุณภาพชีวิตของญาติผู้ดูแลผู้ป่วยโรคจิตเภท

สรุป

จากผลการศึกษาในครั้งนี้สรุปได้ว่าญาติผู้ดูแลที่มีภาวะสุขภาพดี รับรู้ว่าคุณสมบัติของของผู้ป่วยได้ รับรู้ว่าการสนับสนุนทางสังคมดี และมีภาระดูแลไม่หนัก มีคุณภาพชีวิตดี อย่างไรก็ตาม การศึกษาคั้งนี้ยังไม่ครอบคลุมตัวแปรอื่นๆ ซึ่งอาจมีความสัมพันธ์กับคุณภาพชีวิตของญาติผู้ดูแลผู้ป่วยจิตเภท

คำสำคัญ : คุณภาพชีวิต ญาติผู้ดูแล ผู้ป่วยจิตเภท

Abstract

Background: Providing prolonged care and support for patients with schizophrenia can be burden some for family caregivers. Caregiving might affect to the continuity of treatment of patients. Thus, the family caregivers could be considered as one health resource to promote health of patients with schizophrenia. On the other hand, caregiving activities experienced by the caregivers are stressful events that could relate to quality of life of both patients and the caregivers.

Objective : To examine the relationships between health status, perceived control of symptoms, caregiver burden, perceived social support, and quality of life among family caregivers of patients with schizophrenia in Indonesia

Methods : A descriptive correlational approach was used in this study. Data were collected during July to August 2014 from 137 family caregivers of patients with schizophrenia in Indonesia. Data were analyzed by descriptive statistics, and Pearson's Product Moment correlation coefficients were employed to determine the relationships.

Results : The results revealed that health status, perceived control of symptoms, and perceived social support were significantly positively correlated with quality of life among the family caregivers, while the caregiver burden showed a significantly negative related to the quality of life. Moreover, the perceived social support was found as the strongest factor related to the family caregiver' quality of life.

Conclusion : The results of this study suggest that the family caregivers who have lower caregiver burden, perceived the higher control of symptoms, and perceived the higher social support were more likely to have higher quality of life. Other factors which were not included in this study should be taken into consideration for further study related family caregiver' quality of life.

Keywords : Quality of Life, Family Caregivers, Schizophrenia

Introduction

According to Global Burden of Disease Study 2010, it was pointed out that mental disorder was a common cause of disability.¹ In addition, schizophrenia was included as one of the leading causes of disability in the world.¹ Schizophrenia as a severe mental illness has caused disability situations and has disturbed the capabilities of people with mental illness and in turn could have an impact on their families.

The impact of schizophrenia is overwhelming caused by its cognitive and social dysfunction ;^{2,3} therefore, reducing the impact of schizophrenia is noteworthy. The shifting of health care from hospital-based care to community-based care, forced families to take an important role in the caregiving task of the patients with schizophrenia. However, caregiving activities for the patients with schizophrenia were experienced by family caregivers as stressful events that showed the relationship with the quality of their lives.^{4,5}

The quality of life is defined as an "individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. As a multi-dimensional concept, the quality of life consist of physical, social, psychological, and environmental domains. Previous studies found that significant factors associated with the quality of life of family caregivers of patients

with schizophrenia consisted of three factors, including caregiving situation, caregiver factors, and environmental factors.⁶

Caregiving situation is perceived as a burden by the caregiver. The term of 'burden' is defined as the care in usage and consisted of the objective and subjective burden.⁷ Moreover, caregiver burden could associate with the quality of life of the caregiver. Previous studies found the relationship between caregiver burden and quality of life.^{5,8} In turn, it might affect the continuity of care of patients with schizophrenia.⁹ Moreover, the perception of caregiver to be able to control the symptoms of the patients is an essential factor that related to how they perceived the quality of life.

Caregiver factor is the characteristic of caregiver such as the perception of caregiver related to their health status. Previous studies found inconsistent findings regarding the relationship with quality of life.^{4, 10, 11, 12}

Environmental factor is the perceived social support from significant other, family, and friends of the caregivers while taking care patient with schizophrenia. Social support is considered as a protective factor that could help to keep psychologically healthy in stressful life events; however, few studies explored the impacts of perceived social support to the health of family caregivers¹³ and the quality of life of family caregivers of schizophrenia.^{5, 12,14}

Some previous studies examined the quality of life of the caregiver by using the general instrument of quality of life.^{4, 12, 15, 16, 17} Very few studies have been carried out to assess the quality of life of family caregivers with other factors by using instruments that were developed based on the point of views of the caregivers. Therefore, this study was conducted.

The general purpose of this study was to examine the relationships between health status, perceived control of symptoms, caregiver burden, perceived social support, and quality of life among family caregivers of patients with schizophrenia.

Materials and Methods

Burden Assessment Schedule (BAS) was used to measure caregiver burden.¹⁸ The BAS consists of 20 items measured both objective and subjective burden. Higher scores represent higher perceived of caregiver burden. The Cronbach's alpha reliability coefficient in this study was 0.78.

A questionnaire to assess perceived control of symptoms was developed by the researcher. The family caregivers were asked to rate their perception of ability to control the symptoms of patients with schizophrenia from 0 to 10 scales.

A questionnaire assessing health status of the caregiver was developed by the researcher. Regarding the health status, the

caregivers were asked to rate their current health status from 0 to 10 scales.

The Multidimensional Scale of Perceived Social Support (MSPSS) that developed by Zimet et al.¹⁹ was used to measure perceived social support of the caregivers. The MSPSS consists of 12 items measured social support from significant other, family, and friends perceived by the caregivers. The Cronbach's alpha reliability coefficient in this study was 0.85.

Quality of life was measured by Schizophrenia-Caregiver Quality of Life questionnaire (S-CGQoL). The S-CGQoL was developed by Richieri et al.²⁰, which consists of 25 items that measured 7 dimensions. For instance, physical and psychological well-being, psychological and burden daily life, relationship with spouse, relationship with psychiatric team, material burden, relationship with family, and relationship with friends. The Cronbach's alpha reliability coefficient in this study was 0.85.

A cross-sectional design with a descriptive correlation approach was used to examine the relationships between caregiver burden, perceived control of symptoms, health status, perceived social support, and quality of life among family caregivers of patients with schizophrenia in Indonesia.

The participants in this study were family caregivers accompanied a family member with schizophrenia to the outpatient department of a Mental Hospital in Jakarta,

Indonesia. The total participants in the present study were 137 family caregivers. The family caregivers were selected by purposive sampling with these following inclusion criteria: (1) 18-65 years old; (2) have taken care a patient with schizophrenia, according to the International Classification of Disease-10 (ICD-10); (3) have taken care a patient who was functioning stably in the community that was indicated by no need for hospitalization in the last 3 months; (4) accompanied a patient with schizophrenia to the outpatient department; (5) had been a family caregiver for at least one year. The exclusion criteria were caregivers who: (1) have taken care of more than one family member with mental illness; (2) have taken care of a patient with schizophrenia with other comorbid and substance abuse.

The study had been granted for an ethical approval by Borromarajonani College of Nursing Nopparat Vajira Review Board. The data collection was begun by self-introduction and provision of information related to the purpose of study via participants information sheet. The family caregivers who met the inclusion criteria and who were willing to participate were asked to signed the informed consent form. The questionnaire was completed about 60 minutes. The data was collected for two months (July to August, 2014) at the outpatient department of Mental Hospital Dr. Soeharto Heerdjan, Jakarta,

Indonesia.

The data were analyzed by descriptive statistics and Pearson's Product Moment correlation coefficients were employed to determine the relationships.

Results

The results from 137 respondents showed that 74.45 percent were female. Regarding the level of education, the study found that out of 137 family caregivers, 37.22 percent of respondents had education in elementary school. The period of being caregivers ranged from 1 to 18 years (SD = 4.89 years). Regarding the employment status, 57.66 percent of respondents were unemployed. The caregiver's perception of current health status showed that 69.34 percent of respondent rated their health status as good health. The perceived control of symptoms showed that 70.07 percent of respondents perceived the ability to control the symptoms as showed in Table 1.

Table 1. Socio-demographic data of family caregivers of patients with schizophrenia (n = 137)

Variables	n	percent
• Gender		
Female	102	74.45
Male	35	25.55
• Level of education		
Elementary school	51	37.22
Junior high school	25	18.25
Senior high school	47	34.31
Higher education	14	10.22
• Employment status		
Employed	58	42.34
Unemployed	79	57.66
• Health status		
Poor health	42	30.66
Good health	95	69.34
• Perceived control of symptoms		
Uncontrolled	41	29.93
Controlled	96	70.07

Table 2. Mean and standard deviation of health status, perceived control of symptoms, perceived social support, and quality of life among family caregivers of patients with schizophrenia (n = 137)

Variables	Scores of Variables		
	Mean	SD	Range
• Health status	6.59	2.15	0-10
• Perceived control of symptoms	6.65	2.16	0-10
• Caregiver burden	29.88	5.21	20-60
• Perceived social support	4.63	0.96	1-7
Significant other	4.77	1.18	1-7
Family	5.18	1.11	1-7
Friends	3.93	1.41	1-7
• Quality of life	60.98	14.66	25-125

In the Table 2, the results showed that the total mean score of health status was 6.59 (SD = 2.15) out of the possible score, which was ranged from 0 to 10 scale; the total mean score of perceived control of symptoms was 6.65 (SD = 2.16) out of the possible score, which was ranged from 0 to 10 scale; the total mean score of caregiver burden was 29.88 (SD = 5.21), out of the possible total score, which was ranged from 20 to 60. The total mean

score of perceived social support was 4.63 (SD = 0.96) out of the possible total score, which was ranged 1 to 7. In addition, out of the possible total score ranged from 1 to 7, the mean score of perceived social support from family was the highest among other sources of support (M = 5.18, SD = 1.11). The total mean score of quality of life was 60.98 (SD = 14.66) out of the possible total score, which was ranged from 25 to 125.

Variables	Correlations with the QoL	
	r	p-value
• Health status	0.33	<0.001
• Perceived control of symptoms	0.36	<0.001
• Caregiver burden	-0.56	<0.001
• Perceived social support	0.58	<0.001
Significant other	0.34	<0.001
Family	0.51	<0.001
Friends	0.48	<0.001

In the Table 3, there was statistically significant positive relationship between health status and quality of life ($r = 0.33$, p -value <0.001). Thus, it can be stated that the higher the caregiver rated their current health status, also the higher score the caregiver perceived the quality of life. The result showed a significant positive relationship between perceived control of symptoms and quality of life ($r = 0.36$, p -value = < 0.001). It can be pointed out that the higher the caregiver perceived their ability to control the symptoms of patients, the

higher the caregiver perceived the quality of life. Moreover, caregiver burden was statistically significantly related to the quality of life. The caregiver burden was strongly negatively correlated to quality of life ($r = -0.56$, p -value = < 0.001). The result indicated that the higher the caregiver perceived caregiver burden, the lower the score the caregiver perceived the quality of life.

With regard to perceived social support, all subscales of perceived social support were significantly positively related to quality of life,

with perceived social support from family showing the greatest magnitude of the relationship ($r = 0.51$, p -value = < 0.001), followed by perceived social support from friends ($r = 0.48$, p -value = < 0.001), and perceived social support from significant other ($r = 0.34$, p -value = < 0.001). The result also showed that the caregiver's perception of social support was strongly correlated to their quality of life ($r = 0.58$, p -value = < 0.001).

Discussion

From the results in this study, it is revealed that there are relationships between health status, perceived control of symptoms, caregiver burden, perceived social support and quality of life among family caregivers of patients with schizophrenia were explained in the following discussion.

Regarding the relationship between health status of the family caregivers and their quality of life, the moderate relationship between health status and quality of life was found. The result indicated that family caregivers who perceived their current health status as good were perceived their quality of life higher than the family caregivers who rated their health status as poor health. The result was consistent with other studies stated that health status was a factor associated with the caregivers' quality of life.^{6,15} The possible reason why the QoL increases with health status may include better health conditions of

caregiver is required for taking care the patient, thus the healthy caregiver tends to perceive their quality of life higher. A previous study found that the family caregivers who did not have any medical problems reported significantly higher QoL score in physical, psychosocial, and environmental domains.²¹ Therefore, the health status of the family caregivers is one important factor from the caregivers that need to be preserved while providing care for their loved one.

Also, the result showed that perceived control of symptoms was significantly positively correlated with the quality of life. This finding indicated that the family caregivers who perceived themselves being capable to control the symptoms of the patients with schizophrenia in caregiving task were more likely to have a good perception related to their quality of life. Previous studies revealed that symptoms of the patients, for example, the bizarre and disturbing behaviors of the patients showed as the greatest difficulties faced by the caregivers.⁶ Moreover, the family caregivers reported a greater distress related to their perception of being incapable to control symptoms of the patients.²² As a previous study revealed that sense of mastery mediates effect of education on mental health.²³ Thus, it can be assumed that for improving the perceived control of symptoms, the caregivers need to be more knowledgeable to handle the patient's symptoms. Hence, the perception of

the family caregivers related their ability to control the symptoms of patients is needed to take into consideration for achieving better quality of life.

Moreover, in this study, it was also found that caregiver burden as the perception of the family caregivers related to the negative impacts of taking care patients with schizophrenia was a strong significantly negatively related to the quality of life. The finding indicated that the family caregivers who perceived high caregiver burden were more likely perceived lower quality of life. The result from the current study was consistent with others studies.^{4, 8, 15} However, this finding was contrary to that reported by Kate et al.¹² who found that caregiver burden was not significantly correlated to the quality of life. The possible reason for this difference could be the characteristics of caregivers, including gender and employment status. The majority of the caregivers in this study were females. On the other hand, the previous study found that the majority were males¹³. Thus, it could be related to how they perceive caregiver burden while taking care the patients.

There were some other studies supported that taking care patients with schizophrenia might have been experienced as a stressful event for the family caregivers. The family caregivers reported having to go through economic problems, enjoyed less time for socialization and distress feeling.²⁴

Consequently, the family caregivers reported the low score on their quality of life.^{6,16,17} Hence, attempts to alleviate the caregiver burden are essential for the quality of life of the family caregivers.

Regarding the relationship between perceived social support and quality of life, it was revealed that the perceived social support was strong significantly positively correlated with the quality of life. Also, all subscales in the perceived social support showed a positive relationship with quality of life. The moderate relationship between QoL and perceived social support from significant other and friends and the strong relationship between QoL and perceived social support from family were found in this study. It means, the family caregivers who have high perceived social support, also perceived higher quality of life. The finding of this study was consistent with previous studies.^{5,14,25} However, the finding was inconsistent with study conducted by Kate et al.,¹² which revealed that social support was not statistically significant related to the quality of life. The possible reasons for this difference could be the characteristic of caregivers, such as gender. Previous study revealed that two-third of respondents were male family caregivers;¹² Otherwise, the current study showed two-third of respondents were female family caregivers, which could perceive differently regarding the availability of social support. Interestingly, the perceived

social support from family showed as the strongest relationship with the quality of life compare to other sources of social support. The finding was consistent with a study conducted by Wang and Zhao,²⁶ which revealed that social support from family was a strong factor related to quality of life. It could be appointed that the caregivers who got help and support from other family members for taking care the patients were more likely reported higher quality of life. These findings are in line with the Lakey and Cohen' theory of social support explaining that the belief that support was available could decrease the effect of stress and might have protected the individual against the adverse effects of stressor. It could be appointed that the adverse effect, which is the low quality of life of the caregivers could be prevented by strengthening the social support as a protective factor. Thus, to improve the quality of life among the family caregivers, it is important to encourage the caregivers to obtain and maintain the social support from three sources, including significant other, family, and friends.

The results of this study showed that health status as a caregiver' factor was moderately significantly related to quality of life. Caregiver situation, including, perceived control of symptoms and caregiver burden were found to correlate with the quality of life. Additionally, a positive relationship between perceived social support as an environmental

factor and quality of life was also found. The results indicated that the family caregivers who perceived better health status, higher perceived control of symptoms, lower caregiver burden, and high perceived social support were more likely to have the higher quality of life. The results of study can be a source of information to develop an intervention for improving the quality of life by enhancing the capability of the caregivers to control the symptoms of patients, maintaining the social support, and alleviating the caregiver burden by considering their current health status.

In conclusion, this study only describes the relationships between health status, perceived control of symptoms, caregiver burden, perceived social support with quality of life. The reviewed literature explains that many factors correlated with quality of life, for instance, psychological morbidity of the caregivers, coping strategies, and satisfaction with health services. Other factors which were not included in this study should be taken into account for further research related to quality of life.

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