

The Burden in Providing Caregiving Service to Mentally Ill Patients in Ponorogo

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Abstract

Introduction: The provision of caregiving to patients with a mental illness are under the burden of continuous and difficult processes. Some factors are responsible for this burden and the determination of these factors will help to address it. The objective of this study is to investigate the caregiver burden of patients with mental illness in *Ponorogo*.

Method: Sixty-seven caregivers of patients with mental illness in *Paringan* village were included in the study. Socio-demographic data, level of knowledge about mental disorders and caregivers burden were measured and observed.

Results: The socio-demographic variables show the average age of the respondents to be 50.0597, 57% of caregivers are women, as much as 100% caregiver Javanese, 37% of the caregivers are farmers, and 54% of these caregivers only have elementary school education. Total caregiver burden shows a mean of 23.28 (SD = 9.224). Findings on the level of burden of these caregivers revealed that 18 respondents were on the light burden level, the intermediate burden level had 4 respondents, while the level that did not experience any burden had 45 respondents. Caregiver burden was positively correlated with the age of caregivers ($p = 0.000$), employment of caregivers ($p = 0.001$), and level of education ($p = 0.000$).

Recommendation: Since these caregivers who care for people with mental disorders showed a higher financial burden compared with other types of caregiver burden, these findings suggest that a model of nursing intervention is needed to prevent the occurrence of a community-based caregiver load increase.

Keywords: Caregivers burden, mental illness, Paringan village, nursing.

Introduction

The increase in the prevalence of mental disorders will be followed by the need for additional caregivers who provide care in various homes¹. The ability of caregivers to provide care depends on the caregiver's health status². However, it has been discovered that caregivers often neglect their physical and mental health, prioritizing the health of their patients. Consequently, chronic stress has been identified as the main risk factors of poor health state of most caregivers³. Interventions to reduce the severity will increase repair process and in turn improve the quality of life of patients a caregiver attends to⁴ A caregiver provides care for a spouse, parent, or his loved ones having chronic diseases such as mental disorders and the likes. Thus, understanding

the function and presence of a caregiver mainly nurses at home is very important⁵.

An estimated number of 43.5 million Americans need the services of caregivers on a average of 19 hours per week⁶. In the United Kingdom, approximately 1% of the population are diagnosed with mental disorders⁷. Iran has about 7 million people suffering from mental disorders⁸. The prevalence of severe psychiatric disorders in Indonesia is at 1.7 per million; that is 1 to 2 people out of 1,000 inhabitants of Indonesia suffered severe mental disorders⁹. Caregiver burden is simply the perception that the caregiver has in relation to his/her physical health, social life, emotion and status, as a result of caring for a family member, resulting in the concept of burden as the product of a specific, subjective and

interpretive process of chronic disease. A high caregiver burden, if left untreated, will affect the caregiver's life quality¹⁰. And decrease in the quality of life of a caregiver will have a direct negative impact on the quality of care rendered to the patient with mental disorder.

Various problems caregivers face with patients/family members suffering from mental disorders include: 1) inability to understand the behavior of people with mental disorders, how to manage them, and their erratic behavior, making the caregiver helpless; 2) sadness, mental tension and loss of sense; 3) future concerns of sufferers and other family members; 4) financial problems⁸. The family as a source of the most important supporters of patients with schizophrenia, which caused an increase in burden and responsibility¹¹. Caregiver burden negatively impact the families of patients with mental disorders¹⁶. An estimated 50-90% of patients with chronic mental illness live with their families⁸. The impact on family members of those who have mental disorders are so bad that it affects the lives of clients and caregivers, socially and work⁷.

Method This study design was a descriptive cross-sectional study. A purposive sampling method was employed to obtain the needed sample which were 67 caregivers caring for people with mental disorders. Variables of the research include sociodemographic characteristics (age, gender, ethnicity, employment status, educational level) and caregivers' burden. The research instrument employed is the modified version of Zarit Burden Interview (ZBI), which consists of five Likert-scale points with 22 questions. There are four sub-variables of caregiver burden which are mental burden, physical burden, the burden of social and financial burden. Each question has five points burden level and the criteria are: a score of 0 = never; a score of 1 = rarely; 2 = sometimes; 3 = rather often; and then 4 = almost always. Based on the total value of ZBI, there are four levels of burden: 1) score ≤21 = no burden; 2) score 21-40 = light; 3) score of 41-60 = moderate; 4) score 61-88 = weight.

Result

A total number of 67 caregivers who treated people with mental disorders participated in the study. The average age of the subjects was 50.0597, the youngest caregiver was 30 years old while the oldest was 69 years old. Majority of the 67 respondents were women. All these caregivers are from Javanese. of these 67 caregivers, 25 are farmers. And as many as 36 respondents have elementary education. The descriptive statistics for all the variables used are presented in Table 1.

Table 1. Characteristics of Statistics in Sociodemographic Variabl

Variable	SUM (%)
Age	
30 - 50	-
51 - 70	
Gender	
Male	30 (45)
Female	37 (55)
Ethnicity	
Javanese	67 (100)
Non Javanese	0 (0)
Employment	
Civil servants	4 (6)
Farmer	25 (37)
IRT	22 (33)
Private	16 (24)
Education	
No school	10 (15)
SD	36 (54)
SMP	8 (12)
SMU	12 (18)
PT	1 (1)

The Total Caregiver Burden of the 67 respondents has an average of 23.28, with a minimum value of 12 and a maximum value of 47. Sub-variables Caregiver Burden due to mental issue has an average value of 9.8806 with a least value of 3 and a maximum of 22. Sub-variables Caregiver burden due to physical issues has an average value of 5.8060 with a lowest value of 0 and a maximum of 11. Sub-variables Caregiver burden as a result of social stress has an average value of 1.5075 with a minimum value of 0 and a maximum of 2. Sub-variables Caregiver burden due to financial issues has an average value of 4.7313 with a minimum value of 2 and a maximum of 7. of all the sub-variables caregiver burdens, mental burden has the highest valu. The descriptive Statistics for Caregiver Burden is presented in Table 2.

Table 2. Descriptive Statistics for Caregiver Burden

Variable	Mean	SD	Min	Max
Total Caregiver Burden	23.28	9224	12	47
Mental burden	9.8806 *	5.12428	3.00	22.00
Physical burden	5.8060 *	2.59509	.00	11.00
Social burden	1.5075	2.53684	.00	2
Financial burden	4.7313 *	1.33237	2.00	7.00

* +

Considering the correlation between the levels of burden with sociodemographic variables from the gender point of view shows that among the males, 4 respondents have medium burden level, 9 have a light burden level and 17 respondents did not experience any burden. Among the females, 9 respondents experienced light burden level while 28 respondents did not experience any burden. The result of Chi-square statistics test shows that there is a relationship between the burden level and gender ($p = 0.49$). While the burden level did not show any significant relationship with employment ($p = 0.758$) and education (0.087). The correlation of the Burden Levels of Caregivers and Sociodemographic Variables are presented in Table 3.

Table 3. Correlation between Burden Levels of Caregiver and Sociodemographic Variables

Variable	Level Burden			Chi Square (p)
	No burden	Light	Medium	
Age				
30-50	22	8	0	0.000 *
51-70	23	10	4	
Gender				
Male	17	9	4	0.392
Female	28	9	0	
Employment				
Civil servants	2	1	1	0.001 *
Farmer	16	8	1	
IRT	16	5	1	
Private	11	4	1	
Education				
No school	7	3	0	0.000 *
SD	26	9	1	
SMP	7	1	0	
SMU	4	5	3	
PT	1	0	0	

* $P < .05$

Discussion

This study shows the burden level of caregivers providing care for people with mental disorder. These burden experienced by the caregivers include the following: mental burden, physical burden, social burden, and financial burden. The results of this research showed that of the four types of burden, caregivers experienced only mental, physical, and financial burden (Table 2). And the correlation between the burden levels of caregivers and sociodemographic variables showed that these sociodemographic variables: age ($p = 0.000$), occupation ($p = 0.001$), and education (0.000) are related to the burden level (Table 3).

Mental Burden: The relationship between caregiver burden and age is significant ($p = 0.000$). Caregivers with age more than 51 years (51-70) are more likely to experience caregiver burden than those within 30 and 50 years. Caregiver with mental disorders had the feelings that despite having to care for patients with mental disorders with a vengeance, but still felt it should still be and need to do more to treat these patients. This simply means that these caregivers were experiencing mental burden.

Caregiver with less social support manifested an increase in the prevalence of burden experienced¹². Based on the length of treatment time caregivers give their patients, 32% had higher caregiver burden and 19% had lower caregiver burden¹³. The level of burden experienced by these caregivers that treat people with mental disorders are in the mild and moderate region. Caregivers experiencing caregiver burden had the risk of experiencing depression¹⁴. We can use the concept of family caregiver burden model to explain this, the family caregiver burden as an output is affected by the process of reciprocity in the variable coping, spiritual health, social support, and the quality of relationships, as antecedents a variable dependency needs activity daily living sufferers¹⁵.

Caregivers are not ashamed to care for people with mental disorders. As a matter of fact, they constantly care for people with mental disorders and rarely get angry. When the members of the family of the patient with mental disorder care for him or her properly, such person can recover in no time and the patient can experience a bright future with that stable condition. Caregivers implement an active communication process, and feel their privacy is not hampered in any way. Caregivers feel that with good care, activity daily living (ADL) of those suffering mental disorders would be good. ADL dependent increase in association with increase in the incidence of caregiver burden¹¹. The ability is always there to care for people with mental disorders. Caregivers while treating these patients need to provide enough emotional support and comfort¹². Even though mental disorders including chronic illnesses, comprehensive treatment, that is, balancing the biological, psychological, social, and spiritual treatment in accordance with the standard procedure then it will be discovered that the condition of people with mental disorders will be stable and the recovery process will be faster. Existing social support ranging from the members of the family, and friends who are also family members suffering from mental

disorders, as well as cognitive therapy from professional nurses will give these caregivers no trouble in seeking needed medical help. Caregivers who have strong spiritual beliefs always assume that the mental disorders experienced by members of his or her family are tests which must go and so they are not overwhelmed when it comes to giving them adequate care.

Physical Burden: Caregivers with mental disorders feel that since family members suffer from mental disorders and the condition are not stable, people with mental disorders more often ask the caregivers for help at every point and more rely on the caregiver. All these in a way have various physical impacts on the caregivers and these include: inadequate sleep or sleep disturbances, feeling more tired, and body aches just to mention few.

Caregiver Burden also result in the loss of weight of the caregiver¹². Nevertheless, caregivers with the profession of civil servants, as well as the private sector are able to manage their time properly as they can divide their time between when to care for people with mental disorders and when to take care of other activities, including time for themselves like resting.

Financial Burden: The various jobs of these caregivers are: 1) civil servant; 2) private; 3) farmers; 4) IRT. And statistically, the incidence of burden caregivers was related to the caregivers job ($p = 0.001$). Caregivers who care for people with mental disorders for a long period of time experience lack or insufficient funds to support and cater for the cost incurred while taking care of these people with mental disorders. In addition to being used for financing the daily needs of the patients, daily activities involving finance in the life of the caregivers are also affected as there are no adequate funds.

If assessed economically, it is seen that caregivers treat patients with chronic illness beyond the care of patients in health care facilities¹⁷. The cohort study shows that caregivers treat dementia for \$56,290 per year for each patient, which is far beyond what the patients can afford considering their conditions¹³. Caregivers with peasant work, when compared to other better professions, experience more financial burden. The community where the research was carried out is a community in which the majority of the caregivers are farmers by profession. And the major way of carrying out their farming activities is through the traditional

ways and they rely mainly on legumes. . Even if they harvest for four months, it is not enough to compensate for the needs of caregiving.

Limitation: Several limitations were required in this study which assist in interpreting the results. These are: 1) the research was only conducted on a small area, so it could not be generalized; 2) the subjects of this research are caregivers with impaired psyche, without comparison.

Implication: When compared with a non-caregiver, the caregivers of patients with mental disorder indicate the existence of financial burden. The emergence of burden on the caregivers with those people with mental disorders will affect the caregivers capabilities in running the treatment of mental disorders, thereby affecting the behavior of caregivers towards discharging their duties adequately. This burden on these caregivers simply means that they need adequate intervention in order to cope and be effective in their primary duties. .

Conclusion

In this particular study, considering the fact that the level of caregiver burden in the light region is 25%,, as much as 5% at the level of moderate, and the majority, which is 70% of the caregivers are at the level in which they experience no burden, we can thereby conclude that the caregiver burden experienced by caregivers did not differ according to the patient's status. The caregiver burden was positively correlated with the age of caregivers, employment of caregivers, and level of education.

Model of nursing interventions are required to prevent further escalation of community-based caregiver burden.

Ethical Clearance: The study was given ethical approval from health research ethics committee Faculty of Nursing Universitas Airlangga number 1040-KEPK.

Conflict of Interest Statement: The authors declares that there is no conflict of interest.

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Reference

1. Hwang, B. B., Fleischmann, K. E., Howie-, J., Stotts, N. A., Dracup, K., & Hour, C. E. Caregiving For Patients With Heart Failure: Impact On Patients' Families, 20(6). 2011. p. 31–442.
2. Sadak, T., Korpak, A., Wright, J. D., Lee, M. K., Noel, M., Buckwalter, K., & Borson, S. (2017). Psychometric Evaluation of Kingston Caregiver Stress Scale. *Clinical Gerontologist*. 2017. p1–13. <http://doi.org/10.1080/07317115.2017.1313349>.
3. Fonareva, I., & Oken, B. S. Physiological and functional consequences of caregiving for relatives with dementia. *International Psychogeriatrics*. 2014. 26(5), 725–747. <http://doi.org/10.1017/S1041610214000039>.
4. NAPA. Clinical Care Recommendations. Advisory Council on Alzheimer's Research, Care and Services. Retrieved from <https://aspe.hhs.gov/advisory-council/april-2016-meeting-presentation-clinical-care-recommendations>. 2016.
5. Sautter, J. M., Tulsy, J. A., Johnson, K. S., Maren, K., Burton-chase, A. M., & Lindquist, J. H. Caregiver Experience During Patients' Advanced Chronic Illness and Last Year of Life. 2015. 62(6), 1082–1090. <http://doi.org/10.1111/jgs.12841>.
6. National Alliance for Caregiving, A. Caregiving in the U.S.: A focused look at those caring for someone age 50 or older. 2009.
7. Smith, G. Schizophrenia. In I. Peate (Ed.), *Mental Health Nursing at a Glance* (First Edit. UK: John Wiley&Sons, Ltd. 2015. p. 34).
8. Von Kardorff, E., Soltaninejad, A., Kamali, M., & Eslami Shahrabaki, M. Family caregiver burden in mental illnesses: The case of affective disorders and schizophrenia - a qualitative exploratory study. *Nordic Journal of Psychiatry*. 2016. 70(4), 248–254. <http://doi.org/10.3109/08039488.2015.1084372>.
9. Riskesdas. *Riset Kesehatan Dasar*. Jakarta: Litbang. 2013
10. Nogueira PC, Assad S, Rabeh N, Helena M, Caliri L, Haas VJ. Caregivers of individuals with spinal cord. *Rev Esc Enferm USP*. 2013;47(3):605-612. doi:10.1590/S0080-623420130000300012.
11. Tanriverdi, D., & Ekinci, M. The effect psychoeducation intervention has on the caregiving burden of caregivers for schizophrenic patients in Turkey. *International Journal of Nursing Practice*. 2012. 18(3), 281–288. <http://doi.org/10.1111/j.1440-172X.2012.02033.x>
12. Adelman, R. D., Tmanova, L. L., Delgado, D., & Dion, S. Caregiver Burden A Clinical Review. *JAMA*. 2015. 311, Numbe, 1052–1059. <http://doi.org/10.1001/jama.2014.304>
13. Hurd MD, Martorell P, Delavande A, M. K. Monetary costs of dementia in. *N Engl J Med., United Sta*. 2013. 368(14).
13. National Alliance for Caregiving and AARP. Caregiving in the United States . Retrieved from <http://www.caregiving.org/data/04finalreport.pdf.%0A>. 2009
14. Rodakowski J, Skidmore ER, Rogers JC, S., & R. Role of social support in predicting caregiver burden. *Arch Phys Med Rehabil*. 2012. 93(12).
15. Yeh, P., & Bull, M. Use of the resiliency model of family stress , adjustment and adaptation in the analysis of family caregiver reaction among families of older people with congestive heart failure. 2011. 117–126. <http://doi.org/10.1111/j.1748-3743.2011.00275.x>
16. Gonçalves-Pereira, M., González-Fraile, E., Santos-Zorrozúa, B., Martín-Carrasco, M., Fernández-Catalina, P., Domínguez-Panchón, A. I. Ballesteros, J. Assessment of the consequences of caregiving in psychosis: a psychometric comparison of the Zarit Burden Interview (ZBI) and the Involvement Evaluation Questionnaire (IEQ). *Health and Quality of Life Outcomes*. 2017. 15(1), 63. <http://doi.org/10.1186/s12955-017-0626-8>
17. Arno PS, Levine C, M. M. The economic value of informal caregiving. *Health Aff (Millwood)*. 1999.