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# Caring for a Spouse with ADL Dependency: Perceived Social Support and Stress Level among Elderly Spousal Caregivers

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## Abstract

**Background:** Taking care for an individual with Activity of Daily Living (ADL) dependence is often very demanding and stressful. With an increasing in life expectancy, an elderly spouse often becomes a caregiver for an aging or ill loved one. However, changing in family structure, shrinking social circle and aging process itself might influence caregiver's social support and their stress level. This study aimed to examine perceived stress and social support among spousal caregivers of elderly with ADL dependence and correlation between these two variables.

**Methods:** This is a descriptive quantitative study with cross sectional design. A convenience samples of 30 caregivers aged 60 years or over who taking care for spouse with ADL dependence. Perceived social support and care giving-related stress were measured using social support questionnaire and the King stone Caregiver Stress Scale (KCSS) respectively. Data was analyzed using descriptive statistics and Somer's D test.

**Results:** Result showed that a half of respondents were lack of social support and the remaining only had moderate level of support (46.7%). Very few of them had good social support (3.3%). Most respondents experienced moderate stress level (56.7%), even severe (16.7%). Statistical analysis showed no relationship between social support and stress level ( $p > 0.05$ ).

**Conclusion:** Elderly spousal caregiver was lack of social support and experienced moderate stress level.

**Keyword:** *Activity of daily living; elderly; spousal Caregiver; social support; stress*

## Introduction

As people age, their body functions, including immune function are decreased. As a result, they become more susceptible to diseases and disability (1). About 26% of elderly people worldwide was estimated to live with disability in activities of daily living (ADL) (2). The number is even bigger in institutional care setting. A previous study found that 72% of the nursing home's residents were partially dependent and 14% of them are totally dependent (3). When individuals gradually lose their independence, they definitely need assistance from others. Caregiver is an individual who provides care and assistance to those who have ADL disability or dependence (4). Family members such as spouse, children, or parents most often have to play a role as an informal caregiver. With an increasing in life expectancy, elderly often become caregivers for their aging or ill spouse. A spouse is considered to be an ideal caregiver because they can provide both physical care and emotional support to their partners (5–7). Putra on his study found that 23.3% of elderly became caregivers for their ill spouse (7). The long process of taking care for individual with ADL dependency undoubtedly becomes a stressor for the caregiver.

The stress experienced by caregiver might relate to physical, psychological, social, and financial burdens. Compare to younger caregiver, the older one tend to feel depressed and are at greater risk of experiencing physical and psychological problem if it left untreated (8,9). Elderly are more susceptible to have stress because they usually have to deal with other stressors, not only the care giving responsibility. For example most elderly caregiver find themselves struggling with physical and mental health issues, economics hardship because of retirement, and also changes in social network, and family structure (10,11). People have different appraisal process of potential stressor. As a result, they deal with stress in different ways. Some people deal with it just fine and others have a hard time. According to the Buffering Hypothesis Theory by Cohen and Wills, stress appraisal can be influenced by social support (12). Social support also plays a role in reappraisal process, inhibition of maladaptive responses, and facilitation of adaptive ones which are important to counter the negative effects of stress. Social support for caregivers can be from children, siblings, spouse, other family members, neighbors, friends and health workers (13).

However, differ from younger caregiver, most elderly caregivers may find their social circles shrinking. Most often, spouse becomes the most significant person for them.

However, spouse can be turnout to be a significant stressor, for example when they suffers from debilitating diseases (14). The issue of care giving-related stress and social support have been commonly studied among younger caregivers (15).

However, little is known about that of elderly caregivers who caring for spouse with ADL dependence. This study is undertaken to examine perceived social support and stress level among spousal caregivers of elderly with ADL dependence and correlation between these two variables.

## Method

This is a descriptive quantitative study with cross sectional design. This study was conducted in 7 villages in Baturraden District, Purwokerto in 2019. A total of 30 caregivers who met the study criteria was participated in this study. The inclusion criteria were aged 60 years or over, taking care for spouse with ADL dependence, have been in care giving role  $\geq 6$  months and willing to participate in this study. The studied variables were social support and care giving stress level. Social support was measured using an adapted social support questionnaire from previous research (16).

The instrument consists of 20 items using 4 point rating scale (1=never to 4=always).

The total score is ranging from 20-80 and then categorized into three levels of social supports: low (20-40), moderate (41-60) and high (61-80). Meanwhile, caregiving-related stress were measured using the King stone Caregiver Stress Scale (KCSS). There are 10 items with 5 point rating scale (1=feeling no stress to 5=extreme stress).

The total score is ranging from 10-50 which then categorized into three levels of care giving stress: low (10-15), moderate (16-24), and high (25-50).

Data were analyzed using descriptive statistics and Somer's D test. Prior to data collection, respondents were given explanation about aim and nature of this study and then signed informed consent if they were agreed to participate.

Ethical principles, including autonomy, confidentiality and anonymity were maintained throughout the study. Ethical approval was gained from the Health Research Ethics Committee of Faculty of Health Sciences, Jenderal Soedirman University (No. 070.1/1162/IX/2019).

with different level of ADL dependency, but majority was mild one (76.7%). In regards to education, most of caregivers had a low level of education either just graduate from primary school (80%) or even never taken any formal education (10%). All caregivers in this study also had low social economic status and majority of them had no paid job (70%).

## Results

**Table 1. Characteristics of respondents (n=30)**

Category		
Age (Mean, SD)	71	8.836
Education Level (n, %)		
Uneducated	3	10.0
Primary School	24	80.0
Junior High School	1	3.3
Senior High school	2	6.7
College	0	0
Employment Status (n, %)		
Employed	9	30.0
Unemployed	21	70.0
Caregiver's Status (n, %)		
Wife	14	46.7
Husband	16	53.3
Social Economics Status (Income)		
Under standard ( $\leq 1,750,000$ )	30	100
Above standard ( $> 1,750,000$ )	0	0
ADL status of the treated spouse		
"Mild" dependency	23	76.7
"Moderate" dependency	2	6.7
"Severe" dependency	1	3.3
"Total" dependency	4	13.3

**Table 1** shows that mean age of caregivers was 71 years old. Caregivers were either husband or wife of the ill one (53.3% and 46.7% respectively). They treated for spouse with different level of ADL dependency, but majority was mild one (76.7%). In regards to education, most of caregivers had a low level of education either just graduate from primary school (80%) or even never taken any formal education (10%). All caregivers in this study also had low social economic status and majority of them had no paid job (70%).

**Table 2. Caregiver's Stress Level (n = 30)**

Category	Frequency	Percentage
Low	8	26.6
Moderate	17	56.7
High	5	16.7

**Table 2** shows that most caregivers in this study experienced significant stress when caring for their ill spouses. This was indicated by more than half of them experiencing moderate level of stress (56.7%), and some caregivers even experiencing a severe stress (16.7%).

**Table 3. Perceived Social Support (n = 30)**

Category	Frequency	Percentage
High	1	3.3
Moderate	14	46.7
Low	15	50.0

**Table 3** shows that most caregivers tended to not receive significant amount of support. Half of the caregivers received low social support and just very few of them had the high one. The remaining had moderate level of social support (46.7%)

**Table 4. Relationship between social support and stress level (n = 30)**

		Stress				P Value
	Low	Moderate	High	Total		
	f(%)	f(%)	f(%)	f(%)		
Social Support						
High	0(0)	0 (0)	1(100)	1(100)	0.289	
Moderate	3(21.4)	9(64.3)	2(14.3)	14(100)		
Low	5(33.3)	8(53.3)	2(13.4)	15(100)		

**Table 4** shows a cross tabulation between social support and stress level. However, Somer's d test showed that there was no significant relationship between those two variables ( $p > 0.05$ ).

## Discussion

This study described perceived social support and stress level among elderly spouse in regards to caregiving and analysed relationship between those two variables. Results showed that most respondents experienced moderate and severe level of stress. This finding was similar to a previous study that found caregivers tend to experience moderate and severe level of stress while caring for the elderly (17). Caregiver felt a significant amount of stress due to a variety of factors. Caring for spouse with ADL dependence, caregivers often feel overwhelmed by the caregiving responsibility. Taking care for elderly with ADL dependence is most often very time consuming (17). This issue is significant especially for those who have other responsibilities than just caregiving. They have to spend time caring for their ill loved one and at the same times doing household chores or job responsibilities.

Besides, care giving process itself seems never ending due to the nature of diseases. Caregivers in this study had been in care giving role at least for six months. They didn't know how long they had to be in that role because their spouses were suffering from chronic debilitating diseases such as stroke and diabetes melitus. Moreover, elderly caregivers most often also had to deal with other situations than can worsen the stress, including decrease in body functions, psychological issues, and changes in social and economic functions (10,11).

Caregiving-related stress that continues without relief can lead to physical problems such as fatigue and sleep problem, psychological problems such as anxiety and depression, and social problems such as impaired social interaction and isolation (18). It was interesting that some caregivers in this study only experienced low level of stress. Possible explanation for this finding was that caregiving seen as expression of love and devotion to the loved one. Thus, they were likely to appraise the caregiving experience in a positive way which can hinder them from extreme stress. In regards to social support, findings showed that caregivers in this study were more likely to have less social support. A study by Andriyani, Anggreny, & Utami demonstrated that majority of elderly had a lower level of support (66,7%) (19). The low level of social support received by the caregivers can be caused by the fact that the elderly caregivers have different conditions than the younger one. Husband or wife is considered to be the greatest source of support for a married couple. Thus, when their loved ones suffer from debilitating disease, they most often lose their main source of support (14). Family members particularly adult children also becomes the main source of support. Thus, when their adult children get married and start to live independently, they lose source of support (20). However, the availability of adult children in the family doesn't guarantee the availability

of support. It is very possible that they could not take part in care giving because of work responsibility. Meanwhile, married children are usually busy taking care for their own family. Friends and neighbours can also be source of social support. However, the elderly caregivers usually have entered retirement age so they might lose friends from workplace (21). Because of demanded caregiving tasks, many caregivers also left their social activities and had less social interaction with their neighbours. Besides, changes in social norms might cause people to mind their own business only and neglect others (22). Those might cause caregivers were likely to be lack of social support from their neighbours. This study demonstrated that social support did not associate to caregiving-related stress. This finding seems not to support the theory of The Buffering Hypothesis by Cohen & Wills, which assume that the presence of a social support system helps buffer or shield, an individual from the negative impact of stressful events (12). Possible explanation for this finding was elderly caregivers might have specific characteristics that differ to other age groups which possibly influence their mechanism to encounter stressful life events. Elderly people are less likely to rely on external support, rather more on themselves, their most significant person, or even a superior being. The latter is known as spirituality. The stage of human development affects a person's spiritual level. As people get old, they reaches maturity in thinking and behaving (23). Spirituality can also give meaning to life, comfort and strength during difficult times, so extreme stress can be avoided (24). Even though majority of elderly in Indonesia is still living in a three generational type family, the present study has provided an insight about the issue around elderly care giving and old age support. This issue is expected to increase along with the changing in preferred living arrangement. A previous study found that about 11% of adult children wanted their parents to live independently either alone or only with spouse in their old age (25).

Few limitations were identified in this study. First, the number of participants were considered small for a quantitative study. Second, type of living arrangement of participants were not considered.

## Conclusions

Elderly spousal caregiver was likely to experience caregiving-related stress and lack of social support. Because social support was found not to relate to stress level, elderly caregivers are suggested to develop mechanism to encounter stress which more focus on self or a supreme being. Further researches which involving larger number of study participants with specified criteria are needed to produce a more conclusive findings.

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