Original Article

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A Descriptive Study of Quality of Life of Caregiver in the Family of Schizophrenia Patients

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ABSTRACT

People with Schizophrenia frequently live with their families. Family is required to support schizophrenia patients. However, Family caregivers who take care of patients with schizophrenia tend to have burdens and stigma. Burden among family caregivers had an effect on the decreased quality of life. The purpose of this study was to describe the quality of life among family caregivers of schizophrenia patients. This study was a cross-sectional design. The inclusion criteria of this study were family caregivers with Schizophrenia outpatients in Menur Mental Hospital. The total sample in this study was 160 family caregivers using a simple random sampling technique. We collected the data from June to July 2021. We used the Schizophrenia Care Giver Quality of Life Questionnaire (S-CGQoL) to measure the quality of life among care givers. All data were inputted in SPSS. Descriptive statistics were used to calculate the mean, median, frequency, standard deviation, and percentage of variables. Most of the family caregivers had a very good quality of life (41.3%). The sociodemographic showed that most of the participants were female (54.4%), adult (55.0%), had senior high school degrees (51.9%), unemployed (45.6%), and the majority gender of patients was female (47.5%). In addition, all of the participants regularly check-up at Menur Mental Hospital (100.0%). Managing quality of life among family caregivers is required to provide for patient needs and the well-being of family caregivers.

Keywords: Quality of life; Family Caregiver; Schizophrenia

INTRODUCTION

People with Schizophrenia frequently live with their families, and family is required to support the schizophrenia patients (Caqueo-Urízar *et al.*, 2015). However, Family caregivers who take care of patients with schizophrenia tend to have burdens and stigma (Fitryasari *et al.*, 2018). Burden among family caregivers had an effect on the decreased quality of life of the family caregiver (Caro, Costa, & Da Cruz, 2018; Farzi *et al.*, 2019) as well as their performance to provide care for patients (Zendjidjian & Boyer, 2022). Family caregivers also experience changes in daily activities and all aspects of life (Chen *et al.*, 2019). The results of interviews with family caregivers of schizophrenic patients revealed that they were boring and tired. They also experience decreased concentration during work and get stigma.

The number of people with mental disorders was

around 24 million people worldwide with a similar ratio of males and females (James *et al.* 2018). In Indonesia, the number of mental disorders increased in 2018 (Riskesdas, 2018). In addition, there were 9,994 outpatients with schizophrenia in Menur Mental Health Hospital (Sustrami *et al.*, 2022). This number also had an effect on the total of the family caregiver, and it may have an effect on the negative effect on family caregivers.

Based on this background, the family caregiver is an important part of the patient's health outcome and play important role in caring the patients (Akbari *et al.*, 2018; Hamann & Heres, 2019). There were many studies regarding quality of life among family caregiver (Gilbertson *et al.*, 2019; Kang *et al.*, 2019), however this study focused on family caregiver who take care of schizophrenia patients. Therefore, the purpose of this

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study was to describe the quality of life among family caregivers with schizophrenia patients. This study is needed to understand the quality of life of family caregivers and to provide management for family caregiver.

METHODOLOGY

We used a cross-sectional design in this study. The inclusion criteria of this study were family caregivers with Schizophrenia outpatients in Menur Mental Hospital. The total sample in this study was 160 family caregivers using a simple random sampling technique. We collected the data from June to July 2021.

All of procedure in this study approved by ethical clearance number 070/3131/305/2021 from Menur Mental Hospital Surabaya dated June, 12. 2021. The data were collected using a self-report questionnaire. We used the Schizophrenia Care Giver Quality of Life Questionnaire (S-CGQoL) to measure the family caregiver's quality of life. It has 25 item and had 7 dimensions, namely psychological burden and daily life, psychological and physical well-being, relationship with spouse, relationship with family, relationship with psychiatric team, relationship with friend, and material burden. It uses Likert scale and five answer score: never, rarely, sometimes, often, and always. Score between 0-20 was very low/poor, 21-40 was low/poor, 41-60 was moderate, 61-80 was high/good, and 81-100 was very high/good. The Cronbach alpha of this questionnaire was 0.900. We already obtained permission from the previous author to use this questionnaire (Tristiana et al., 2019). All data were inputted in SPSS. Descriptive statistics were used to calculate the frequency, percentage of variables mean, median, and standard deviation.

RESULTS

Table 1 exhibited the demographic characteristic of the participants (n=160). The participants were predominantly categorized as adult (55%). The gender was equal, male (54.5%) and female (45.6%). Most of participants were unemployed (45.6%). About 59.4% participants had income less than Rp 1.800.000. Nearly 46.3% were parents of patients. There were 22.5% family caregiver had more than 10 years duration for caring the patients. In addition, 100% of patients with schizophrenia had routine treatment.

Characteristic	Total participants		
	Frequency	Percentage	
	(n)		
Age			
Children	22	13.8%	
Adolescents	50	31.3%	
Adult	88	55.0%	
Gender			
Female	73	45.6%	
Male	87	54.4%	
Occupation			
Unemployed	73	45.6 %	
Employee (civil servant and private)	60	37.5 %	
Freelancer	20	12.5 %	
Personal assistant	7	4.4 %	
Education degree			
No degree	5	3.1%	
Elementary school	21	13.1%	
High school (junior and senior high	111	69.4%	
school)			
Bachelor's degree	23	14.4%	
Income			
< Rp 1.800.000	95	59.4%	
>Rp 1.800.000	65	40.6%	
Relationship with patient		-	
Father or mother	74	46.3%	
Husband or wife	19	11.9%	
Children	17	10.6%	
Sibling	50	31.3%	
Duration for caring the patients			
0-5 years	81	50.6%	
6-10 years	43	26.9%	
>10 years	36	22.5%	
Treatment routine			
Yes	160	100.0%	

Tables 2 and 3 showed the descriptive statistics of quality of life among participants. The minimum and maximum scores of the quality of life are 3 and 5, respectively. The mean (SD) of quality of life was 4.24 (0.731) and the median was 4.00. The participants had a very high/good quality of life (41.3%), high/good quality of life (39.4%), moderate quality of life (17.5%), and only 1.9% of participants had low/poor quality of life.

Table 2: Descriptive Statistics of Quality of Lifeamong Participants

Variables	Min	Max	Mean	Med	SD
Quality of	3	5	4.24	4.00	0.731
life					

Table 1: Demographic Characteristic of Participants		
Characteristic	Total participants	

Quality of life score	F	%	Category
0-20	0	0%	Very low/poor
21-40	3	1.9%	Low/poor
41-60	28	17.5%	Moderate
61-80	63	39.4%	High/good
81-100	66	41.3%	Very high/good
Total	160	100%	

Table 3: Frequency Distribution of Quality of Lifeamong Participants

DISCUSSION

The results showed that the quality of life for family care giver with schizophrenia had the criteria of good quality of life and very good quality of life. This condition may occur because the patient is able to control their behavior and not relapse. Previous study mentioned that quality of life was developed by physical and mental health, social relationships, and supportive environment (Richieri *et al.*, 2011). Quality of life can trigger well-being (Spatuzzi *et al.*, 2019), so they can understand patient need.

In this study we also consider the demographic data had affect the quality of life such as age, gender, occupation, income, relationship with patients, duration for caring the patients, and treatment routine. Previous study mentioned that family caregiver related (spouse, parents, kid) had relationship with quality of life (Li *et al.*, 2018). Financial burden and duration of illness also related to quality of life (Leng *et al.*, 2019). Further study is needed to consider these variables that were related with quality of life among family caregivers.

Managing quality of life among family caregiver is required to provide patient need and the wellbeing of family caregiver, such as psychoeducation. According to Stuart (2014), psychoeducation is a therapy by providing information and education among family and it can reduce stress and the burden among family caregiver and develop adaptive coping (Sulung & Foresa, 2018; Walke, Chandrasekaran, & Mayya, 2018).

CONCLUSION

The most of family caregivers had a very good quality of life (41.3%). The sociodemographic showed that the participants were predominantly by female (54.4%), adult (55.0%), had senior high school degrees (51.9%), unemployed (45.6%), and the majority gender of participants was female (47.5%). In addition, all the participants regularly check-up at Menur Mental Hospital (100.0%).

Conflict of Interests

The authors declare that they have no conflict of interests.

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REFERENCES

- Akbari, M., Alavi, M., Irajpour, A., & Maghsoudi, J. (2018). Challenges of family caregivers of patients with mental disorders in Iran: A narrative review. *Iranian Journal of Nursing and Midwifery Research*, 23(5), 329-337. https://doi.org/10.4103/ijnmr.IJNMR 122 17
- Caqueo-Urízar, A., Rus-Calafell, M., Urzúa, A., Escudero, J., & Gutiérrez-Maldonado, J. (2015). The role of family therapy in the management of schizophrenia: challenges and solutions. *Neuropsychiatric Disease and Treatment, 11*, 145. https://doi.org/10.2147/NDT.S51331
- Caro, C. C., Costa, J. D., & Da Cruz, D. M. C. (2018). Burden and quality of life of family caregivers of stroke patients. *Occupational Therapy in Health Care, 32*(2), 154-171. https://doi.org/10.1080/07380577.2018.1449046
- Chen, L., Zhao, Y., Tang, J., Jin, G., Liu, Y., Zhao, X., . . . Lu, X. (2019). The burden, support and needs of primary family caregivers of people experiencing schizophrenia in Beijing communities: A qualitative study. *BMC Psychiatry*, 19(1), 1-10. https://doi.org/10.1186/s12888-019-2052-4

Farzi, S., Farzi, S., Moladoost, A., Ehsani, M., Shahriari, M., & Moieni, M. (2019). Caring burden and quality of life of

family caregivers in patients undergoing hemodialysis: A descriptive-analytic study. *International Journal of Community Based Nursing and Midwifery*, 7(2), 88-96. https://doi.org/10.30476/IJCBNM.2019.44888

- Fitryasari, R., Yusuf, A., Tristiana, R. D., & Nihayati, H. E. (2018). Family members' perspective of family Resilience's risk factors in taking care of schizophrenia patients. *International Journal of Nursing Sciences*, 5(3), 255-261. https://doi.org/10.1016/j.ijnss.2018.06.002
- Gilbertson, E. L., Krishnasamy, R., Foote, C., Kennard, A. L., Jardine, M. J., & Gray, N. A. (2019). Burden of care and quality of life among caregivers for adults receiving maintenance dialysis: a systematic review. *American Journal* of Kidney Diseases, 73(3), 332-343. https://doi.org/10.1053/j.ajkd.2018.09.006
- Hamann, J., & Heres, S. (2019). Why and how family caregivers should participate in shared decision making in mental health. *Psychiatric Services*, 70(5), 418-421. https://doi.org/10.1176/appi.ps.201800362
- James, S. L., Abate, D., Abate, K. H., Abay, S. M., Abbafati, C., Abbasi, N., ... Abdelalim, A. (2018). Global, regional, and national incidence, prevalence, and years lived with disability for 354 diseases and injuries for 195 countries and territories, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017. *The Lancet*, 392(10159), 1789-1858. https://doi.org/10.1016/S0140-6736(18)32279-7
- Kang, A., Yu, Z., Foo, M., Chan, C. M., & Griva, K. (2019). Evaluating burden and quality of life among caregivers of patients receiving peritoneal dialysis. *Peritoneal Dialysis International*, 39(2), 176-180. https://doi.org/10.3747/ pdi.2018.00049
- Leng, A., Xu, C., Nicholas, S., Nicholas, J., & Wang, J. (2019). Quality of life in caregivers of a family member with serious mental illness: Evidence from China. Archives of Psychiatric Nursing, 33(1), 23-29. https://doi.org/10.1016/j.apnu.2018.08.010
- Li, Q., Lin, Y., Xu, Y., & Zhou, H. (2018). The impact of depression and anxiety on quality of life in Chinese cancer patient-family caregiver dyads, a cross-sectional study. *Health and Quality of Life Outcomes*, 16(1), 1-15. https://doi.org/10.1186/s12955-018-1051-3
- Richieri, R., Boyer, L., Reine, G., Loundou, A., Auquier, P., Lancon, C., & Simeoni, M. (2011). 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. *Schizophrenia Research*, 126(1-3), 192-201. https://doi.org/10.1016/j.schres.2010.08.037
- Riskesdas, L. N. (2018). Kementerian Kesehatan RI Badan Penelitian dan Pengembangan Kesehatan. https://ejournal2.litbang.kemkes.go.id/index.php/lpb/article/view/3757
- Spatuzzi, R., Giulietti, M. V., Ricciuti, M., Merico, F., Fabbietti, P., Raucci, L., . . . Vespa, A. (2019). Exploring the associations between spiritual well-being, burden, and quality of life in family caregivers of cancer patients. *Palliative & Supportive Care*, *17*(3), 294-299. https://doi.org/10.1017/S1478951518000160
- Stuart, G. W. (2014). Principles and Practice of Psychiatric Mursing-e-book: Elsevier Health Sciences.
- Sulung, N., & Foresa, N. (2018). Efektivitas Intervensi Psikoedukasi Terhadap Kepatuhan Berobat Pasien Skizofrenia. *REAL in Nursing Journal*, 1(1), 1-11. https://doi.org/10.32883/rnj.v1i1.226
- Sustrami, D., Yusuf, A., Fitryasari, R., & Suhardingsih, A. S. (2022). Family Burdens in patients with Schizophrenia. *Journal Ilmiah Keperawatan*, 17(1), 30-37.
- Tristiana, R. D., Triantoro, B., Nihayati, H. E., Yusuf, A., & Abdullah, K. L. (2019). Relationship between caregivers' burden of schizophrenia patient with their quality of life in Indonesia. *Journal of Psychosocial Rehabilitation and Mental Health*, 6(2), 141-148. https://doi.org/10.1007/s40737-019-00144-w
- Walke, S. C., Chandrasekaran, V., & Mayya, S. S. (2018). Caregiver burden among caregivers of mentally ill individuals and their coping mechanisms. *Journal of Neurosciences in Rural Practice*, 9(02), 180-185. https://doi.org/10.4103/jnrp.jnrp_312_17
- Zendjidjian, X. Y., & Boyer, L. (2022). Challenges in measuring outcomes for caregivers of people with mental health problems. *Dialogues in Clinical Neuroscience*. https://doi.org/10.31887/DCNS.2014.16.2/xzendjidjian