



THE RELATIONSHIPS BETWEEN CHARACTERISTICS OF CAREGIVERS AND QUALITY OF LIFE AMONG FAMILY CAREGIVERS OF PATIENTS WITH SCHIZOPHRENIA IN INDONESIA

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ABSTRACT

Limited research has been undertaken regarding quality of life among family caregivers of patients with schizophrenia in Indonesia despite the burden they perceived as the impact of caregiving. This study explored the caregiver burden and identified the relationships between characteristics of caregivers and the quality of life. A cross-sectional design was used with 137 family caregivers were recruited from the outpatient department of mental hospital. The characteristics of caregiver form, Burden Assessment Schedule (BAS) and Schizophrenia Caregiver Quality of Life (S-CGQoL) were provided based upon the validity and reliability test. Statistical analyses were conducted by employing descriptive and bivariate analyses. The significant factors related to quality of life consisted of gender, level of education, and employment status. This study suggests that female family caregivers who had low education, and being employed suppose to be the priority regarding the attempts to improve the QoL.

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KEYWORDS: Quality of life, Caregiver burden, Family caregivers, Schizophrenia.

INTRODUCTION

Mental illness is increasingly becoming an issue which has been impairing caused by the impact of the illness in many countries around the world. Schizophrenia as severe mental illness was reported as one of the important causes of disability in the world (Murray *et al.*, 2012). Furthermore, the prevalence of schizophrenia reached 26.3 million people in the world and 6.2 million in South-East Asia (World Health Organization (WHO), 2008). For Indonesia, the report of the Ministry of Health Republic of Indonesia (2013) showed that the prevalence of severe mental illness in Indonesia was 17 per 10,000 people, which the prevalence in Jakarta as the capital city of Indonesia was still higher than the majority of provinces in Indonesia (Ministry of Health Republic of Indonesia, 2013).

The significance of the mental illness has been given attention showed by an amount of previous studies about the impact of mental illness to the patients (Greenberg *et al.*, 2006), (Hwang *et al.*, 2009). Even though the impact of mental illness to patient was widely studied, but the impact to the quality of life of family caregivers while caring for their patients had not been given much attention and this should receive more consideration.

The impacts of schizophrenia were devastated because the patients developed a dysfunction in the cognitive and social ability (Hooley, 2010), (Foldemo *et al.*, 2005); therefore, reducing the impact of schizophrenia is important. The family of patients with schizophrenia are required to take an important role in the caregiving caused by the shifting of healthcare from hospital-based care to community-based care. Therefore, the family members assumed the role as caregivers of the patients could be considered as one resource to promote the health of the patients. A previous study found that patients with schizophrenia living and having a close relationship with their families had achieved the highest score in terms of their quality of life (Greenberg *et al.*, 2006). On

the other hand, caregiving activities for the patients with schizophrenia were experienced by family caregivers as demanding events affected the quality of their lives (Foldemo *et al.*, 2005). As a result, family caregivers of patients with schizophrenia perceived poor quality of life (Boyer *et al.*, 2012). Moreover, the family caregivers of patients with schizophrenia also perceived poor quality of life compared to the general population (Foldemo *et al.*, 2005), (Angermeyer *et al.*, 2006). Thus, the negative impact of caregiving to the family caregivers is an important issue that needs to be further explored. The quality of life is a multi-dimensional concepts. The quality of life was 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” (WHOQOL Group, 1997). As a multi-dimensional concept, the quality of life consists of physical, social, psychological, and environmental factors. Thus, the taking care patient with schizophrenia might influence to the perception of the family caregivers related to some aspects in their life that perceived as their quality of life.

Previous studies revealed that the relationships between characteristics of caregivers, including gender, level of education, period of being a caregiver, and employment status were still inconclusive (Foldemo *et al.*, 2005), (Wong *et al.*, 2012), (Maldonado *et al.*, 2005). It might be caused by cultural differences in the setting of the study, which mostly conducted in Western and Europe countries. Thus, the results of previous studies might not be able to apply for all countries. Interestingly, the characteristics of caregivers made the highest contribution to the quality of life among other factors, including from the stress or the satisfaction of the health service (Wong *et al.*, 2012). Furthermore, most of the previous studies investigated the QoL of the caregivers were measured by using the general instrument (Foldemo *et al.*, 2005), (Boyer *et al.*, 2012). Thus, it seemed to be important to identify the relationships between characteristics of caregivers and quality of life among family caregivers of patients with schizophrenia by using an instrument developed based on point of view of the caregivers. The findings of this study are expected to be used as the basis of sources for intervention development to improve the quality of life, specifically by organizing their characteristics.

LITERATURE REVIEW

Families living with patients with schizophrenia condition could experience the disturbing role and function of the family and the relationship between the caregivers and their loved one. A previous study found that the family member who assumed the role to be a caregiver experienced a role distress and role overload caused by the caregiving (Quah, 2013). Moreover, families living with mentally ill patients had a negative feeling and dissatisfied with their life related to the aspect of financial, leisure opportunity, and the availability of information (Awadalla *et al.*, 2005). Previous studies revealed that taking care patients with schizophrenia perceived as a burden for the caregivers (Darwin *et al.*, 2013), (Kate *et al.*, 2013). Correlating the burden, family caregivers of patients with schizophrenia in Indonesia showed that 67.8 % of the caregiver perceived high caregiver burden (Darwin *et al.*, 2013). Thus, the perception of caregiver regarding the difficulties while providing care for the loved-one need to be assessed.

Moreover, the characteristics of the caregiver as a personal attribute of the family caregivers could be one of mainly factors that related to the quality of life. In general, female family member in Indonesia were the greater proportion that commonly assumed the role as family caregivers (Rafiyah *et al.*, 2011). Moreover, in this culture, it was common for the caregivers to feel hesitant to share the problem related to caregiving (Rafiyah *et al.*, 2011). Also, the greater number of the caregivers had the lowest level of education (Darwin *et al.*, 2013), (Rafiyah *et al.*, 2011). The characteristics might be different with family caregivers in Western countries that have higher levels of education and better provision of health care services. Numerous studies attempted to identify the relationships between characteristics of caregivers and quality of life. For instance, the female family caregiver were more likely to perceive lower quality of life (Awadalla *et al.*, 2005), (Richieri *et al.*, 2011). Regarding the level of education, previous studies suggested that the degree of education was associated with the caregiver’s quality of life (Wong *et al.*, 2012), (Zamzam *et al.*, 2011). Likewise, the period of time that family member assumed role as caregiver also related to the quality of life. Previous study suggested that the longer time the caregiver provided care

were more likely to perceive low quality of life (Quah, 2013). Other previous studies showed that characteristics of caregivers, that is employment status was significantly related to the quality of life (Maldonado *et al.*, 2005), (Zamzam *et al.*, 2011).

Hence, the relationships between characteristics of caregiver and the quality of life remained unclear and needed further explored.

METHODOLOGY

A. Design

A cross-sectional study design was employed.

B. Sample

The total participants in this study were 137 family caregivers who selected by purposive sampling according to inclusion and exclusion criteria. The inclusion criteria were caregivers who: (1) 18-65 years old; (2) had taken care a patient with schizophrenia, according to the International Classification of Disease-10 (ICD-10); (3) had taken care a patient who is functioning stably in the community that is 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) had taken care of more than one family member with mental illness; (2) taken care patient with comorbid schizophrenia and substance abuse.

C. Data Collection

An ethical approval had been granted previously 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 participant information sheet. The family caregivers who met the inclusion criteria and who were willing to participate were asked to sign the informed consent form. The data were collected in two months (July to August, 2014) at the outpatient department of Mental Hospital Dr. Soeharto Heerdjan, Jakarta, Indonesia.

D. Measurement Tools

All questionnaires were granted the permission from the authors and translated by using back-translation technique by sworn translators.

1). *The Schizophrenia Caregiver Quality of Life questionnaire (S-CGQoL)*: The questionnaire was developed by Richieri *et al.* (2011), which consists of 25 items 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 questionnaires were rated using a six point Likert scale, defined as "1 = Never", "2 = Rarely", "3 = Sometimes", "4 = Often", "5 = Always", and "6 = Not applicable". All dimensions score linearly transformed into a 0 to 100 scale, with 100 indicating the best possible level of QoL and 0 the worst. The Cronbach's alpha reliability coefficient in this study was 0.85.

2). *Characteristics of Caregiver Form*: The questionnaire was developed by the researcher based on literature review, including gender, level of education, period for being a caregiver, employment status of the caregiver.

3). *Burden Assessment Schedule (BAS)*: The questionnaire was used to measure the burden of the family which developed by Thara *et al.* (1998) and translated in Bahasa Indonesia version by Djatmiko (2005). The BAS consists of 20 items measured both objective and subjective caregiver burden. The higher score indicated higher caregiver burden. The Cronbach's alpha reliability coefficient in this study was 0.78.

E. Data Analyses

The statistical analyses employed by a computer program. Mean, standard deviation, range, and percentage were used to describe the characteristics of caregivers. Mean and standard deviation were calculated for further analyses of quality of life and its domains. The correlation

between the characteristics of caregivers and quality of life were analyzed by Spearman-Rank Order correlation.

RESULTS

A. Characteristics of Caregivers

Total respondents in the current study were 137 family caregivers which revealed that 74.45 % were females. Regarding the level of education, 37.22 % of respondents were in elementary school, followed by senior high school (34.31%), junior high school (18.25 %), and higher education (10.22 %). The period of being a caregiver ranged from 1 year to 18 years ($M = 6.51$ years, $SD = 4.89$ years). Regarding the employment status, 57.66 % of respondents were unemployed.

B. Caregiver Burden among Family Caregivers of Patients with Schizophrenia

Table-1. Mean, Standard Deviation, and Percentage of High Level of Caregiver Burden and Its Domains among Family Caregivers of Patients with Schizophrenia (N = 137)

Caregiver Burden and Domains	High burden (%)	Mean (SD)
Caregiver burden	67 (48.90)	29.88 (5.21)
• Impact on well-being	25 (18.25)	7.18 (1.69)
• Marital relationships (N =53)	20 (37.73)	6.98 (1.94)
• Appreciation for caring	17 (12.41)	7.29 (1.27)
• Impact on relations with others	48 (35.03)	5.94 (1.61)
• Perceived severity of the disease	53 (38.68)	6.74 (1.74)

Table 1 showed that nearly half of the family caregivers reported high level of caregiver burden ($M = 29.88$, $SD = 5.21$). Regarding to the domains, the high level of caregiver burden was reported mainly related to the perceived severity of the illness (38.68 %). In addition to that, the results revealed that the highest mean score amongst domains was appreciation for caring ($M = 7.29$, $SD = 1.27$).

C. Quality of Life among Family Caregivers of Patients with Schizophrenia

The score of quality of life were normally distribute among the family caregivers. The descriptive and bivariate analyses as follows:

Table 2 displayed the global quality of life index and dimension of quality of life perceived by the family caregivers. The total mean score of quality of life, the global quality of life index was 60.9 ($SD = 14.66$). The highest score of domain of quality of life was relationship with psychiatric team ($M = 70.66$, $SD = 22.68$), followed by material burden ($M = 66.91$, $SD = 23.32$), relationship with family ($M = 66.14$, $SD = 27.99$), psychological burden and daily life ($M = 58.83$, $SD = 19.23$), psychological and physical well-being ($M = 55.07$, $SD = 18.64$), relationship with spouse ($M = 50.21$, $SD = 28.85$), and relationship with friends ($M = 49.63$, $SD = 31.07$).

Table-2. Mean and Standard Deviation of Quality of Life and Its Domains among Family Caregivers of Patients with Schizophrenia (n = 114)

Quality of Life and Dimensions	Mean	Standard Deviation
Quality of life	60.98	14.66
• Psychological and physical well-being	55.07	18.64
• Psychological burden and daily life	58.83	19.23
• Relationship with spouse	50.21	28.85
• Relationship with psychiatric team	70.66	22.68
• Material burden	66.91	23.32
• Relationship with family	66.14	27.99
• Relationship with friends	49.63	31.07

Table-3. The Correlations between Gender, Level of Education, Period of being a Caregiver, Employment Status, and the Quality of Life (QoL)

Characteristic	Correlation with the QoL	
	<i>rho</i>	<i>p</i> - value
• Gender	0.198	0.035*
• Level of education	0.324	0.000**
• Period of being a caregiver	-0.084	0.374
• Employment status	0.191	0.042*

Note: * $p < 0.05$; ** $p < 0.001$

The results revealed that the greatest magnitude of the relationship was the level of education ($rho = 0.324$, p -value < 0.001), followed by gender and employment status ($rho = 0.198$, p -value < 0.05 ; $rho = 0.191$, p -value < 0.05 , respectively). The findings indicated that level of education, gender, and employment status were positively significantly correlated with the quality of life.

DISCUSSION

A. Caregiver Burden among Family Caregivers of Patients with Schizophrenia

Regarding the caregiver burden, the results pointed out that nearly half of the caregivers experienced the difficulties while taken care the patients. The difficulties perceived by the caregivers, mostly about the caregiver's perception related to the severity of the patient's illness that showed unpredictable behavior and about appreciation that they had for caring the patients from others. The result was supported by previous studies (Darwin *et al.*, 2013), (Kate *et al.*, 2013). Therefore, this study suggested that for maintaining the level of caregiver burden, the health care provider need to involve other family member to be more appreciated the role of caregivers by being engaged in the treatment of the patients. Moreover, the perceived of severity of the disease also could not be underestimating that made the caregivers need to be knowledgeable related to the symptoms of the illness. Thus, they could manage their burden.

B. Quality of Life among Family Caregivers of Patients with Schizophrenia

In this study, the quality of life among family caregivers were measured by the Schizophrenia Caregiver Quality of Life (S-CGQoL) (Richieri *et al.*, 2011). The result showed that the total mean score for global quality of life index was 60.98 (SD = 14.66). The finding showed a lower mean score compare to the total mean score of QoL from a previous study conducted in Europe (Richieri *et al.*, 2011). Taking care patient with schizophrenia might have been perceived as a stressful event for the caregiver that made the caregiver perceived their quality of life as poorer. Moreover, the lower total mean score might have been caused by different culture and characteristics of caregivers between the population of the current study and previous study (Richieri *et al.*, 2011) that could lead to the family caregivers in this study perceived the quality of life lower.

Interestingly, regarding the result in TABLE 2 showed that the highest mean score of quality of life' domain were relationship with psychiatric team, followed by material burden, and relationship with family. The findings pointed out that the majority of the caregivers satisfied with the health services provided by psychiatric health provider, including a routine nursing consultation for the patients and family, beside psychiatric consultation and examination that made the family caregivers more likely to perceive higher in its domain. The finding was consistent with a previous study, which revealed that satisfaction with mental health services was positively significantly related to the quality of life of the family caregivers (Wong *et al.*, 2012). However, a concern should be taken that the finding might also source of bias since this study conducted in health care service, which could make the respondents tended to report the favorable answers in this study.

With regard to the relationships between characteristics of caregivers and the QoL, the results showed that gender, level of education, and employment status were related to the quality of life. Correlating with that, the level of education showed the strongest relationship amongst other

characteristics. The finding pointed out that the higher the level of education, also the highest score of quality of life perceived by the caregivers. The finding was consistent with previous studies (Wong *et al.*, 2012), (Zamzam *et al.*, 2011). The finding is expected that higher level of education could make the caregivers have a better understanding and knowledge about the role in taking care patient with schizophrenia. Regarding the gender, this study revealed that gender was weak positively related with the QoL. This found that female family caregivers were more likely to perceive the low quality of life. The finding confirmed previous studies, which revealed that female family caregivers tended to report poor quality of life (Awadalla *et al.*, 2005), (Zamzam *et al.*, 2011). Moreover, employment status was weak positively related with the QoL. It pointed out that the family caregivers who were unemployed were more likely to perceive higher quality of life. The finding was consistent with a previous study (Zamzam *et al.*, 2011). The results from current study can be concluded that the family caregivers who were unemployed were assumed to have more time to manage the difficulties in the daily caregiving activities; thus, it could relate to how they perceive the QoL.

Although the findings of the current study bring about information regarding significant factors influencing quality of life, limitation of the study need to be addressed. For example, the sample was selected by purposive sampling, which was drawn from the family caregivers in only one geographical in Jakarta, Indonesia; therefore, it is limited to generalize the result of the study. Moreover, it might have other modifiable factors from the characteristics of caregivers related to QoL, which could not explain in this study, for instance, previous study suggested the relationships between perceived health status and quality of life.

CONCLUSION

The study aimed to identify the relationships between gender, level of education, period of being a caregiver, employment status and quality of life among family caregivers of patients with schizophrenia in Indonesia. The dimension of relationship with psychiatric team was founded as the highest mean score, among other dimensions of QoL. Therefore, nurses as part of health care providers have an important role to help the family caregivers to achieve a better quality of life while taking care patients with schizophrenia. Statistically significant relationships were found between gender, level of education, employment status and quality of life. The current study suggested that the level of education was the strongest factors related to QoL amongst the other characteristics. The findings suggested that the lower educated, being females and employed caregivers were more likely to report low score of QoL. The findings could be used as the sources for intervention development for family caregivers of patients with schizophrenia by organizing the characteristics supposed to be the priority for improving the quality of life.

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