Proceedings of the International Conference on Nursing and Health Sciences
Volume 1 No 1, November 2020
http://jurnal.globalhealthsciencegroup.com/index.php/PICNHS
Global Health Science Group

THE QUALITY OF LIFE FOR FAMILY CAREGIVERS IN CARING FAMILY MEMBERS UNDERGOING HEMODIALYSIS

Uswatun Hasanah*, Sapti Ayubbana, Supardi
Akper Dharma Wacana, Jl. Kenanga No. 3 Mulyojati 16 C Kota Metro, Lampung, Indonesia, 34125
*emailnyauus@gmail.com

ABSTRACT

Family caregivers who care for family members undergoing hemodialysis are affected quite difficult. The impact on family caregivers in caring for patients undergoing hemodialysis is emotional, social, physical, and financial so that it has an impact on their quality of life. The aims of this study is to describe the quality of life of the family caregiver in patients undergoing hemodialysis. This research is a quantitative study with an analytic descriptive approach. The research sample consisted of 56 family caregivers. The sampling technique used purposive sampling. Measurement of quality of life data for family caregivers using the WHOQOL-BREF quality of life instrument. Data were analyzed univariately with a frequency distribution. The results showed that the majority of family caregivers experienced a low quality of life with an average value below 50. The lowest average results were in the domain of social relationships (mean: 32.928), followed by psychological domains, environmental domains and physical health.

Keyword: family caregiver; hemodialysis; quality of life

INTRODUCTION

Family caregivers provide home care for family members who undergoing hemodialysis for a long period of time, which creates the risk of changes in their life (Stanhope, M. & Lancaster, 2004). These risks include biological risk factors, social risk factors, economic factors, risk factors for lifestyle changes, and risk factors for transition in life. Hemodialysis puts pressure and stress on the family because they have to take time off from work to deliver and accompany patients during hemodialysis and various other things that come with it, including lost work time (Kumar & Grimmer-Somers, 2007). Research shows that family caregivers experience depression, anxiety, fatigue, social isolation, stress in dealing with others and financial burdens (Cukor et al., 2007).

The condition of kidney failure patients which is getting more chronic which is exacerbated by the emergence of various complications causes changes in the patient's lifestyle causing the family caregiver to experience a high burden (Abbasi et al., 2011). Several studies have shown that patient caregivers experience a high burden in caring for patients with hemodialysis (Bayoumi, 2014); (Abbasi et al., 2011); (Mashayekhi et al., 2015) and are exposed to various physical and psychological risks (A. Belasco et al., 2006). The results showed that the family caregivers of hemodialysis patients experienced an increase in the level of care burden that affected their quality of life (A. G. Belasco & Sesso, 2002). An increase in the burden of care and a decrease in quality of life can lead to depression. The burden of care affects the quality of life of the family caregiver and can result in reduced quality of care and worsening of the patient's condition. The worsening of the patient's condition can increase the burden of care, causing fatigue in the family caregiver.

METHOD

The research was conducted with a descriptive analytic approach. Sampling using random permutation with a sample size of 56 family caregivers. Measurement of quality of life data for family caregivers uses the WHOQOL-BREF quality of life instrument which consists of 26 questions covering four domains, namely physical, psychological, social and environmental relationships. The WHOQOL-BREF measure does not have a composite score of the four domains of quality of life, and there are two question items that measure perceptions of general quality of life. Each question is assigned a score of 1 to 5, and higher scores represent the better quality of life. The score from the domain is calculated by multiplying the average of each facet by 4. Domain is not given a score, if ≥ 20% of questions are not answered by the respondent. Univariate data includes data on the characteristics of the respondent and the quality of life of the family caregiver. The research data were analyzed by univariate and presented in a frequency distribution.

RESULTS AND DISCUSSION

Table 1.
Characteristics Based on Family Caregiver
Gender, Length of Patient Undergoing Hemodialysis, Occupation, Education, Relationship with Patients (n=56)

Respondent Characteristics	Total	
	f	%
Gender		
Male	4	7
Female	52	93
Education		
Elementary School	18	50
Junior High School	11	19,6
Senior High School	16	28,6
University	1	1,8
Profession		
Doesn’t work	38	67,9
Work	18	32,1
Duration of patient undergoing hemodialysis		
≤ 1Years	3	5,4
2-5 Years	52	92,9
> 5 Years	1	1,8
Relationship with patients		
Husband / wife	28	50
Dad/Mom	3	5,4
Child	18	32,1
Sibling	7	12,5

Table 2.
Characteristics of Family Caregiver Based on Age (n=56)

Usia			
Mean	SD	(Min-Max)	95% CI
33,34	6,299	26-50	31,31-36,19

As family caregivers age, their quality of life decreases. Family caregivers experience more psychological disorders than physical illnesses (Preedy, V., & Watson, 2010). In addition, family caregivers who work say they experience more stress than family caregivers who don't work (Yagoda, 2004). As many as 35% of family caregivers show a poor quality of life status (Ho, A. Collins, S., Davis, K., Doty, 2005).

The results showed that the majority of family caregivers were women, with an average age of 30 years, primary school education and unemployed. The majority of family caregivers are partners of patients caring for couples between 2-5 years.

Tabel 3
Quality of Life for Family Caregiver(n=56)

Domain *Quality of Life*	Hasil		
	n	Mean	Min-Max
Question 1	56	2.4107	1-4
Question 2	56	2.0714	1-3
Domain 1	56	38.499	25-63
Domain 2	56	34.910	19-63
Domain 3	56	32.928	19-56
Domain 4	56	37.695	13-63

Based on the results of the study, it shows that the average score for each quality of life domain is below 50 with the lowest average in domain 3, namely social relations.

Measurement of quality of life for family caregivers using WHOQOL-BREF. WHOQOL-BREF consists of 24 facets covering 4 domains and is proven to be used to measure a person's quality of life. The four domains are: i) physical health consisting of 7 questions; ii) psychological (psychological) 6 questions; iii) social relationship (social relationship) 3 questions; and iv) environment (8 questions). WHOQOL-BREF also measures 2 facets of quality of life in general, namely: i) overall quality of life; and ii) general health (Salim et al., 2016).

The results showed that the four domains showed a low mean score (score less than 50) indicating a low quality of life. The lowest domain score is in domain 3 (social relations) compared to other domains with a mean value of 32.928. The highest domain score is in domain 1, namely physical health (38,499). The family caregiver's mental status is worse than physical. Mental health and family caregiver vitality are the emotional dimensions most affected (A. G. Belasco & Sesso, 2002). Another factor that directly affects the quality of life of family caregivers is that they start living older lives, reducing social relationships from friends and relatives due to lack of time and opportunities for recreation, working outside the home, and changing family routines (Amendola F, Oliveira MAC, 2011). This finding is supported by the results of this study, where the main disruption to the quality of life of the family caregiver is satisfaction with the social domain. The social support network will primarily affect the improvement of the emotional aspects of the family caregiver, which in turn can affect all other domains. Family caregivers who maintain or receive some social support have better scores in the social relationship domain (Guedea MTD, Damacena FA, Carbajal MMM, Marcobich PO, Hernández GA, 2009). Providing support to family caregivers contributes to the stressful situations they experience. Family also has a key role in improving the quality of life, although family ties are not always maintained because of changes when the subject becomes a family caregiver (Rodríguez-Sánchez E, Pérez-Peñaranda A, Losada Baltar A, Pérez-Arechaederra, Gómez-Marcos MA, Patino- Alonso MC, 2011).

In this study, the presence of sequelae showed a statistically significant effect on the WHOQOL-BREF physical and psychological domains, and the presence of disease showed a statistically significant effect on the environmental and social relationship domains. These findings are corroborated in the literature, which shows that family caregivers who work overtime and experience fatigue show anxiety, depression, and somatization. The relationship is therefore two-way, with sequelae and disease disrupting the quality of life domain and a low quality of life affecting disease involvement and producing sequelae.

Lower scores in the physical and environmental domains were also associated with the family caregiver's status as the primary caregiver. These family caregivers dedicate themselves full time to patients, often with no time left to look after their own health21. One study found that pain and physical limitations were the main complaints of family caregivers (Silveira TM, Caldas CP, 2006).

Quality of life is a global concept that emphasizes the dimensions of health status including finance, place of residence and work. The concept of quality of life as a center for health promotion is based on three areas of human life which are important dimensions in human experience, namely Being, Belonging and Becoming. Patients suffering from chronic kidney disease and undergoing hemodialysis will experience various psychological changes as well as psychosocial problems. Stressors generally occur due to feelings of inadequacy and lack of control over illness, medication, interfering therapy, restrictions on medical regimens, changes in body shape, and changes in sexuality. Meanwhile, common psychosocial problems include changes in body shape, dependence on technology, and uncertainty of the future. Relationships with relatives and friends, jobs, and community roles and responsibilities change frequently. The client's need for self-reliance continues to be threatened by reliance on dialysis equipment and care providers (Black & Hawk, 2014).

There are many difficulties faced by family caregivers such as changing sleep patterns, experiencing changes in health, changing social activities, and changing vacation plans (Fast & Keating, 2001). In addition, patients and family caregivers must spend a minimum of three days a week on dialysis which places restrictions on social life and creates a feeling of dependence on the dialysis center. So, they have to make many modifications to their lifestyle (Sezer et al., 2003). The continuation of patients undergoing hemodialysis with the many problems faced by chronic kidney disease sufferers who undergo hemodialysis has a higher psychological effect on the level of quality of life for clients and families (Inayati, 2013).

CONCLUSION

The quality of life of the patient's family caregiver undergoing hemodialysis needs attention. family caregivers need assistance to improve their quality of life from both the government and non-governmental organizations, such as developing special support groups consisting of patients, family caregivers and health workers. family caregivers can share knowledge, experiences, and share ways of dealing with crises faced while treating patients with hemodialysis.

REFERENCES

Abbasi, ali, asayesh, hamid, rahmani, hossein, shariati, alireza, hosseini, seyyed abedin, rouhi, ghanbar, & molaie, einollah. (2011). The Burden on Cargivers from Hemodialysis Patients and Related Factors. *Journal of Research Development in Nursing & Midwifery*.

Amendola F, Oliveira MAC, A. M. (2011). Influence of social support on the quality of life of family caregivers while caring for people with dependence. *Rev Esc Enferm USP.*, 884–889.

Bayoumi, M. M. (2014). Subjective Burden on Family Carers of Hemodialysis Patients. *Open Journal of Nephrology*. https://doi.org/10.4236/ojneph.2014.42011

Belasco, A., Barbosa, D., Bettencourt, A. R., Diccini, S., & Sesso, R. (2006). Quality of Life of Family Caregivers of Elderly Patients on Hemodialysis and Peritoneal Dialysis. *American Journal of Kidney Diseases*. https://doi.org/10.1053/j.ajkd.2006.08.017

Belasco, A. G., & Sesso, R. (2002). Burden and quality of life of caregivers for hemodialysis patients. *American Journal of Kidney Diseases*. https://doi.org/10.1053/ajkd.2002.32001

Cukor, D., Cohen, S. D., Peterson, R. A., & Kimmen, P. L. (2007). Psychosocial aspects of chronic disease: ESRD as a paradigmatic illness. In *Journal of the American Society of Nephrology*. https://doi.org/10.1681/ASN.2007030345

Guedea MTD, Damacena FA, Carbajal MMM, Marcobich PO, Hernández GA, L. L. (2009). Need for social support in caregivers of elderly Mexican family members. *Psicol Soc*, *21*(2). http: //dx.doi. org / 10.1590 / S0102-71822009000200011

Ho, A. Collins, S., Davis, K., Doty, M. (2005). A Look at working-age caregivers' roles health concern and need for support. *Common W. Found*, *854*, 1–12.

Kumar, S., & Grimmer-Somers, K. (2007). A synthesis of the secondary literature on effectiveness of hospital avoidance and discharge programs. In *Australian health review : a publication of the Australian Hospital Association*. https://doi.org/10.1071/ah070034

Mashayekhi, F., Pilevarzadeh, M., & Rafati, F. (2015). The Assessment of Caregiver Burden in Caregivers of Hemodialysis Patients. *Materia Socio Medica*. https://doi.org/10.5455/msm.2015.27.333-336

Preedy, V., & Watson, R. (2010). *Handbook of Disease Burdens and Quality of Life Measures* (1st ed.). Springer Science and Business Media.

Rodríguez-Sánchez E, Pérez-Peñaranda A, LosadaBaltar A, Pérez-Arechaederra, Gómez-Marcos MA, Patino-Alonso MC, et al. (2011). Relationships between quality of life and family function in caregiver. *BMC Fam Pract.*, *12*, 1–7. http://dx.doi.org/10.1186/1471-2296-12-19

Salim, O. C., Sudharma, N. I., Kusumaratna, R. K., & Hidayat, A. (2016). Validitas dan reliabilitas World Health Organization Quality of Life-BREF untuk mengukur kualitas hidup lanjut usia. *Universa Medicina*.

Silveira TM, Caldas CP, C. T. (2006). Caring for highly dependent elderly people in the community: a study on primary family caregivers. *Cad Saude Publica.*, *22*(8), 1629–1638. http://dx.doi.org/10.1590/ S0102-311X2006000800011

Stanhope, M. and Lancaster, J. (2004). *Community and Public Health Nursing* (6th Editio).

Yagoda, L. (2004). Working family caregivers: issues and opportunities for social work practice. *National Association of Social Workers. USA.* http://www.socialworkers.org/practice/aging/aging0804.pdf.