FACTORS AFFECTING QUALITY OF LIFE AMONG FAMILY CAREGIVERS OF PATIENTS WITH SCHIZOPHRENIA IN INDONESIA

Karina Megasari Winahyu[1, *], Monthana Hemchayat[2], Sukjai Charoensuk[3]

[1] Universitas Muhammadiyah Tangerang, Banten, Indonesia
[2] Boromarajanani College of Nursing Nopparat Vajira, Bangkok 10230, Thailand
[3] Boromarajanani College of Nursing Chakriraj, Ratchaburi 70110, Thailand

ABSTRACT:

Background: Schizophrenia is a severe mental illness that has significant effects for patients and their families. The impact of the illness has forced the family to assume the role of caregiver for their loved one. Since the caregiving activities help the patients functioning stably in the daily life, this situation could bring negative consequences for the quality of life (QoL) of the family caregivers. The study aimed to examine the factors affecting quality of life among family caregivers of patients with schizophrenia in Indonesia.

Methods: A cross-sectional study recruited 137 family caregivers of patients with schizophrenia in a mental hospital in Jakarta, Indonesia. The characteristics of caregiver form, Burden Assessment Schedule, Perceived Control of Symptom Scale, Multidimensional Scale of Perceived Social Support, and Schizophrenia Caregiver Quality of Life were provided based upon the validity and reliability test. A linear regression was performed to determine factors affecting the quality of life.

Results: The study revealed that caregiver burden negatively affected the QoL, though employment status and perceived social support positively affected quality of life among family caregivers taking care patients with schizophrenia in Indonesia, while gender, period of being a caregiver, education, health status, and perceived control of symptoms were not significant factors.

Conclusion: This study suggests that maintaining low caregiver burden, encouraging the caregivers to obtain high social support, and prioritizing the employed caregivers need to be considered for improving the QoL of family caregivers.

Keywords: Quality of life, Family caregivers, Schizophrenia, Indonesia

DOI: 10.14456/jhr.2015.52 *Received: May 2015; Accepted: June 2015*

INTRODUCTION

Schizophrenia is a severe mental illness, resulting in impairing and debilitating worldwide. The Global Burden of Diseases Report [1] revealed that schizophrenia mainly contributed to the disability around the world. The disability of the patients has disturbed the capabilities of people with mental illness and in turn could have an effect on their families.Consequently, the living skills of patients with schizophrenia will be dependent on their families.

As the shifting of health care system from hospital-based care to community-based care, family members assumed the role as caregivers could give a positive contribution to the health status of the patients living in the family in the community. However, the situation also might bring a negative impact to the family caregivers while fulfilling their caregiving task. Previous studies found that family caregivers experienced physical and psychological problems while taking care patients with schizophrenia [2, 3]. Because of the chronicity of the illness, family caregivers have to provide long term care for their loved-one, and this situation in turn could affect to their quality of life as the impact of caregiving.

Quality of life (QoL) is defined by World Health Organization (WHO) [4] as an individual's perception of their position in life in the context of

[*] *Correspondence to: Karina Megasari Winahyu*
E-mail: karinawinahyu@yahoo.com

Cite this article as: Winahyu KM, Hemchayat M, Charoensuk S. Factors affecting quality of life among family caregivers of patients with schizophrenia in Indonesia. J Health Res. 2015; 29(Suppl.1): S77-82. DOI: 10.14456/jhr.2015.52

the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. The multi-dimensional concept of QoL consists of physical, social, psychological, and environmental domains. A conceptual model developed by Wong and colleagues pointed out that the characteristics of caregivers, caregiving situation, and environmental factors were factors affecting quality of life perceived by family caregivers of patients with mental illness [5]. Moreover, several previous studies found that factors influencing QoL of the caregivers consisted of characteristics of caregivers, caregiver burden, perceived control of symptoms, and perceived social support [5-12]. These might be caused by cultural differences in the setting of the study, which mostly conducted in Western and Europe countries. Therefore, the results of previous studies might not be able to apply to all countries. Thus, it is important to examine factors influencing the QoL by using an instrument developed based on point of view of the caregivers and using a conceptual model purposed to assess the factors affecting QoL among family caregivers of patients with schizophrenia in Indonesia.

METHODS

Research design and sample

A cross-sectional study recruited 137 family caregivers of patients with schizophrenia by purposive sampling. The inclusion criteria were caregivers who (1) 18-65 years old; (2) have taken care a patient with schizophrenia according to 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 patient with comorbid schizophrenia and substance abuse.

Research instrument

Data were collected by using five questionnaires which three of them had been granted the permission from the authors and other two of them were developed by the researcher. The content validity of the instrument carried out by three experts who were experienced working with the family in mental health services in Indonesia, including, mental health nurse, psychiatrist, and psychologist in the outpatient department in the setting of this study. The internal consistency of reliability was conducted with 30 family caregivers who had the same inclusion criteria with the sample of the study.

1. The characteristics of caregiver questionnaire assessing the characteristics of caregivers, including age, gender, level of education, period of being a caregiver, employment status, and health status. The Content Validity Index for Scale (S-CVI) measured for content relevance that was 0.98 and for content clarity 0.95.

2. The Schizophrenia Caregiver Quality of Life Questionnaire (S-CGQoL) was developed by Richieri and colleagues, assessing the quality of life of caregivers consisted 25 items were rated using a six point Likert scale, defined as 1 = Never, 2 = Rarely, 3 = Sometimes, 4 = Often, 5 = Always, and 6 = Not applicable [13]. All dimensions score linearly transformed into 0 to 100, with 100 indicating the best possible level of QoL and 0 the worst [13]. The Cronbach's alpha reliability coefficient in this study was 0.85.

3. Burden Assessment Schedule (BAS) was used to measure the burden of the family, which developed by Thara and colleagues [14] and translated in Bahasa Indonesia version by Djatmiko [15]. The BAS consisted 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.

4. Perceived control of symptoms scale was developed by the researcher. The scale measured the perception of the caregiver to control the symptoms of patients by ranging from 0 to 10, which 0 represented completely cannot control the symptoms to 10 represented completely able to control the symptoms. The content validity of the questionnaire was examined by the three experts and the content validity index showed 0.91 for both content relevant and content clarity. The content validity index for the scale met Lynn's criteria for content validity ≥ 0.90 [16]

5. Multidimensional Scale of Perceived Social Support (MSPSS) consisted of 12 items assessing perceived social support of the caregivers from significant others, family, and friends [17]. The Cronbach's alpha reliability coefficient in this study was 0.85.

Data collection and ethical consideration

Data were collected during July-August, 2014. After getting approval from the Review Board Committee for Research Involving Human Research Subjects, Boromarajonani College of Nursing

Table 1 Descriptive statistic of the characteristics of caregivers taking care patients with schizophrenia (n = 137)

Characteristics of caregiver	Number	%
Gender		
Female	102	74.45
Male	35	25.55
Level of education		
Elementary	51	37.22
Junior high	25	18.25
Senior high	47	34.31
Higher education	14	10.22
Period of being a caregiver (years)		
1 - 5	77	56.20
6 - 10	36	26.28
>10	24	17.52
Health status		
Poor	42	30.66
Good	95	69.34
Employment status		
Employed	58	42.34
Unemployed	79	57.66

Table 2 Descriptive statistic of caregiver burden, perceived control of symptoms, perceived social support, and quality of life (n = 137)

Variables	M	SD	Range[a]	Range[b]
Caregiver burden	29.88	5.21	19 - 41	20 - 60
Perceived control of symptoms	6.65	2.16	1 - 10	0 - 10
Perceived social support	4.63	0.96	2.17 - 6.58	1 - 7
Quality of life (n = 114)	60.98	14.66	25.15 - 97.24	25 - 125

Range[a] = Range of score based on sample's responses
Range[b] = Range of score based on the questionnaires

Nopparat Vajira Ethics (ERB No. 42/2014) and permission letters from the head of Mental Hospital Dr. Soeharto Heerdjan Jakarta to collect data in the outpatient department of Mental Hospital Dr. Soeharto Heerdjan Jakarta. For family caregivers who met the inclusion criteria were offered to be the participants of the study. The participation was voluntary. For the confidentiality of participants' data, a protective password computer was used and the results would be destroyed after two years.

Data analysis

The data analysis was performed by using a computer software program. The data analyses were begun by descriptive analysis of caregiver burden, perceived social support, and quality of life. Descriptive analysis was performed to compute the mean and standard deviation for continuous variables, and frequency and percentage for categorical. The linear multiple regression was performed to determine factors influencing quality of life among family caregivers of patients with schizophrenia.

RESULTS

Characteristics of caregiver

Out of 137 family caregivers 74.5 % were females, the level of education were elementary school (37.2 %) and unemployed (57.7 %). Out of the total respondent, periodof being a caregiver ranged from 1 year until 18 years (M = 6.51 years, SD = 4.89 years) and 69.3 % of family caregivers rated their health status as good health (Table 1).

Table 2 showed that the maximum reported score of caregiver burden was 41 with the mean score was 29.88 (SD = 5.21). For the perceived control of symptoms, the mean score was 6.65 (SD = 2.16). Concerning the perceived social support, the maximum reported score was 6.58 with the mean score was 4.63 (SD = 0.96). Regarding the quality of life, the total mean score was 60.98 (SD = 14.66) out of 125 as the possible total score of the quality of life.

Standard multiple regression was used to assess the ability of gender, level of education, period for being a caregiver, employment status, health status,

Table 3 Standard multiple regression of variables on quality of life among family caregivers of patients with schizophrenia (n = 114)

Model	b	SE	Beta	*t*	*p*-value
Gender	0.33	2.26	0.01	0.14	0.884
Level of education	3.66	2.01	0.12	1.82	0.071
Period of being a caregiver	-0.17	0.19	-0.05	-0.90	0.369
Employment status	4.42	1.93	0.15	2.28	0.024
Health status	0.60	0.48	0.08	1.25	0.211
Perceived control of symptoms	0.36	0.50	0.05	0.72	0.471
Caregiver burden	-1.09	0.19	-0.39	-5.67	<0.001
Perceived social support	6.05	1.10	0.40	5.47	<0.001
Dependent variable: Quality of life					
Constant = 52.57, R^2 = 0.576, Adjusted R^2 = 0.544, F (8, 105) = 17.86, p<0.001					

*p< 0.05, **p< 0.001

perceived control of symptoms, caregiver burden, and perceived social support to predict quality of life. Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, multicollinearity and homoscedasticity. Regarding the result from Table 3, factors significantly influencing to quality of life were perceived social support (Beta = 0.40, p <.001), followed by caregiver burden (Beta = -0.39, p <.001), and employment status (Beta = 0.15, p<.05). All variables in the regression model explained 54.4 % of variance of quality of life in this study. The predicted equation is as follows:

Quality of life' = 52.57 + 0.33gender + 3.66level of education – 0.17period of being a caregiver + 4.42employment status + 0.60health status + 0.36perceived control of symptoms – 1.09caregiver burden + 6.05perceived social support.

DISCUSSION

Regarding the results of factors affecting quality of life, three factors, including perceived social support, caregiver burden, and employment status were found statistically significantly influenced to quality of life among family caregivers of patients with schizophrenia in Indonesia. Perceived social support showed the strongest unique contribution to explaining the quality of life, followed by caregiver burden and the employment status, which made a less unique contribution to explaining the quality of life. The findings indicated that the quality of life of the caregivers was influenced by their perception related to the availability of social support from significant others, family, and friends.

Concerning the employment status, the result showed that employment status positively influenced the quality of life. The finding indicated that being unemployed will increase the quality of life perceived by the family caregivers. The study showed that the majority of family caregivers were unemployed, which means that they did not have regular income by themselves. The possible reason to explain this finding is in the culture of Indonesia, it was common that other family members will support each other, including the financial support; thus, it might affect to how the family caregivers evaluate some aspects of their life. The finding was consistent with a study reported by Zamzam et al. [10] who suggested that family caregivers who were unemployed were more likely to report higher in physical and psychological domain of the quality of life. The possible reason to explain the consistency is the unemployed family caregivers are more likely to have more time to manage the difficulties in caregiving task and have less adjustment between the working life and the caregiving activities, which could influence to the better perception regarding the quality of life.

For the caregiver burden, it made a moderate unique contribution to explaining the quality of life compare to the perceived social support and employment status. The finding pointed out that higher score of caregiver burden will influence to lower quality of life. This could possibly happen since providing long term care for the patient is perceived as a stressful event might lead to the family caregivers evaluate themselves as poor quality of life. This finding was supported by previous studies found that the caregiver burden had a stronger effect on the quality of life and predicted the physical, psychological, social, and environmental domains of the quality of life [8, 18]. The caregiving situation, as demanding activities for the caregivers resulted to the caregivers go through economic problems, enjoyed less time for socialization and caused distressed feelings [19]. Therefore, the finding of the present study confirmed that taking care of a patient with schizophrenia was perceived as a burden by the

family caregivers and in turn, the difficulties experienced by the family caregivers affect to how they perceived the quality of life.

Concerning the perceived social support, the current study found that perceived social support made the strongest unique contribution to explaining the quality of life, when the variance explained by gender, level of education, period of being a caregiver, employment status, health status, perceived control of symptoms, and caregiver burden was controlled. The finding revealed that perceived social support positively influenced the quality of life. It means that the higher perceived social support will influence to higher quality of life. The possible reason to explain this finding is that the perception of availability of support from three resources of support, including significant other, family, and friends might have been used as the emotional support, which helped the family caregivers relieving the distress feeling caused by the caregiving activities. Thus, the family caregivers may feel more satisfied in evaluating the aspects of life as the impact of taking care the patients for the family caregivers perceived that they had other people to rely on in the stressful events. As a result, it could contribute to the high score of the QoL.

The finding of the study was in line with a previous study suggested that social support of the caregiver influenced the quality of life among family caregivers with mental illness [8]. Moreover, Cohen and Hoberman [20] stated that the belief that the support was available decreased the effects of stress. Thus, social support perceived by the family caregivers in this present study could be a factor helped to reduce the negative impact of caregiving. Therefore, the perceived social support is an important factor could be used to prevent the negative impact, which is the poor quality of life while providing care for the patients.

Regarding the result of the model of standard multiple regression in this study, it pointed out that 54.4 % of the variation in quality of life of family caregivers of patients with schizophrenia in Indonesia can be explained by differences in gender, level of education, period of being a caregiver, employment status, health status, perceived control of symptoms, caregiver burden, and perceived social support. However, gender, level of education, period of being a caregiver, health status, and perceived control of symptoms were not making statistically significantly unique contribution to the prediction of the quality of life of family caregivers. The results indicated that even though female or male, low or high level of education, the amount of years of being a caregiver, perceived poor or good health status, and perceived controlled or uncontrolled the symptoms of patients could not predict the quality of life of the family caregivers. The finding of this study was supported by previous study [3, 18, 21, 22]. It could be caused by the multicollinearity between the predicting factors in this study. According to Tabachnik and Fidel [23], the multicollinearity between each independent variable affect their own contribution to the multiple regression model. Thus, gender, level of education, period of being a caregiver, health status, and perceived control of symptoms did not directly influenced the QoL in this study.

CONCLUSION

The findings revealed that the significant factors influencing the QoL were perceived social support, caregiver burden, and employment status. In addition, it was also found that the perceived social support showed the strongest contribution to the quality of life, followed by caregiver burden, and employment status when the variance explained by other factors were controlled. The study also reported that the model of the standard multiple regression accounted for 54.4 per cent of the variance in the quality of life among family caregivers of patients with schizophrenia in Indonesia. Thus, this means there are other factors, which could explain the variability of QoL that the findings of this study could not explain. Concerning the generelizeability of the findings, a probability sampling need to be applied for further studies. In conclusion, this study suggests that the higher score of QoL will be achieved by maintaining the caregiver burden and social support, especially for the employed family caregiver.

ACKNOWLEDGEMENTS

The deepest gratitude goes to Directorate General of Higher Education (DGHE) of Indonesia for supporting this study and thank to all of the participants in this study and Mental Hospital Dr. Soeharto Heerdjan Jakarta. The highest appreciation is directed to Kasetsart University, the Ethics Review Board Committee for the ethical consideration approval, and Boromarajonani College of Nursing Nopparat Vajira for providing the facilities during the period of study of the principal investigator in Thailand.

REFERENCES

1. Murray CJ, Ezzati M, Flaxman AD, Lim S, Lozano R, Michaud C, et al. GBD 2010: design, definitions, and metrics. Lancet. 2012 Dec; 380(9859): 2063-6. doi: 10.1016/S0140-6736(12)61899-6.

2. Caqueo-Urizar A, Gutierrez-Maldonado J, Miranda Castillo C. Quality of life in caregivers of patients with schizophrenia: a literature review. Health Qual Life Outcomes. 2009; 7: 84. doi: 10.1186/1477-7525-7-84.
3. Kate N, Grover S, Kulhara P, Nehra R. Relationship of quality of life with coping and burden in primary caregivers of patients with schizophrenia. Int J Soc Psychiatry. 2014 Mar; 60(2): 107-16. doi: 10.1177/0020764012467598.
4. World Health Organization [WHO]. Programme on mental health: WHOQOL measuring quality of life [Internet]. Geneva: WHO; 1997. [Cited 2013 Aug 20]. Available from: http://www.who.int/mental_health/media/68.pdf
5. Wong DF, Lam AY, Chan SK, Chan SF. Quality of life of caregivers with relatives suffering from mental illness in Hong Kong: roles of caregiver characteristics, caregiving burdens, and satisfaction with psychiatric services. Health Qual Life Outcomes. 2012; 10: 15. doi: 10.1186/1477-7525-10-15.
6. Awadalla AW, Ohaeri JU, Salih AA, Tawfiq AM. Subjective quality of life of family caregivers of community living Sudanese psychiatric patients. Soc Psychiatry Psychiatr Epidemiol. 2005 Sep; 40(9): 755-63. doi: 10.1007/s00127-005-0947-x.
7. Li J, Lambert CE, Lambert VA. Predictors of family caregivers' burden and quality of life when providing care for a family member with schizophrenia in the People's Republic of China. Nurs Health Sci. 2007 Sep; 9(3): 192-8. doi: 10.1111/j.1442-2018.2007.00327.x.
8. Chou YC, Pu CY, Lee YC, Lin LC, Kroger T. Effect of perceived stigmatization on the quality of life among ageing female family carers: a comparison of carers of adults with intellectual disability and carers of adults with mental illness. J Intellect Disabil Res. 2009 Jul; 53(7): 654-64. doi: 10.1111/j.1365-2788.2009.01173.x.
9. Weimand BM, Hedelin B, Sallstrom C, Hall-Lord ML. Burden and health in relatives of persons with severe mental illness: a Norwegian cross-sectional study. Issues Ment Health Nurs. 2010 Dec; 31(12): 804-15. doi: 10.3109/01612840.2010.520819.
10. Zamzam R, Midin M, Hooi LS, Yi EJ, Ahmad SN, Azman SF, et al. Schizophrenia in Malaysian families: A study on factors associated with quality of life of primary family caregivers. Int J Ment Health Syst. 2011; 5(1): 16. doi: 10.1186/1752-4458-5-16.
11. Boyer L, Caqueo-Urizar A, Richieri R, Lancon C, Gutierrez-Maldonado J, Auquier P. Quality of life among caregivers of patients with schizophrenia: a cross-cultural comparison of Chilean and French families. BMC Family Practice. 2012; 13(1): 42. doi: 10.1186/1471-2296-13-42.
12. Gomez-de-Regil L, Kwapil TR, Barrantes-Vidal N. Predictors of expressed emotion, burden and quality of life in relatives of Mexican patients with psychosis. J Psychiatr Ment Health Nurs. 2014 Mar; 21(2): 170-9. doi: 10.1111/jpm.12071.
13. Richieri R, Boyer L, Reine G, Loundou A, Auquier P, Lancon C, et al. The Schizophrenia Caregiver Quality of Life questionnaire (S-CGQoL): development and validation of an instrument to measure quality of life of caregivers of individuals with schizophrenia. Schizophr Res. 2011 Mar; 126(1-3): 192-201. doi: 10.1016/j.schres.2010.08.037.
14. Thara R, Padmavati R, Kumar S, Srinivasan L. Instrument to assess burden on caregivers of chronic mentally ill. Indian J Psychiatry. 1998 Jan; 40(1): 21-9.
15. Djatmiko P. Validity and reliability of the Burden Assessment Schedule (BAS) to assess the burden of care experienced by the family of schizophrenia patients in Bahasa Indonesia. Indonesia: University of Indonesia; 2005.
16. Polit DF, Beck CT. The content validity index: are you sure you know what's being reported? Critique and recommendations. Res Nurs Health. 2006 Oct; 29(5): 489-97. doi: 10.1002/nur.20147.
17. Zimet GD, Dahlem NW, Zimet SG, Farley GK. The multidimensional scale of perceived social support. J Pers Assess. 1988; 52(1): 30-41. doi: 10.1207/s15327752jpa5201_2.
18. Fan CC, Chen YY. Factors associated with care burden and quality of life among caregivers of the mentally ill in Chinese society. Int J Soc Psychiatry. 2011 Mar; 57(2): 195-206. doi: 10.1177/0020764009348440.
19. Moller-Leimkuhler AM, Wiesheu A. Caregiver burden in chronic mental illness: the role of patient and caregiver characteristics. Eur Arch Psychiatry Clin Neurosci. 2012 Mar; 262(2): 157-66. doi: 10.1007/s00406-011-0215-5.
20. Cohen S, Hoberman HM. Positive events and social supports as buffers of life change stress1. J Appl Soc Psychol. 1983; 13(2): 99-125. doi: 10.1111/j.1559-1816.1983.tb02325.x.
21. Angermeyer MC, Kilian R, Wilms HU, Wittmund B. Quality of life of spouses of mentally ill people. Int J Soc Psychiatry. 2006 May; 52(3): 278-85.
22. Moller T, Gudde CB, Folden GE, Linaker OM. The experience of caring in relatives to patients with serious mental illness: gender differences, health and functioning. Scand J Caring Sci. 2009 Mar; 23(1): 153-60. doi: 10.1111/j.1471-6712.2008.00605.x.
23. Tabachnick BG, Fidell LS. Using multivariate statistics. 5th ed. Boston, Mass.: Pearson/Allyn & Bacon; 2007.