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The Correlation Between Family Burden And Giving Care for Dementia Elderly at Leihitu Sub-District, Central Maluku, Indonesia

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Abstract
Prevalence of dementia was estimated around 3,9% in the age of 60 years old with various prevalence from 1,6% to be 6,4% around the world (Andrieu, 2011). Ponce (2012)stated that from 98% of dementia cases which were investigated that there were 92% families who cared for elderly continuously as long as his/ her life. Hence, it caused a feeling of burden that was often known as caregiver burden (Miller, 2004). This research aimed at knowing the correlation between family caregiver burdens and caring for dementia elderly at Leihitu Sub-district, Central Maluku, Indonesia. Moreover, this research utilized cross sectional design. The population of this research was family who had elderly dementia (247 families). The measuring tools which were utilized were MMSE (Mini Mental State Examination) and ZBI (Zarit Burden Interview). The data was analyzed by utilizing Chi Square and the result showed that there was the correlation between family burden (psychology, social, physique, and finance) with p value= 0,000. Besides, the data was also analyzed by utilizing multiple logistic regressions. However, among all family burden types, the most relevant burden of the family was psychology burden (OR = 8,711).

Keywords: *Dementia, Caregiver, Psychological burden, Social burden, Physical burden, Financial burden*

I. INTRODUCTION

Dementia is a disease that was often suffered by elderly. Globally, the prevalence of dementia was estimated around 3,9% in the age of 60 years old with various prevalence from 1,6% to be 6,4% around the world (Andrieu, 2011). The number of the occurrence of dementia in Asia Pacific in 2005 was 4,3 million people and it would increase to be 19,7 million people in a year in 2050. In Indonesia it would be estimated around 1 million people who suffered dementia in 2010 and increased to be 3 million of people in 2050 (Martina, 2012 in Kompas). Videbeck (2008) stated that most of caregiver and responsibility in caring for elderly who suffered dementia was family (75% was adult daughters, 29% was wives, and 13% was husbands). Ponce (2011) stated that among 98% of dementia cases, 92% of them was investigated. The family who gave care for dementia elderly also needed long time and needed a mentoring continuously that could cause an effect for the family who was as a caregiver who felt a burden (caregiver burden) as what Zarit had stated (1980) in Miller, 2004. Mace and Rabins (2006) said that caregiver burdens were involved physical burden, emotional burden, social burden, and economic burden. This idea was supported by a research that was conducted by Dom Kim et al (2009) regarding in caring for dementia in Korea who stated that caregiver burden was a factor that influenced in treating to the dementia patient. The burden that was felt by caregiver was such as physical burden, psychological burden, social burden, and economic burden.

Netchan (2012) stated that physical burdens which were felt by the family who gave care for dementia elderly were such as muscle tension, lower back pain, arm and leg weakness as the effect of helping elderly. Meanwhile, social burdens were such as conflict in marital relation and family and there was restriction on activity. The psychological burdens which were told by family or caregiver such as depression, anxiety, irritability, frustrated, and stress between informal nurse (family) and recipient care (Sink etal,2006; Quinn et al, 2009). Andrieu (2011) stated that the cost in caring dementia elderly in developed countries, especially China who had 6,35 millions of dementia elders in 2010, the medical cost in the average for each family was estimated $ 2.000 or Rp 2 million. Due to these burdens, elderly was sometimes treated persecution by the family and the elderly was placed in improper institution (Esqueda, 2010). Yilmaz, Turan & Gundogar (2009) stated that caregiver or family who gave care for dementia elderly was like a hidden patient. Besides, a care was not only given to dementia elderly but it had shifted with the family or caregiver who gave the care for the elderly. Thus, the family who gave care for the dementia elderly was often stated as second hidden patient (Bordaty, 2009).

According to BPS of Maluku Province 2010, elderly who suffered difficulty in remembering and concentration reached 2% - 3% of elders in Maluku. The total of elderly who were at Leihitu sub-district was 3043 people and who suffered dementia were 330 elders. Moreover, the interview result with seven families at Leihitu sub-district, Central Maluku district which had dementia elderly in January 2013 stated that forgetful elderly was natural

process and behavior change of the elderly was considered as childhood behavior . Hence, in caring for the elderly, family would feel confusion for facing elderly. However, they still gave care for elderly as a responsibility as a son or daughter to the parents.

II. RESEARCH METHOD

Population of this cross sectional research was family who had dementia elderly at Leihitu sub-district, Central Maluku district, Maluku Province, Indonesia. In addition, elderly population was 3043 people and dementia elderly population was 330 people. The sample was chosen by utilizing purposive sampling technique with inclusion criteria: 1) He or she (family) could read and write, 2) He or she was in 25 years old (minimum), 3) His or her minimum education was in primary school, 4) She or he lived together (in a house) with dementia elderly who had been screening by utilizing MMSE, 5) He or she had responsibility directly for the elderly's health. However, the data that had been collected was analyzed by utilizing logistic regression test.

III. RESEARCH RESULT

Family who gave care for dementia elderly at Leihitu sub-district, Central Maluku district was 39,98 year old (average) with 39,98 (95% CI: 38,87-41,09) and deviation standard was 8,86 years old. Furthermore, the youngest age was 25 years old and the oldest age was 59 years old. Meanwhile, the most number of gender was female (74,5%), having senior high school as the last education (49 %), having income more than Rp1,2 million (161 people (50,6%)), muslim (all respondents), and the most number of proportion was having profession as a farmer (43,7%). The most number of proportion for family who gave care for dementia elderly underwent hard burden (62,3%). Whereas, based on the burden types as followed: the family who underwent psychological burden while caring for dementia elderly in either easy burden or hard burden was almost similar which meant having easy psychological burden (49,8%) and hard psychological burden (50,2%). In other word, the difference between easy and hard psychological burden was 0,4%. The most number of proportion in social burden was in hard level (57,9%), The most number of proportion in physical burden was in easy level (62,3%), Meanwhile, the most number of proportion in financial burden was in hard level (51%).

Result of chi square test showed that p-value <0,05; thus, it was interpreted that there was a significant correlation between the family burden and giving care for dementia elderly either psychological burden, social burden, physical burden, and financial burden as in Table 1, Table 2, Table 3, and Table 4.

Table 1. Analysis of the Correlation between Family Psychological Burden and Giving Care for Dementia Elderly at Leihitu sub-district, Central Maluku District (n=247)

Level of Family Psychological Burden	Dementia				Total		OR (95%CI)	P value
	Easy		Hard					
	n	%	n	%	n	%		
Easy	104	84,6	19	15,4	123	100	26,847	0,000
Hard	21	16,9	103	83,1	124	100	13,632-52,874	

Table 2. Analysis of the Correlation between Family Social Burden and Giving Care for Dementia Elderly at Leihitu sub-district, Central Maluku District (n=247)

Level of Family Social Burden	Dementia				Total		OR (95%CI)	P value
	Easy		Hard					
	n	%	n	%	n	%		
Easy	87	83,7	17	16,3	104	100	14,141	0,000
Hard	38	26,6	105	73,4	143	100	7,467-26,780	

Table 3. Analysis of the Correlation between Family Physical Burden and Giving Care for Dementia Elderly at Leihitu sub-district, Central Maluku District (n=247)

Level of Family Physical Burden	Dementia				Total		OR (95%CI)	P value
	Easy		Hard					
	n	%	n	%	n	%		

Easy	115	74,7	39	25,3	154	100	24,474	0,000
Hard	10	10,8	83	89,2	93	100	11,562-51,806	

Table 4. Analysis of the Correlation between Family Financial Burden and Giving Care for Dementia Elderly at Leihitu sub-district, Central Maluku District (n=247)

Level of Family Financial Burden	Dementia				Total		OR (95%CI)	P value
	Easy		Hard					
	n	%	n	%	n	%		
Easy	88	72,7	33	27,3	121	100	6,414	0,000
Hard	37	29,4	89	70,6	126	100	3,686-11,164	

Result of logistic regression test showed that there was a significant correlation between family psychological burden, family social burden, family physical burden, and giving care for dementia elderly. Meanwhile, there was no significant correlation between family financial burden and giving care for dementia elderly. Family psychological burden had greater correlation rather than family social and physical burden. OR value = 8, meant that family psychological burden had a chance of increase in 8,711 if the signs and symptoms of dementia increased after being controlled by family social and physical burden (Table 5)

Table 5. Analysis of the Correlation of the most Influenced of Family Burden with Dementia at Leihitu sub-district, Central Maluku district (n=247)

	B	SE	Wald	df	Sig	Exp (B)	95%CI	
							Lower	Upper
Psychological Burden	2,165	0,394	30,123	1	0,000	8,711	4,021	18,871
Social Burden	1,312	0,400	10,737	1	0,001	3,714	1,604	8,141
Physical Burden	1,743	0,477	13,372	1	0,000	5,716	2,245	14,551
Constant	-7,641	0,856	79,668	1	0,000	0,000		

IV. DISCUSSION

A. The Correlation between Family Burden and Giving Care for Dementia Elderly

The most number of proportion of the family who gave care for dementia elderly underwent family burden in hard scale was in 62,3% and the statistical analysis result showed that there was a significant correlation between family burden and giving care for dementia elderly with p-value ≤ 0.05.According to conducted result by Dom Kim et al (2009) regarding dementia caring in Korea stated that caregiver burden was one of the factors that influenced dementia patient care. Videbeck (2008) stated that most of caregiver and a person who had responsibility in caring for dementia elderly was family. The family who gave care for dementia elderly needed long time and needed mentoring continuously. Hence, it could cause a certain effect, which was a burden that was felt by the family as caregiver. This burden was known as caregiver burden as what Zarit had stated (1980 in Miller, 2004). Caregiver burden was speculated as a concept that was used to describe an assessment toward whole caregiver's experiences, including some caregiver's condition aspects such as anger, role conflict, stress, unhealthy physical condition, psychological change particularly anxiety and depression (Zarit et al, 1980; Oyebode, 2003; Burce et al, 2005; Schubert et al, 2008; Cooper et al, 2008 in McLennona, 2010). This idea was supported by Esqueda (2010) who stated that caring for dementia elderly was a very challenging job because the caregiver must adapt himself / herself with the conditional change that was always undergone by the elderly any time, started from the easy change until the hard one. Thus, the elderly who spent his or her life was very depended to the family. The family perhaps needed to make drastic change in their own life, including a role change for giving care for the member of family.

Friedman, Bowden and Jones (2010) said that a role change in family caused role stress / conflict inter-role. The family in giving care for elderly would cause various reactions which were caused by some factors such as gender, age, relation type with elderly, economical social status, psychological factor before, relation quality, family life stage, and social support. Family was a support system for elderly in defending his/ her health. The family roles

in caring for elderly were such as caring and staying physical condition of the member of family who was in elder age so that he or she was still in optimal condition, defending and increasing elderly's mental status, anticipating if there was social and economic change for the elderly, motivating and facilitating elderly for fulfilling spiritual needs. However, in performing this role, it was not all well. The family who gave care for elderly was speculated as a responsibility, obligation, and showing gratitude for the parents which the family would perform the role well, in contrary, the family who did not perform the role well would consider the elderly as a family burden (Widyastuti, Sahar and Permatasari ,2009). This was in accordance with Moreno's idea (2010) who stated that there were some reasons when a person made decision in giving care for elderly such as formerly, it was taught by the parents; as an obligation; as a giving gratitude; strengthened relationship; and willing in giving example for the children. Out of those reasons which were explained by caregiver in doing the job and having the role of it, it was depended on his or her ability for doing those jobs. If the family could not adapt themselves with their role, it would cause role stress which was identified as a claim in giving care that burdened the caregiver. Indication of role stress involved fatigue that did not recover by taking rest; alcohol using or other drugs; social isolation; no paying attention more for private needs; inability and unwillingness in receiving help from other people; feeling unappreciated, anger, depression, anxiety, and feeling guilty because he / she did not do the job competently in new role. This role stress was a family burden that could influence either physical health or mental health (Videbeck, 2008).

Oliveros (2007) stated that caregiver burden was speculated as multidimensional respond toward physique, psychology, emotion, social, and finance which were correlated with caregiver's experience in giving care for dementia elderly. This was in accordance with Yilmaz, Turan & Gundogar (2009) who explained that caregiver or family who gave care for dementia elderly was like a hidden patient. Besides, a care was not only given to dementia elderly but it had also shifted with the family or caregiver who gave the care for the elderly. Thus, the family who gave care for the dementia elderly was often stated as second hidden patient (Bordaty Henry, 2009).

Moreover, this idea was supported by the observation and interview result with some families who explained that during giving care for dementia elderly, they often underwent either physical problem or mental problem. The complaints which were told by the family were various each other such as feeling fatigue, back pain, arm and leg pain, difficulty in sleeping due to awakened in the night, headache, muscle strain, and dizzy. The family also reported that they were often angry, impatient, stress, sad, worry, and guilty because sometimes they behaved roughly to the dementia elderly. However, there was a family who could not tell the condition to the other members of family because it would be a serious problem in family, violate the culture and ethics of the family, and feel to be sinful toward the parents. Problem that was felt by the family was depended on how seriousness of the dependency and how long the care was given to the elderly. Furthermore, this idea was strengthened by the result of conducted research by Hirakawa, et al (2007), Pinquart, and Sorensen (2007) who stated that the increase of family burden was influenced by dementia level that was suffered by elderly and how long the care was given by the family.

The increase of family burden was also caused by the minimum health service system for elderly and lack of family understanding about the problem that was undergone by elderly. Government effort for preventing the problem was through the service program at Public Health Center there as the basic service by involving society through *posyandu* (integrated service center) which did not operate maximally. This was caused by lack of socialization from the health worker about the use of Integrated Service Center (*posyandu)* for elderly. Therefore, it caused inability either for elderly or for society in utilizing the available facility of health service.

The result of researcher's observation was the implementation of elderly *posyandu* was still combined with toddler *posyandu* because lack of socialization about elderly *posyandu.* Hence, either society's impression or elderly's impression was the implementation of *posyandu* was only for toddlers. Nonetheless, the *posyandu* activity for elderly focused more on physical problem (measuring blood pressure, body weight, body height, and handling elderly's physical complaint). Meanwhile, mental and emotional problem were speculated as a problem that had less attention because they were private problems and could be solved by self. This condition was perhaps influenced by lack of health workers' understanding, particularly for the program holder of elderly health service regarding a problem which was undergone by elderly and regarding of how to overcome it. This was caused by the program leader who was midwife in the village who had competency in doing midwifery care.

Based on the explanation above, it could be concluded that family burden was an effect regarding caring job that must be done by the family in caring for dementia elderly either physically, psychologically, socially, or financially and it was influenced by health service system in society.

B. The Most Correlated Family Burden in Caring for Dementia Elderly

Psychological burden was the highest and was often undergone by family or caregiver who gave care for dementia elderly. Psychological burden in this research was the most dominant burden that was felt by the family in giving care for dementia elderly because the family could not adapt with the claim and expectation from the elderly, other member of the family, and culture in society. According to the result of this research, it could be meant that the highest the level of dementia, the psychological burden would increase more. The role change made caregiver must make a change in his/ her life to be able to perform multiple roles as parent caregiver and having life or activity and responsibility toward his / her own family. Besides, the family must be able to provide an environment that could increase health, satisfaction, and good relationship in family. Thus, he or she could adapt with the condition. When the caregiver could not be able to adapt herself/himself, it would be occurred a conflict of role that was felt as a burden. The psychological burdens which were felt most by the family were depression, anxiety, anger, frustration, embarrassment, and feeling guilty because he or she could not perform the role well. (Videbeck, 2008; Chin Chan, 2010; Branscum A, 2010) stated that the effect of family psychological burden influenced toward caregiver's health either physical health or mental health.

Lavretsky (2005) explained that if psychological burden (depression) was not treated, it would increase the morbidity and mortality for the elder caregiver including suicide risk. Meanwhile, hard depression adult caregiver had a risk to reoccur and to decrease the life quality. Family psychological burden would also influence to the receiver of the caring (dementia elderly) which the elderly would receive wrong behavior from the family such as oppression and placing the elderly to the improper institution. The psychological burden that was felt by family seriously influenced because the family who felt depressed must perform multiple roles, role conflict, feel unappreciated by the other members of the family, feel guilty toward him/herself, feel sinful. In addition, there was a claim from the family or society to give good care for elderly, to feel fearful and embarrassed if he / she could not give care as well as for the parents or parents in law because it would become a topic of conversation in family or society if he/she did not behave well to the elderly although the caregiver knew that the problem was due to the elderly's fault. Besides, the public order speculated that parent or elderly was the most right person and it was required for the son/daughter or son/ daughter in law relented to the parent although they felt that if what they had said or done was right.

V. CONCLUSION AND RECOMMENDATION

The level of family burden in caring for dementia elderly was 62,3% who underwent hard burden. Furthermore, there was a significant correlation between family burden and giving care for dementia elderly. However, each burden which was either psychological burden, social burden, or physical burden in caring for dementia elderly had p value = 0,000.

This research was expected to be able to become a source in deciding the program of proper nursing service and it was in accordance with the family needs in giving care for dementia elderly. Nevertheless, this research could be an additional reference and comparison for further researcher who researched about similar problem.

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