A Systematic Review of Factors Influencing the Burden of Family Caregivers in Caring for Elderly with Dementia

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ABSTRACT

Background: The aging is the final cycle of human life, and one of the disturbances of aging which occurs in the elderly is dementia. Elderly with dementia will experience changes in the pattern of daily life activities, and therefore require total care from the family. There are some reasons of the family for caring for the elderly at home, among others, include the expression of devotion to the parents, respect, and affection towards the parents. The burden of elderly caregivers may lead to a stressful condition which can manifest in depression and frustration, and will finally affect the welfare of the elderly and the family.

Purpose: This study aimed to describe the factors influencing the burden of the family caregivers in caring for the elderly with dementia, and to identify the physical and psychologic factors associated with the caregiver burden.

Methods: A systematic review of three databases, including CINAHL, PubMed, and ScienceDirect was carried out by exploring relevant articles published in 2008 to 2017. The keywords of burden, elderly caregiver, and dementia were used. Seventy potentially relevant articles were selected out of 4.210. After a further review, 16 articles met the inclusion criteria and were used in this study.

Results: The results revealed that factors influencing the burden of family caregivers in caring for the elderly with dementia include family support, family socioeconomic ability, and family coping mechanisms. The burden will get higher when the caregivers play double roles, i.e., caring for the elderly and working to earn a living. The quality of life of the family caregivers can be well promoted if the influencing factors can be resolved.

Conclusion: Three factors influence the caregivers' burden, including family support, socioeconomic factor, and family coping. Of the three factors, family support is the most influential factor in caring for the elderly with dementia.

Keywords: Burden; caregivers; elderly; dementia

BACKGROUND

The aging is the ultimate cycle of human life, and one of the disturbances in aging that occurs in the elderly is dementia. Dementia is a chronic or progressive syndrome in which there is a cognitive decline and leads to disorders of memory, orientation, comprehension, language skills and impaired daily activities (WHO, 2015). Dementia experienced by the elderly will influence the burden of family caregivers. In practice, although caregivers feel overwhelmed with caring for older adults with dementia, they

find that affection is the reason why they keep the health of the elderly (Vugt & Verhey, 2013). The number of older adults in Indonesia is estimated to be 234,181,400 inhabitants, and the proportion of the elderly population will increase by 11.34% by 2020. Risk factors for cognitive impairment include age, sex, race, age, genetics, heart rate, cholesterol, diabetes mellitus (Farid et al., 2013). The burden of elderly caregivers can lead to stressful conditions manifested in depression and frustration, and ultimately affect the welfare of parents and families. Zarit et al. (1986) defined caregivers' burden as the degree to which an individual's emotional or physical health, social life or financial status develop the caring for his relatives.

The burden of the family caregiver is to help the elderly meet their needs of daily life. Since the caregivers continuously accompany the elderly during treatment, the caring given is then called as long-term care (Onishi, 2016). Caregiving for the elderly with dementia is highly stressful and has negative consequences for the caregivers such as the emergence of burden. Stress experienced by caregivers can be manifested physically and psychologically. Family support is importantly needed to minimize stress in the caregivers. Family support in the form of affection to the elderly can be shown in the form of assistance for daily needs (Marian, I. Z., Marja, J., & Aartsen, 2015).

Dementia is a disorder that is manifested by cognitive impairment, chaotic behavior, impairment of sensory function, and inability to function optimally due to progressive disorders in the brain (Alzheimer Association, 2012). Physical burden of elderly caregivers can be in the form of compromised immune function, unstable emotions, social isolation, and depression and anxiety (Razani & Quilici, 2014; Aschbacher et al., 2006). Stress management interventions are appropriate for elderly caregivers to function optimally in caring for the elderly at home (Alzheimer Association, 2012). Caregiver burdens are associated with the work overload, sleep disturbance, and economic disability, and lack of leisure time to interact with society.

Caregivers should have knowledge and skill in caring for the elderly with dementia since they are key factors in providing educational assistance and information to the elderly. Family support is a key factor in the treatment of the elderly with dementia. Studies on factors influencing the burden of family caregivers in caring for the elderly with dementia have been massively conducted. However, there are limited studies which investigate specific primary caregivers of the elderly with dementia undergoing treatment at home. Therefore, this review is important to know the factors influencing family caregiver burdens in caring for the elderly with dementia.

OBJECTIVE

This study aimed to describe the factors influencing the burden of the family caregivers in caring for the elderly with dementia and to identify the physical and psychologic factors associated with the caregiver burden.

METHODS

Search strategy and article selection

This study describes a systematic review which was conducted by exploring relevant articles published in the databases of CINAHL, PubMed, ScienceDirect and Google

Scholar. The review was limited to the articles published in 2008 to 2017. The studies were eligible for inclusion in this study when they reported on the burden of family caregivers in caring for the elderly with dementia. The keywords used in the search were burden, elderly, caregiver, and dementia.

The selection of articles in this study was performed in two steps. The first step was reviewing the articles based on the title and abstract, and the second step was selecting the full-text articles in accordance with the inclusion criteria. If there were several articles which reported similar results, only the full-text articles were used. The types of studies included in this review were correlation studies, longitudinal studies, qualitative studies, cross sectional studies, observational studies and case control studies. The participants in the studies were family caregivers who provided care to the elderly with dementia living in the family. The burdens of caregivers included the factors that influenced the delivery of care to the elderly and the elderly needs which should be met during the care.

Data abstraction

Information abstracted was based on the study designs, objectives, sampling method, source and type of data, characteristics of participants, and details of diagnosis of the caregiver burden.

Quality Assessment

A review that identifies dementia in the elderly has been extensively studied, but a review explaining caregiver burdens has not been widely studied. This review explores the factors that influence the burden of caregivers of the elderly with dementia with some differences in the caregivers and elderly characteristics.

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RESULTS

This study explored 4,210 titles and abstracts for eligibility in the first step. After a further review, 225 articles were selected. Out of 225, 209 articles were excluded since they did not investigate the factors influencing the burden of caregivers (183), and 26 were reviews/editorials. Finally, 16 full-text articles were determined for this review. All articles were written in English.

Table 1. Quality control of the studies

Title/ years	Author(s)	Study population and design	Instrument used in the study	Main Findings
Cultural Correlates of Burden in Primary Caregivers of Older Relatives: A Cross-sectional Study/2014	Mill, Palomino-moral, & Fr, 2014	Primary home caregiver of older relatives of 65 years. Cross sectional study and 208 populations.	Caregiver strain index.	The cultural factors in the perception of burden in caregiving situations.
Caregiver burden associated with behavioral and psychological symptoms of dementia (BPSD) in Taiwanese elderly/ 2012	Huang, Lee, Liao, Wang, & Lai, 2012	The study had a cross- sectional design and involved 88 patients with dementia.	Neuropsychiatric inventory	Improvement of treatments for delusions, agitation/aggression, anxiety, irritability/ lability, and dysphoria/depression among dementia patients may reduce caregiver burden.
Caregiver Burden in Alzheimer-type Dementia and Psychosis: A Comparative Study from India/2017	Sinha, Desai, Prakash, Kushwaha, & Tripathi, 2017	Comparing two continuous studies and 32 population	Zarit burden interview	Dementia carries a greater caregiver burden when compared with elderly patients with psychosis. Innovative interventions are needed to remove the burden from caregiving.
WHEDA study: Effectiveness of occupational therapy at home for older people with dementia and their caregivers-the design of a pragmatic randomized controlled trial evaluating a Dutch programme in	Voigt-radloff et al., n.d)	Single blind randomized controlled trial	Mini Mental State Examination (MMSE	WHEDA interventions have positive implications for older adults with dementia.

seven German centres
/2009

The Association Between the Burden on Formal Caregivers and Behavioral and Psychological Symptoms of Dementia (BPSD) in Korean Elderly in Nursing Homes/2015	Song & Oh, 2015	The study was to examine the association between BPSD and the burden on formal caregivers of nursing homes in South Korea and samples of 143 formal caregivers	The research instrument used Korean Version of Mini Mental State Examination (K-MMSE), Korean-Physical Activities of Daily Living (K-PADL), Neuropsychiatry Inventory Questionnaire (NPI-Q)	Results showed that the total severity score of BPSD had a statistically significant positive correlation with the total distress score.
A Controlled Naturalistic Study on a Weekly Music Therapy and Activity Program on Disruptive and Depressive Behaviors in Dementia/ 2010	Han, Chen, & Yusoff, 2011	Correlational study	MMSE AND Referral memory behavior problem	Music intervention could reduce the behaviors and burden of caregivers caring for the elderly with dementia.
The Effectiveness of Psychoeducational Interventions in Reducing the Care Burden of Family Members Caring for the Elderly in Turkey/ 2016	Boyacioglu	This study was conducted using pre and post-test control group and the older person aged 65 years or older in this service area of 84.	The older person aged 65 years or older in this service area, The General Self-Efficacy Scale – GSE, The Cognitive Emotion Regulation Questionnaire – CERQ	The psychoeducational intervention based on the McGill Nursing Model was efficient.
Telephone-delivered psychosocial intervention reduces burden in dementia caregivers/2008	Glueckauf et al., 2012	The study is randomized control trial	Psychosocial intervention for dementia caregivers (FITT-D) dementia severity (Clinical Dementia Rating (CDR)	Caregivers receiving FITT-D exhibited significantly lower burden scores and less severe reactions to memory and behavior problems than caregivers in the standard care condition
Telephone-Based, Cognitive-Behavioral Therapy for African American Dementia Caregivers With Depression: Initial Findings/ 2012	Glueckaufs	Randomized pilot study	Revised Memory and Behavior Problem Checklist (RMBPC)	Cognitive behavior therapy can effectively reduce the burden of elderly caregiver with dementia
Factor associated with the burden of	Sakurai et	Cross sectional study and of 48 participants	Zarit burden interview (ZBI)	Caregiver's burden is strongly associated

caregivers of patient with dementia/ 2016	al., 2016	from our classes for caregivers		with the quality of life of patients.
Prevalence and predictor of burden in caregiver of people with dementia/ 2013	Ames, Psych, Balshaw, & Ph, 2013s	Prospective cohort study and 732 primary caregivers	Zarit burden interview	People with dementia have high and persistent rates of burden. Identification of caregivers likely to have high levels of burden at 12 months may allow more accurate targeting of interventions.
Religious coping and caregiver well-being in Mexican-American families/ 2009	Herrera, Lee, Nanyonjo, Laufman, & Torres-vigil, 2015	Qualitative longitudinal study	Religious Coping (Rames et al., 2013) COPE) Scale	Spiritual beliefs of caregivers are pertinent to their ability to adapt to physical and mental health problems, even though some aspects of their beliefs may have an unintended negative impact.
Comparative analysis of informal caregiver burden in advance cancer, dementia and Acquired brain injury/ 2015	Harding, et al	Comparative study and the 131 participate caregiver elderly with dementia	Zarit burden interview(ZBI	The subscale shows some individuals and varies depending on the person and role of the caregiver
Psychosocial intervention for family caregivers of people with dementia reduces caregiver's burden: development and effect after 6 and 12 months/ 2009	Andren	Longitudinal control design	The Carers' Assessment of Satisfaction Index (CASI)	Psychosocial therapy is most effective and has a positive effect on follow-up for 1 year, so improvement of dementia can be seen
Experience of Dementia-related Anxiety in Middle-aged Female Caregivers for Family Members with Dementia: A Phenomenological Study/ 2016	Kim, et al	A descriptive phenomenological study and	-	Considering the significance of DRA in the caregivers of an FMWD, health promotion strategies including dementia prevention and social support should be developed and provided to improve their attitudes and help them make behavior changes.

Family caregivers of people with dementia/ 2009	Brodaty	Correlational study	-	The results showed psychosocial intervention can reduce the elderly caregiver burden in the family
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Summary of research

Table 2. Burden of caregivers in caring for the elderly with dementia

Characteristics	Author
Factors influencing the burden of caregivers in caring for the elderly with dementia	Brodaty et al., 2009; Andren et al., 2009; Herera et al., 2009;
Family coping	Asbhacher et al., 2006; Kim et al., 2011; Jensen et al., 2017; Song et al., 2015; Lai et al., 2012; Bayacioglu et al., 2016; Brodaty et al., 2009;
Socioeconomic ability	Chan, 2011; Harding 2015; Brodaty et al., 2009; Glueckauf et al., 2012;
Family supporting	
Physical factors of caregiver burden	
The physical factors of the caregivers of the elderly with dementia are related to the activity daily living needs of the elderly. To meet the needs, caregivers must spend sufficient time to maintain good care. The caregivers should be able to set the time for all tasks that can be implemented properly.	Shim et al. 2015; Kim et al., 2011; Putri et al., 2013; Sakurai et al., 2016; Brodaty et al., 2009
Psychological factors of the caregiver burden	
Depression, stressor, uncomfortable feeling, stress, predicting things that are not good, anxiety, depression, fatigue	Palacio et al; Brodaty et al. 2009; Andren et al. 2008;

Factors influencing caregiver burden in caring for the elderly with dementia

Family support

The majority of the elderly in Indonesia live more with their family. Love and affection become the reason why the elderly are not cared in a nursing home. Besides, the religious values also become the reason to care for the elderly with family. Health support in elderly care becomes an important factor and reduces the burden of elderly care with dementia (Schoenmakers, Buntinx, & Delepeleire, 2010). Elderly with dementia has a long-term care tendency. Health care has shifted to family-centered care,

and families become care partners (Chan, 2011). Family support is important during the care. All family members must be able to understand the elderly since good family supports will reduce the caregiver burden of the elderly with dementia. The assistance provided by the families includes dressing, bathing, toilets, care, and around (sometimes referred to as personal care), and the help with ADL merges, including Instrumental Daily Life Activities (IADL), such as shopping, preparation food using transportation, and managing personal finance, as well as supervision to perform behavioral symptoms or to prevent the elderly from dangerous incidents.

Family support in caring for the elderly is demonstrated by helping the daily activities of the elderly. The wife is to be the primary caregiver in the care of the elderly. Wives with higher affection are neglected with other family members at home, other than that unemployed wives have enough time to care for the elderly with dementia (Rezende et al., 2017). Families who treat elderly with chronic illness have a high risk of burden which influences the caregiver quality of life.

Socioeconomic ability of family

Lack of financial resources is one of the main difficulties in caring for sick family members, and the consequence is that the families should reduce the budget for other expenses. This will cause more burden to the family members who make a living, and to mothers who are in charge of spending the money. Costs required include the cost of medicines, emergencies, transportation, daily necessities, and other unpredictable needs. The social characteristic is social being since the time required is very little; most daily time is given to the elderly with dementia (Jensen et al., 2017).

The balance in family finance arrangements is the solution to the caregiver's economy. The need for great sacrifice in caring for the elderly with dementia will affect the quality of life of the caregivers and the elderly. This sacrifice includes the goods and the quality of life of other family members (Ames et al., 2013).

Caregivers need financial assistance in caring for the elderly with dementia. In some advanced countries, the care of the elderly with dementia is very good, such as by providing insurance for the elderly care with dementia. This provision of insurance can reduce the burden of caregivers and families of elderly dementia patients (WHO, 2015).

DISCUSSION

Caring for the elderly with dementia requires more affection and care. The provision of total care can increase the quality of life of the elderly; this will have an impact on the family especially the primary caregivers. In many cases, primary caregivers can have dual roles, i.e. being the elderly caregiver and meeting the needs of other family members (Ames et al., 2013). Due to these dual roles, the process of caring for the elderly will run dynamically (Choi & Stone, 2012).

This systematic review revealed that the factors influencing the burden of caregivers caring for the elderly with dementia include family support, socioeconomic ability of family, and family coping. The family support includes family roles and functions. The

roles and functions are operationally performed by assisting the elderly in daily needs, such as eating, shifting, dressing, toileting (Kim, Chang, Rose, & Kim, 2011). Another factor is related to the socio-economic capacity. The family needs a lot of costs to care for the elderly at home. As a result, the elderly family will have to use the budget of other expenses. The balance between the cost of elderly care and sufficient source of financial resources can decrease the burden of the elderly care givers.

Caregivers of the elderly with dementia are very susceptible to stressful and physical events. The elderly with dementia have many experiences which give an interference in cognitive function including the mindset. This makes the elderly caregivers vulnerable to physical and psychological stressors, and effective coping strategies become the main key in caring for the elderly with dementia (Gilhooly et al., 2016).

Furthermore, in caring for the elderly, the caregivers often experience physical fatigue. It is because the treatment takes a long time. Sometimes, the caregivers experience sleep interference in their care of the elderly, and this becomes one of the driving factors of stress. Constructive coping patterns are needed to decrease the burden of the caregivers.

CONCLUSION

Three factors influence the burden of caregivers in caring for the elderly, including the family support, family socioeconomic ability, and coping mechanism. Of these three factors, family support is the most influential factor in caring for the elderly with dementia.

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