

© 2016 The Author(s)

This is an Open Access article distributed under the terms of the Creative Commons Attribution 4.0 International License which permits unrestricted non-commercial use, distribution, and reproduction in any medium, provided the original work is properly cited

REVIEW ARTICLE

ISSN: 2477-4073

BURDEN OF FAMILY CAREGIVER

Faida Annisa*

Lecturer, Department of Psychiatric Health Nursing, Kerta Cendekia Nursing Academy, East Java, Indonesia

***Corresponding author:**

Faida Annisa, RN, MNS

Kerta Cendekia Nursing Academy. Jalan Lingkar Timur, Rangkah Kidul, Kec. Sidoarjo, Kabupaten Sidoarjo, Jawa Timur 61234, Indonesia. E-mail: nio_annisa@yahoo.com

ABSTRACT

Shifting from hospital-based care to community-based care involves the family as advanced caregivers to the patients with schizophrenia at their home. Yet, they have need of knowledge and skill in caring the patients as well as support from health care providers and society. Family caregivers should be well-prepared to take care the patients with schizophrenia at home since it gets some negative consequences on their physical, psychological, social, and financial. Nurse needs to assess the factors that might influence the family caregivers to feel burden, and include the family caregivers into nursing care in which would not only to improve the patients' mental health but also the family caregivers.

Keywords: schizophrenia, family caregivers, factors of burden

INTRODUCTION

Schizophrenia is a complex disorder with an extremely varied presentation of symptoms.¹ World Health Organization (WHO) estimated that globally about 29 million people have schizophrenia. Although its incidence is low (3 per 10,000), its prevalence is high due to the chronicity of this illness.² Data from the Health Ministry of Indonesia stated there were 18,800 schizophrenic patients in Indonesia that were confined in 2011.³

The essential in caring the patients is maintaining the wellness while

encouraging the self-care ability on the patients and the family caregivers. Patients with schizophrenia have long duration of illness, and extent disabilities both of daily functions and social interactions, therefore their family have to look after them to prevent the relapse episode. In Indonesia, most of the caregivers of patients with schizophrenia are their own family. In order to help the family caregivers in caring for the patients at home, nurses need to understand the burden they may feel during caring the patients. This paper aims to provide the insight of knowledge

about the burden of family caregiver, its related factor, and the assessment of the burden.

DEFINITION OF FAMILY CAREGIVER BURDEN

Definition of family caregiver. Caregivers or carers are people who provide care to family members, life partners or friends whose sick, elderly or disabled, without paid.⁴ Family caregiver is someone who is responsible for the physical, emotional, and financial supports of the family members who are unable to care for him/herself due to illness, injury or disability.⁵

Definition of burden. From literature review, burden has been defined since 1966. Grad and Sainsbury⁶ stated that burden is any negative impact to the family caused by caring for ill member. Hoenig and Hamilton⁷ divided burden into objective and subjective. Objective burden as an event or activity associated with negative caregiving experiences, whereas subjective burden referred to feeling that appeared in the caregiver caused by the fulfillment caregiving of the caregiving function. From Chan,⁸ objective burden is related to the patient's symptoms, behavior, and sociodemographic characteristics; and subjective burden is the mental health and subjective distress among family members.⁸ Conceptual clarity is elusive here, however. Rose⁹ stated the conceptual of burden is difficult to find, and what has been described as a "burden" is more accurately described as a "stressor".

Definition of family caregiver burden. The family caregiver burden is the extent to which caregivers perceived their emotional, physical health, social life, and financial status as a result of caring for their ill relatives. They viewed burden as a product subjective perception of caregiver when caring for impaired person.¹⁰ The

term caregiver burden used to express any negative consequences of caring for patients with mental disorders by family caregivers.¹¹ Recently, the area of caregiving burden has been widened to involve the physical, psychological, social, and financial aspects experienced by family caregivers. From World Federation of Mental Health,⁴ burden experienced by family refers to affect for those who close to the person with mental health problems.

Development of Knowledge of Family Caregiver Burden. In the past, patients with schizophrenia who have been cared focus only in hospital; in these days, caring for the patients would be performed by their families at home.¹² Shifting from hospital-based care to community-based care has identified the family as the caregiver. In Western countries, the studies showed about 25%-50% of discharged patients with schizophrenia live and need advanced caring from their families.⁸ Likewise, in Indonesia, almost all discharged patients with schizophrenia will return to their own homes in the communities.

The shift from hospital-based care to community-based care requires the gather role of health care providers, family of patient, the public at large, and policy marker function as well. The essential in caring the patients is maintain the wellness while encourage the self-care abilities on patients, family, and community. Some caregivers report the duties of family caregiver are hard responsibilities that affect their daily lives and include lack of household financial, disrupt of either work or leisure activities, and also their physical and mental health status. For another, they enjoy the time they spend with their spouse, the chance to grow closer to the care receivers, the intimacy of personal care, and the sense of being needed and appreciated.¹³ It represents that some

family caregivers cope the burden better than others.

The concern of family caregiving brings two ways of safety issues in nurse views.¹⁴ First, caregivers refer to “secondary patients”. They need protection and guidance in terms of the high risk for injury and adverse events in caring for the patients at home. Second, family caregivers are “unpaid providers”. They need information to learn how to perform the caregivers’ role in order to properly caring for the patients. Mental health nurses have the ideal opportunity in assisting the families who are living with schizophrenic patients to develop more effective coping behaviors, communication skills, and social support systems.¹⁵

FACTORS RELATED TO FAMILY CAREGIVER BURDEN

Burden of family caregivers leads to negative consequences not only for themselves but also for patients, other family members, and health care system. Numerous studies conducted to examine the factors associated with family caregivers’ burden on various dimensions. In this review, the factors related to family caregiver burden would be classified into internal factors and external factors.

Internal Factors

Internal factors are some aspects of the family caregivers’ characteristics which affect the burden.

1. Socio-demographic factors including gender, age, religion, cultural, marital status, education, occupation, income, relationship with the patient, number of family members.

Gender

Mostly family caregivers are females. Female caregivers have significant higher burden scores on the “emotional strain” and “financial/physical strain domains.”¹⁶ The findings suggest that

female caregivers rather than male caregivers have less positive coping with symptoms of their ill relatives.¹⁷

Age

There is a significant difference between the caregivers’ age groups with those aged 40 or above scored significant higher levels of burden.¹¹ On another study, the younger caregivers have significant higher score on caregiver burden.¹⁸ However, age of caregivers has little influence on caregiving burden.¹⁷ There is no age-specific effect of either the patient's age or the caregiver's age on the amount of burden of caregiving.¹⁹

Religion

The results of the Chien¹¹ study indicated that the caregivers with traditional Chinese religions such as Confucianism and Buddhism reported higher levels of burden than those who are Christians or Catholics. Another study which data collected by in-depth interviews and observation involving 17 caregivers in Thailand, found evidence that the Thai health care system has made little provision for caregiver burden.²⁰

Cultural

The relationship between culture and burden affected by other intervening factors such as socioeconomic status or the sense of obligation and responsibility. The aim of study from Caqueo-Urizar and colleagues²¹ was to describe the levels of burden in Aymaras caregivers (aborigines who are located on the highlands of Northern Chile) from schizophrenic patients, and the finding showed significant differences between Aymara and non-Aymara families in the total burden score and the incompetence subscale.

Marital status

Single (unmarried) caregivers experienced more tension. Higher caregiver burden by the single caregivers may be understood from the perspective

that most of them would be either widowed parents or unmarried siblings and hence having lower social support and thereby perceive more burden.¹⁸

Education

In the context of caring for an adult with schizophrenia, low level of education means that fewer resources are available to caregivers who are faced with challenging behaviors and other caregiver-related stressors.²² Lower educational attainment of the caregiver is predicting higher burden scores in various domains.¹⁶

Occupation

Employed caregivers have significant higher burden scores on the “self-criticism” and “time/dependence” domains. On the other hand, unemployed caregivers reported higher levels of burden on the “financial/physical strain” domain.¹⁶

Income

Studies found that caregivers' burden score was negatively correlated with their household income⁸. The mean of burden scores was significantly higher among caregivers who had lower monthly household income.¹¹ Same result also on Kate and colleagues¹⁸ study that the significant higher score in caregiver burden was associated with lower income. A high burden score is also associated with rural setting and poorer economic circumstances of the family.¹⁹

Relationship with the patients

Caregivers who are parents or spouses of the patients have significant higher burden scores on the “uncertainty” domain.¹⁶ Parents have significant lower scores on all the domains (except tension domain) of caregiver burden compared to spouses.¹⁸ Relationship between parent and patient has a direct impact on the burden, which means that the caregivers who are parents experienced higher perception of burden than those as other relationships.¹⁷

Number of family member

Caregivers of patients living in households with fewer numbers of people have higher burden scores on the “financial / physical strain” and “time / dependence” domains.¹⁶ The number of family members is significant in reducing the demands for care and involvement of caregiving, thus lower the caregiving burden.¹¹

2. Duration of caring the patients

The amount of daily contacts with the patients predicts the burden of family caregivers. The higher the number of hours spent with the patient, the greater the degree of perceived burden by the caregivers.²³ Due to the sociocultural sense of obligation to care for sick family members oneself (rather than delegating care), caregivers who spend lesser time with the patients may be vulnerable to self-reproach.¹⁶

3. Perceived social support

Social support is one of predictors in family caregivers' burden. Poor social support is a predictor of higher burden scores on the “financial/physical strain”, “emotional strain”, and “time/dependence” domains.¹⁶ Chien and colleagues²⁴ explored the effect of the mutual support group intervention on family burden. The findings demonstrated that the efforts by mental health workers to establish and support mutual support groups for family caregivers of patients with schizophrenia is likely to lead to major benefits for family carers and indirect benefits for their relatives with schizophrenia associated with living in a more supportive and harmonious family environment.

4. Coping strategies

There are many significant findings between the burden and the coping strategies in caregivers when they cared

for their relatives with schizophrenia. Caregivers' poor management styles lead to frequent conflicts with their sick relatives, resulting in distress and suffering.²⁵ Tension domain of caregiver burden has significant positive correlation with caregiver's coping strategies of avoidance, collusion, coercion and total coping checklist score.¹⁸ The passive oriented or emotion-focused coping strategies (resignation, avoidance) have less impact on burden than active oriented or problem-focused strategies.²⁶

5. Quality of life

Evidence shows that caregivers' experience negatively changes their quality of life. Decreased quality of life may be associated with caregivers' burden, lack of social support, course of the disease and family relationships problems. In addition, in developing countries, quality of life is affected by caregivers' economic burden.¹² Tension domain of caregivers' burden has significant negative correlation with all the domains of caregivers' quality of life.¹⁸

6. Physical status

According to Bull, as cited in Chou¹⁰, caregivers in poor health are consistently found to have significantly higher burden levels than those in good health. Relationships between burden and health can change over time as the situation becomes more burdensome. The high levels of burden might relate to the poor health condition of older caregivers, which has been consistently found to result in high burden level and subsequently increases the physical and psychological demands of caregiving.¹¹

7. Knowledge about schizophrenia

If caregivers do not have adequate knowledge and support, they may not be able to take up the responsibilities of taking care of the ill persons.⁸ The

relationship between the caregivers' knowledge about schizophrenia and their burden is negatively correlated through the family coping with the patients' symptoms. It means the lesser knowledge caregivers have about schizophrenia, the poorer coping they used, thereby the higher burden they perceived.¹⁷

External Factors

External factors are stimuli of burden that originate in the outside of family caregivers' areas.

1. Socio-demographic factors of patients including age and duration of illness.

Family burden is not affected by patient's previous admissions, age of illness onset and the duration of illness. All these variables are related to patient's psychiatric history and may not have an accumulative effect on the caregiver's well-being.²³ A study from Othman and Salleh¹⁹ found that there is no age-specific effect of either the patient's age or the caregiver's age on the amount of burden of caregiving. However, another study found that the correlates of family caregiver burden with patient's age is negatively significant as well as illness duration that 11 or more years since illness onset, it means young patient age is related to increased family caregiver burden.²⁷ One of predictors that has higher caregiver burden scores is longer duration of illness of patient correlated with higher scores on the "uncertainty" domain.¹⁶

2. Severity of patient illness

The symptoms of schizophrenia patients would impact to the burden of family caregiver as well as the severity of patient illness. Higher Positive and Negative Syndrome Scale (PANSS) scores predict higher caregiver burden scores in several domains.¹⁶ There is a positive correlation between the total amount of symptomatic behavior and the different

burden variables. The more symptomatic behavior the family member reported, the more efforts family members have to make, the more extra works they do, the worse the mood they experience at home, the more emotionally burdened they feel, the more often other family members left home or threatened to do so, and the more inconvenience have been experienced.²⁸ Patient's global psychosocial functioning, incorporating severity of psychotic illness, is also found to be positively associated with perceived burden. Impaired psychosocial functioning (low global assessment scale score) of patients have a direct negative impact on both objective and subjective dimensions of family burden (high family burden scale score).²³ The strong correlation between social problem behavior of patient score with total objective and subjective family caregiver burden also found on Othman and Salleh study.¹⁹ The correlation between symptom severity and caregiver burden underscores the need to ensure effective treatment for patients with schizophrenia as a vital step in addressing caregiver burden.

3. Mental health service and its utilization

Roick et al. as cited on Rafiyah²⁹ conducted a study on 333 Germany caregivers and 170 Britain caregivers with schizophrenia to compare burden experienced by caregivers caring for schizophrenia person in those countries. Results showed that Britain caregivers reported more burden than Germany caregivers. The major cause of difference of burden was the differences in the provision of mental health service. Germany has on average 7,5 psychiatric beds per 10,000 populations, whereas Britain has only 5.8. Therefore, the unmet needs for care (covering the dimension of basic living condition, health care, functioning and service) seem to be higher

among the people with schizophrenia in Britain.

ASSESSMENT OF BURDEN

Family caregiver burden are viewed widely on the physical, psychological, or emotional, social and financial problem experienced by family caregivers. Therefore, some scales are required to measure different aspect or single issue in terms to answer the research questions on study. Numerous questionnaires have been developed to quantify the large subjective domain of caregiver burden, but the Zarit Burden Interview is the most widely referenced scale in studies of caregiver burden.³⁰ However, many researchers use other instruments to assess the family caregiver burden. Some of instruments include Family Burden Interview Schedule, Family Burden Scale, Burden Scale, Burden Assessment Scale, and Caregiver Burden Scale.

The Zarit Burden Interview explores the caregiver burden on the negative physical, mental, social, and economic impacts of caregiving on the life of the caregivers. This instrument was constructed by Zarit et al to assess caregiver burden in dementia, but it has also shown satisfactory psychometric properties in assessing caregiver burden in schizophrenia.¹⁶

The Family Burden Interview Schedule is a 25-item semi-structured interview schedule designed by Pai and Kapur¹¹, which consists of objective and subjective dimensions of burden measurement and also includes six domains of perceived burden, including effects on family finance, routine, leisure, interaction, physical health, and mental health.¹¹

The Burden Assessment Scale designed by Reinhard and colleagues²⁵ measured burden objectively and

subjectively. The objective burden items are the visual behavioral effects of care giving in several areas, including financial problems, limitations on personal activity, household disruption and social interactions; and subjective burden items refer to the feelings, attitudes and emotions expressed by the caregivers and include area of shame, stigma, guilt, resentment, grief and worry.²⁵

CONCLUSION

Many studies were conducted to explore the burden of family caregivers of patients with schizophrenia and its relationship with the other variables. The studies found that the characteristics of family caregivers, including their perceived social support, coping strategies, and knowledge about the disease considered as their internal factors that affect their burden of caring the schizophrenic patients, while the external factors include the characteristics of patients such as severity of illness and mental health service and its utilization. However, the knowledge of family caregiver about caring the schizophrenia patient has not been identified yet. Future study may need to examine that factor related to family caregiver burden.

There are three components to understand the issues of burden of care: 1) the patients, in terms of the impact of the schizophrenia disorder itself, its symptom profile and long-term course; 2) the caregivers, and their ability to cope with the challenges and frustrations; and 3) the community and the context caregiving takes place.³¹ However, the concerns of family caregiving on patients with schizophrenia should not be seen on negative consequences only. Nurse needs to help the family caregivers in preparing themselves to perform the roles while preventing them in perceiving burden. The effectiveness of nursing interventions

through family role as the caregiver of patients should be expanded, thus decreasing the number of relapse period of patients with schizophrenia.

Declaration of Conflicting Interest

Nothing to be declared.

Funding

None.

Authorship Contribution

This study is the original work of the corresponding author.

References

1. Kneisl et al. (2004). *Contemporary psychiatric-mental health nursing*. Pearson Education: USA
2. World Health Organization. 2013 *Schizophrenia*. Retrieved on November 27, 2013 from www.who.int/
3. Ministry of Health of the Republic of Indonesia. (2013). *Penyajian pokok-pokok hasil riset kesehatan dasar 2013 [Presentation of main results of basic health research 2013]*. Retrieved from www.litbang.depkes.go.id
4. World Federation of Mental Health [WFMH]. (2010). *Caring for the caregiver: Why your mental health matters when you are caring for others*. Woodbridge VA: WFMH. Retrieved from www.wfmh.org
5. National Alliance for Caregiving [NAC]. (2010). *Care for the family caregiver: A place to start*. Retrieved from http://www.caregiving.org/data/Emblem_CfC10_Final2.pdf
6. Grad, J. P. D., & Sainsbury, P. M. D. (1963). Mental illness and the family. *Lancet*, 1(7280), 544-547.
7. Hoenig, J., & Hamilton, M. W. (1966). The schizophrenic patient in the community and his effect on the household. *International Journal of Social Psychiatry*, 12(3), 165-176.
8. Chan, S. W-C. (2011). Global perspective of burden of family caregivers for persons with

- schizophrenia. *Archives of Psychiatric Nursing*, 25(5), 339-349.
9. Rose, L. (1996). Families of psychiatric patients: A critical review and future research directions. *Archives of Psychiatric Nursing*, 10(2), 67-76.
10. Chou, K. R. (2000). Caregiver burden: A concept analysis. *Journal of Pediatric Nursing*, 15, 398-399.
11. Chien W-T., Chan, S. W-C., & Morrissey, J. (2007). The perceived burden among Chinese family caregivers of people with schizophrenia. *Journal of Clinical Nursing* 16, 1151-1161.
12. Caqueo-Urizar, A., Gutierrez-Maldonado, J., & Miranda-Castillo, C. (2009). Quality of life in caregivers of patients with schizophrenia: A literature review. *Health and Quality of Life Outcomes*, 7(84), 1-5.
13. Bearon, L. (2013). *The burdens and blessings of family caregiving*. Raleigh: NC State University.
14. Reinhard, S. C., Given, B., Petlick, N. H., & Bemis, A. (2008). Chapter 14: Supporting family caregivers in providing care. In Hughes, R. G. (Ed.), *Patient safety and quality: An evidence-based handbook for nurses* (AHRQ Publication No. 08-0043, pp. 1-64). Rockville, MD: Agency for Healthcare Research and Quality.
15. Saunders, J.C. (2003). Families living with severe mental illness: A literature review. *Issues in Mental Health Nursing*, 24(2), 175-198.
16. Adeosun, I. I. (2013). Correlates of caregiver burden among family members of patients with schizophrenia in Lagos, Nigeria. *Schizophrenia Research and Treatment*, 2013, 1-7.
17. Lim, Y. M., & Ahn, Y-H. (2003). Burden of family caregivers with schizophrenic patients in Korea. *Applied Nursing Research*, 16(2), 110-117.
18. Kate, N., Grover, S., Kulhara P., & Nehra, R. (2013). Relationship of caregiver burden with coping strategies, social support, psychological morbidity, and quality of life in the caregivers of schizophrenia. *Asian Journal of Psychiatry*, 6(5), 380-388.
19. Othman, Z & Salleh, M. 2008. *Burden of care and social behavior problem of patients with schizophrenia*. *International Medical Journal*, 15(4), 269-274.
20. Dangdomyouth et al. (2008). *Tactful monitoring: how Thai caregivers manage their relative with schizophrenia at home*. *Issues in Mental Health Nursing*, 29:37-50.
21. Caqueo-Urizar, et all. (2012). *Burden of care in Aymara caregivers of patients with schizophrenia*. *Psiquiatria Salud Mental*, 5, 191-196
22. Papastavrou, E., Charalambous, A., Tsangari, H., & Karayiannis, G. (2010). The cost of caring: The relative with schizophrenia. *Scandinavian Journal of Caring Sciences*, 24(4), 817-823.
23. Koukia, E. & Madianos, M. (2005). Is psychosocial rehabilitation of schizophrenic patients preventing family burden? A comparative study. *Journal of Psychiatric and Mental Health Nursing*, 12, 415-422
24. Chien, W-T., Norman, I., & Thompson, D. R. (2004). A randomized controlled trial of a mutual support group for family caregivers of patients with schizophrenia. *International Journal of Nursing Studies*, 41, 637-649.
25. Tan et al. (2012). Burden and coping strategies experienced by caregivers of persons with schizophrenia in the community. *Journal of Clinical Nursing*, 21, 2410-2418.
26. Grandon et al. (2008). Primary caregivers of schizophrenia outpatients: Burden and predictor variables. *Psychiatry Research*. 158(3), 335-343.
27. McDonell et al. (2003). Burden in schizophrenia caregivers: Impact of family psychoeducation and awareness of patient suicidality. *Family Process*. 42(1).
28. Lowyck et al. (2004). A study of the family burden of 150 family members of schizophrenic patients. *European Psychiatry*. 19(7), 395-401.

29. Rafiyah, I. (2011). Review: Burden on family caregivers caring for patients with schizophrenia and its related factors. *Nurse Media Journal of Nursing*. 1(1), 29 – 41
30. American Family Physician. *A practical guide to caring for caregivers*. Retrieved on December 30, 2013 from <http://www.aafp.org/afp/2000/1215/p2613.html>
31. Awad, A., & Voruganti, L. (2008). The burden of schizophrenia on caregivers: A review. *Pharmacoeconomics*, 26(2), 149-162.

Cite this article as: Annisa F. Burden of Family Caregiver. *Belitung Nursing Journal*. 2016;2(1):10-18. <https://doi.org/10.33546/bnj.7>