

## ASSOCIATION BETWEEN THE SYMPTOMS OF BEHAVIOR CHANGES IN PEOPLE WITH DEMENTIA (ODD) AND STRESS LEVELS IN CAREGIVERS

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### ABSTRACT

**Background:** Dementia is a cognitive disorder accompanied by mental and behavioral changes, which can cause stress for caregivers, especially families. Stress on caregivers will affect the care of people with dementia, and the well-being of caregivers and the elderly will decrease. This study aims to determine the relationship between symptoms of behavioral changes in people with dementia and stress levels in caregivers. **Method:** This research is observational analytic with a cross-sectional design using an alternative linear-by-linear association test. Symptoms of behavioral changes were measured using the Neuro-Psychiatric Inventory (NPI), while the stress level in caregivers was measured using the Perceived Stress Scale (PSS). **Results:** A total of 50 caregivers were included in this study, most of whom came from the age group 41 – 50 years (28%); dominated by women (66%); 46% of subjects were spouses and children (46%). Most caregivers are self-employed (20%); with income above the Regional Minimum Wage Rp. 2,700,000 as much as 64%, and a third (30%) of dementia had no comorbidity. **Conclusion:** There is a significant relationship between symptoms of behavioral changes in dementia and caregiver stress levels. Stress on caregivers in caring for people with dementia needs attention so that people with dementia and caregivers both achieve well-being in carrying out daily life activities.

**Keywords :** *Dementia, Caregivers, Behavior Changes, Stress*

### INTRODUCTION

Increasing life expectancy will increase the number of elderly people worldwide, leading to an increase in the number of dementia cases.<sup>1,2</sup> Dementia is a chronic and progressive clinical syndrome characterized by cognitive decline, behavioral disorders, and psychological symptoms that disrupt a person's daily functioning and independence.<sup>3</sup> This adversely affects the patient's quality of life, burdens and stress on caregivers, and increases costs to families and communities.<sup>4,5</sup>

Behavioral disorders are common in Alzheimer's Dementia (AD) and contribute greatly to morbidity. As many as 80% of Alzheimer's patients experience behavioral changes, with the frequency increasing as the disease progresses. Behavioral and Psychological Symptoms of Dementia (BPSD) exacerbate cognitive decline and physical dysfunction in patients with AD, placing a great burden and stress on caregivers of patients with dementia. Specifically, family caregivers of patients with dementia were found to be associated with social isolation, decreased physical health, and psychological disorders such as depression.<sup>6-8</sup>

Neuropsychiatric symptoms and behavioral disorders in people with dementia or BPSD are common in patients with

AD and contribute greatly to morbidity. As many as 80% of Alzheimer's patients experience behavioral changes, usually with increasing frequency as the disease progresses. Estimates range from 30 – 50% for delusions or hallucinations and up to 70% for agitated or aggressive behavior.<sup>7,9</sup> Signs and symptoms of dementia are divided into cognitive psychological, behavioral, and neurological symptoms. Several domains that indicate silence in dementia patients, such as, the domains of language (dysphasia/aphasia), praxis (dyspraxia/apraxia), perception (dysgnosia/agnosia), memory (amnesia), and executive function (disinhibition, perseveration, apathy).<sup>10,11</sup>

Behavior changes have been known to contribute to the increased stress of caregivers of AD patients for a long time, with a more recent study finding that 46% of caregivers cited dementia-related conduct disorder as the main reason for the institutionalization of patients. BPSD is a symptom and sign of dementia in the form of disorders of behavior, feelings, thought processes or perceptions. People with dementia who experience BPSD will easily cause physical injury and psychological stressors to people with dementia and their caregivers that cause people with dementia to be placed in nursing homes.<sup>3,12</sup>

The symptoms of behavioral changes that occur in people with dementia are mostly almost two-thirds unknown to the public. Not to mention the stigma against dementia patients that adds to the burden of care and stress on informal caregivers who are mostly families. Caregivers experience high levels of stress when they do not have adequate internal and external resources (financial, assistance from other families, formal care) to adapt to the caregiving situation.<sup>13-15</sup> The burden of caregivers can impact the physical, psychological, social, and economic health of caregivers themselves.<sup>16</sup> This study aimed to determine the relationship between symptoms of behavior changes in people with dementia and the stress levels in caregivers.

## METHODS

The research method uses a quantitative analytical approach with a cross-sectional design to determine the relationship between symptoms of behavior changes in people with dementia with stress levels in caregivers according to the time of study. The data collection method was obtained from interviews and measurement of symptoms of behavior change using the Neuro Psychiatric Inventory (NPI), while the stress level of caregivers was measured by the Perceived Stress Scale (PSS). Symptoms of behavior change will be classified into mild, moderate, and severe. The stress level of the caregiver will be classified into mild, moderate, and severe.

This research has obtained ethical feasibility permission from the Research Ethics Commission of the Faculty of Medicine, Udayana University with letter number: 2047UN14.2.2.VII.14/LT/2023.

This research uses purposive sampling method. The number of samples included in this study is 50 people. The sample in this study was caregivers over 18 years of age who cared for people with dementia who visited the Psychiatric Polyclinic and were treated by the Geriatric Inpatient Room (Gandasturi) from July to September 2023 who met the inclusion and exclusion criteria.

Dementia is established based on a diagnosis from a Mental Medicine Specialist based on the 3rd edition of Guidelines for Classification and Diagnosis of Mental Disorders in Indonesia (PPDGJ-III), and is willing to be assessed for symptoms of behavior change using NPI. The inclusion criterion in this study is that caregivers are willing to participate in the research. Patients without caregivers, caregiver-treated patients who have a history of mental disorders (including delirium), caregivers undergoing therapy from psychiatrists, and refusing to participate in studies are excluded from the study. The sample was then interviewed for assessment of PSS and NPI scores.

Research data is collected and inputted into the Statistical Package for the Social Sciences (SPSS) application in stages, then processed to calculate symptoms of behavior change and stress in caregivers. The chi-square test was used to analyze the relationship between behavioral change symptoms in dementia and stress levels in caregivers. Because the chi-square test requirement is not met, the linear-by-linear association is used.

## RESULTS

A total of 50 caregiver subjects at the Mental Polyclinic and Gandasturi Ward of Prof. Dr. I.G.N.G. Ngoerah General Hospital were included in this study.

In this study, participants were between 29 to 85 years old and most participants came from the age group of 41-50 years (30%). The sample was dominated by women (66%), and most were self-employed (20%). As many as 64% of subjects have income above the regional minimum wage (UMR) which is Rp. 2,700,000. Thirty percent (30%) of people with dementia had no comorbidities (Table 1).

Based on kinsip tie with people with dementia, female caregivers mostly are wives (28%). Male caregivers are mostly children (26%). Caregiver sex characteristics based on the relationship with dementia patients can be seen in Table 2.

Table 1. Sample Demographics and Characteristics

Variable	n	Total	%
<b>Gender</b>			
Men	17	34	
Women	33	66	
<b>Age</b>			
21-30 years old	4	8	
31-40 years old	9	18	
41-50 years old	15	30	
51-60 years old	7	14	
61-70 years old	9	18	
71-80 years old	5	10	
> 80 years old	1	2	
<b>Income</b>			
< Rp. 2.700.000	18	36	
> Rp. 2.700.000	32	64	
<b>Kinship tie to Dementia Patient</b>			
Partner	17	34	
Child	22	44	
Grandchild	1	2	
Child-in-law	7	14	
Nephew	3	6	
<b>Duration of Caregiving</b>			
< 6 months	5	10	
6 months – 1 year	8	16	
1 – 2 year	10	20	
2 – 5 year	16	32	
5 – 10 year	9	18	
> 10 year	2	4	
<b>Occupation</b>			
Housewives	9	18	
Civil servant	6	12	
Lecturer	2	4	
Private officer	3	6	
Retired	5	10	
Self-employed	11	22	
Teacher	4	8	
Farmer	3	6	
Physician	2	4	
Dentist	1	2	
Paramedics	1	2	
Freelance tour guide	1	2	
Unemployed	2	4	
<b>Comorbidity</b>			
Hypertension	7	14	
Epilepsi and Hypertension	1	2	
Hypertension and others	5	10	
Non-hemorrhagic stroke	1	2	
Fracture	1	2	
No Comorbidity	15	30	
<i>Malignancy</i>	7	14	
Rheumatoid Arthritis	1	2	
Benign Prostate Hypertrophy	1	2	
Non-hemorrhagic stroke and other comorbidity	5	10	
Diabetes mellitus and other comorbidity	2	4	
Herpes zooster	2	4	
Dyspepsia	1	2	
Schizophrenia	1	2	

Table 2. Characteristics of Caregiver Gender Based on Kinship Tie to Patient

		Kinship Tie to Dementia Patient											
		Wife		Husband		Child		Grandchild		Son/Daughter in Nephew Law			
Gender		n	%	n	%	n	%	n	%	n	%	n	%
	Female	14	28	0	0	9	18	0	0	7	14	3	6
	Male	0	0	3	6	13	26	1	2	0	0	0	0

Most people with dementia have severe symptoms (62%). Caregiver stress were most prevalent with severe levels (54%). In this study, chi-square analysis is carried out because there is an expected count < 5 at the time of data analysis, a linear-by-linear association alternative test was carried out. From the results of the analysis, it was found that there was a significant association between symptoms of behavior changes in dementia and stress levels (p value = 0.001). The association of dementia behavior change symptoms with caregiver stress levels can be seen in Table 3.

Table 3. The Association of Behavior Changes in Dementia and Caregiver Stress Level

	Behavior Changes in Dementia		Stress Level		p value
	n	%	n	%	
Mild	7	14	18	36	0,001
Moderate	12	24	5	10	
Severe	31	62	27	54	

## DISCUSSION

In this study, the research subjects were mostly women. Around 44% of caregivers are children of the patient ranging from 29 to 85 years, the mean is 51 years with a standard deviation is 14.6. This research is similar to previous research by Liu et al., 2020 and Zahed et al., 2020. Previous studies have also shown that women caregivers experience higher stress, especially if caregivers are not assisted in their daily chores, such as shopping and caring for patients.<sup>18</sup> This is also supported by a global dementia review which found the care of people with dementia is generally carried out by family members (often daughters or daughters-in-law) at home, and being a caregiver is considered part of household chores.<sup>19</sup>

About 60% of people with dementia are cared for at home. Dementia not only affects the patients but also the social environment as well. Several factors contribute to a person becoming an informal caregiver, such as a sense of pride and satisfaction in caring for the elderly. A family's motivation for taking on the role of a caregiver includes a combination of expectations and obligations accompanied by affection and gratitude towards the sufferer. Often being a caregiver is also one way for someone to repay the kindness of parents. Religion or belief factors are also often the motivation for someone to become a caregiver.<sup>19</sup>

Despite the positive factors that make someone a caregiver, many caregivers experience mental issues related to stress. Dementia patients often require assistance and supervision in their daily activities, where the caregiving burden is often shouldered by informal caregivers, namely family members who experience significant stress and heavy workloads. Caregivers often undergo chronic emotional burdens, leading to mental fatigue and burnout. The results of this study indicate a relationship between symptoms of behavior changes and the stress levels of caregivers (p-value

= 0.001). This may be due to behavioral changes, especially problematic behaviors, where difficulties in managing people with dementia contribute to the caregiver's burden in patient care. These findings align with previous research conducted by Liu et al., where patient behavior was associated with caregiver stress.<sup>18</sup>

In this study, the majority of caregivers have a family relationship. Family factors are also identified as one of the predictors of high levels of stress. This is supported by the research findings of Zahed, stating that family factors are strong predictors of high-stress levels in caregivers due to various other burdens and the complexity of the family. Additionally, the emotional relationship between caregivers and people with dementia, combined with the progressive nature of dementia, contributes to caregiver stress.<sup>17</sup> In this study, the most common caregivers are spouses and male children, reflecting the cultural norms in Bali where the patrilineal system influences that male children have the responsibility of caring for parents and inheriting the family legacy.<sup>20</sup>

The challenges faced as a caregiver include an increased incidence of both physical and psychological issues, impacting how caregivers provide care to patients. Addressing these challenges is crucial as they can escalate into depression and anxiety disorders, even across different cultural backgrounds.<sup>17,19</sup> A study in Spain found that female caregivers are more likely to smoke and perceive themselves as physically inactive compared to women who are not caregivers. This has long-term implications for health.<sup>19</sup>

## CONCLUSION

The results of this study lead to the conclusion that there is an association between behavioral changes in individuals with

dementia and the level of stress experienced by caregivers. It is crucial to provide an understanding of behavioral changes in elderly individuals with dementia through training for community health workers to identify and then educate patients and families on how to manage these changes at home. Additionally, offering support to caregivers is essential to help alleviate their burden and stress.

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