



Assistance for the Elderly with Dementia by Caregivers at the Nursing Home

Tri Suratmi^{1*}, Jumiarti², Dinni Agustin¹, Tri Budi W Rahardjo¹

¹ Universitas Respati Indonesia

² Speech Therapy Academy YBW, Indonesia

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Abstract

The incidence of Alzheimer's dementia worldwide is increasing rapidly. It is estimated that nearly 50 million people are diagnosed with dementia worldwide and 20.9 million in Asia Pacific. In Indonesia, it is estimated that there were around 1.2 million people with dementia in 2016, which will increase to 2 million in 2030 and 4 million people in 2050. The elderly/people with dementia need assistance from family members to carry out daily activities because of its limitations. This research aims to understand the needs of elderly people with dementia and caregivers who accompany them in nursing homes, to develop dignified services. The research was conducted in Jakarta with 22 research subjects, consisting of 10 elderly with dementia and ten caregivers as the primary informants and two key informants who were the caretakers of the nursing home. The method used is qualitative, with data collection techniques through participant observation, in-depth interviews, document studies, and Focus Group Discussions. Data analysis used the Interpretative Phenomenological Analysis (IPA) method. The results showed that all elderly with dementia had a history of comorbidities (hypertension, diabetes mellitus, stroke, psychosis, insomnia, dyslipidemia, presbycusis), so they experienced moderate to severe dependence, which indicated the need for long-term care. Meanwhile, all caregivers are formal caregivers (not from the family) but have not received adequate education and training on dementia and methods of assisting the elderly with dementia.

Keywords *Elderly, Dementia, Caregiver, Nursing Home*

INTRODUCTION

Dementia is the most common mental health problem among the elderly, with a population in 2016 reaching 25 million people worldwide and will reach 80 million people in 2040 (Garima et al., 2016). In the Asia Pacific Region, there has been an increase in people with dementia from 23 million in 2015 to 71 million in 2050. In Indonesia, it is estimated that by 2030 there will be 2 million people with dementia and up to 4.3 million in 2050 (Suriastini et al., 2018, p.6). Dementia elderly experience a decrease in cognitive function, which causes a decrease in the ability to carry out activities of daily living (ADL) and Instrumental Activity of Daily Living (IADL), which are indicators of the level of independence of the elderly (Widyantoro et al., 2021).

Furthermore, people with dementia also lose the ability to solve problems and control emotions and can even experience personality changes and behavioural problems such as irritability and hallucinations (Adha & Nurhasanah, 2017). With these conditions, the elderly with dementia need special assistance from family members as caregivers by understanding that dementia is a disease, not part of the natural aging process. Dementia elderly must get special treatment that requires a large amount of money. The Ministry of Health of the Republic of Indonesia estimates that the cost of handling an older person with dementia will reach 1 trillion rupiahs in 2018. Meanwhile, in 2030, it is estimated that there will be a 100% increase in costs from 2018 to 2 trillion rupiahs. One of the efforts that can be taken to reduce the number of costs that must be provided by the Government and families of older people with dementia is to provide the

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Corresponding author's email: tri2209@yahoo.co.id

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best possible care/assistance so that the case does not get worse. Therefore, this research is very important to do in order to obtain a comprehensive picture of the needs of the elderly with dementia and their companions from the physical, mental, social and financial aspects.

Meanwhile, caregivers are divided into two parts; they come from families are called informal caregivers, whereas formal caregivers are physically and mentally ready to be capable of assisting and skilled in providing basic and daily needs, providing attention, assistance, comfort, protection, and supervision of the safety of the elderly (Agustin et al., 2021). Formal caregivers work professionally to accompany the elderly in nursing homes or are hired by the family. Nursing homes should provide dignified services for the elderly with dementia by providing competent caregivers. This is a challenge and an opportunity for society in the development of age in Indonesia (A'yun & Darmawanti, 2022). Understanding the need for assistance for elderly people with dementia according to their conditions and understanding the needs of caregivers who accompany them is essential, so the management of nursing homes strives to fulfil them a service standard for dementia patients.

LITERATURE REVIEW

The health problem currently of concern is Dementia, one of the diseases that are the main focus in the community field of public health studies at the global level. Dementia is a characteristic of a syndrome that interferes with the function of brain centres, orientation, disturbances in a person's understanding, calculation and language, as well as the existence of a disorder of a person's progressive intellectual system or a decrease in a person's memory ability which has an impact on cognitive and functional deterioration, whose real impact is the disruption of a person's ability to socialize (Utami, 2013).

Dementia is an irreversible and chronic progressive disease mainly affecting the elderly, characterized by an ongoing decline in physical, cognitive, and social functioning. Moreover, people with Dementia (PWD) manifest behavioural and emotional symptoms such as physical/verbal aggression, anxiety/depression, sleep problems, and resistance to care (Gitlin et al., 2012).

In Indonesia, the incidence of Dementia occurs in elderly women who do not work. Most of the elderly who were detected to have symptoms of Dementia in Bandung, West Java, had a healthy lifestyle by not smoking or had stopped smoking (Sari et al., 2018). The elderly with Dementia have mild and moderate dependency levels. The moderate form of dependence is during defecation and urination activities, eating, and leaving the house. Meanwhile, elderly people with Dementia with moderate dependence need assistance (accompanied/accompanied) in almost all daily activities except sleep (Fazriana & Luju, 2021). Because of these conditions, they needed a companion (caregiver). For the elderly who live in the family, caregivers can come from the family (children, in-laws, grandchildren, nephews and other relatives). However, the elderly with Dementia can also choose to live in a nursing home.

Family caregivers of people with Dementia (PWD), often called the invisible second patients, are critical to the quality of life of the care recipients. Though sometimes positive, the effects of being a family caregiver are generally negative, with high rates of burden and psychological morbidity as well as social isolation, physical ill-health, and financial hardship (Brodaty & Donkin, 2009). Despite the growing awareness of the poor health-related quality of life (HRQoL) in family caregivers of people with Dementia, their relationship has rarely been explored with population-based samples (Shin & Kim, 2022)

A nursing home is designed as a place that accommodates the physical, mental, spiritual, and social needs of the elderly, so this place can be chosen by the elderly as a place to live with various considerations. Among them is because the elderly want to interact with peers and are not lonely at home when family members have to leave them to work. In big cities in Indonesia, such as Jakarta,

living in a nursing home can be done by paying for services according to the financial capabilities of the elderly and their families. The provision of nursing homes is part of the community's efforts to improve the health status and quality of life of the elderly, build an elderly-friendly society and environment, and strengthen institutions implementing old-age programs, to fulfil elderly rights (Presidential Regulation Number 88 of 2021).

The elderly, regardless of their health condition, have the same rights as other Indonesian citizens (UU No. 13 Years, n.d.). One of these rights is to get health care. In contrast to assisting the elderly in general, caregivers who assist the elderly with Dementia need to involve gratitude (emotional elements) related to spiritual aspects, regarding the true meaning of life, through their work (Setiyoko & Nurchayati, 2021). Caregivers need to understand depression in the elderly with Dementia which is characterized by depressed mood, loss of pleasure or interest, feelings of guilt or low self-esteem, eating or sleeping disorders, lack of energy, and low concentration. In severe cases, depression can lead to suicide (Sopyanti et al., 2019). Because of the breadth and area of responsibility of caregivers who care for the elderly with Dementia, it is appropriate for caregivers to receive adequate financial compensation/salary from the nursing home. The government guarantees a labour wage system, so employers and workers receive their rights proportionally (Labor Law, 2021).

Nursing homes, as one of the institutions that provide full aged care services, are expected to build a service system that synergizes knowledge about health and technological developments and promotes the culture of humanity (PERMENKES NO 67 TAHUN 2015, 2015).

RESEARCH METHOD

To understand the needs of the elderly/people with dementia (PWD) and their caregivers, participant observations were conducted in nursing homes. The researcher acts as a caregiver so that they can experience the daily life of assisting the elderly. Furthermore, in-depth interviews were carried out with one caregiver at a time. The interview results were transcribed and then validated by direct observation or cross-checking with the nursing home managers and families of the elderly with dementia who visited the nursing homes as a triangulation. The focus group discussion was carried out with the managers of the nursing homes to elaborate deeper into efforts to provide adequate services for the elderly and caregivers who are the spearhead of services. This qualitative study was conducted on 10 PWD, ten caregivers, and two managers. The process of data analysis through data reduction, display, and conclusions, as required in the Interpretative Phenomenological Analysis (IPA) data analysis technique.

FINDINGS AND DISCUSSION

PWD who choose/are chosen by their families to live in nursing homes are dominated by females aged over 70 years. Education varies between elementary schools to university. Apart from suffering dementia, they also have a health history of comorbidities, as detailed in the following table:

Table 1. Characteristics of Dementia Elderly

No	Elderly	Sex	Age	Education	Medical History
1	L1	Female	91 yo	SGA	Dementia, hypertension, Dyslipidemia
2	L2	Female	97 yo	SD	Dementia, Presbycusis

3	L3	Male	83 yo	SD	Dementia, hypertension, psychotic
4	L4	Female	82 yo	SMA	Dementia, Diabetes Mellitus, Hypertention, Dyslipidemia, Presbycusis
5	L5	Female	79 yo	SGTU	Dementia, Insomnia
6	L6	Female	82 yo	SMA	Hypertension, Dementia, Diabetes Mellitus, Dyslipidemia
7	L7	Female	76 yo	SD	Stroke Hemoragic, psychotic
8	L8	Female	86 yo	S1	CHF, hypertension, Dementia, Insomnia, Dyslipidemia, Presbycusis
9	L9	Male	86 yo	D3	Diabetes Mellitus, hypertension, Gout, Dyslipidemia
10	L10	Male	81 yo	S1	Hypertension, Parkinson, psychotic, Presbycusis, Dyslipidemia

Based on the results of participant observations, it can be explained that the average level of independence of the elderly depends on caregivers in carrying out daily activities (activities in the bathroom, eating, and sleeping). Decreasing the independence of the elderly can be caused by increasing age and health conditions accompanied by comorbidities (Muharyani, 2010). Meanwhile, an overview of the profile of caregivers who accompany elderly people with dementia is described in the following table:

Table 2. Characteristics of Caregivers Accompanying The Elderly With Dementia

No	Caregiver	Sex	Age	Education	Long worked as a caregiver
1	C1	Female	52 yo	SMEA	10 years
2	C2	Female	46 yo	SMA	4 years
3	C3	Female	50 yo	SD	5 years
4	C4	Female	48 yo	SMA	10 years
5	C5	Female	51 yo	SMA	10 years
6	C6	Female	54 yo	SMPS	2 years
7	C7	Female	54 yo	SMP	12 years
8	C8	Female	51 yo	DIII	10 years
9	C9	Female	54 yo	SMP	12 years
10	C10	Female	43 yo	S1	6 years

All caregivers accompanying the elderly with dementia in the nursing home are women. Working as a caregiver for the elderly, especially the elderly with dementia, requires emotional involvement in carrying out their professional duties (Setiyoko & Nurchayati, 2021). Their formal education is from elementary school to university. They claim no special education as a caregiver and do not come from health institutions. Initially, this work was "forced" because of the difficulty of finding a job in Jakarta. Being a caregiver is sometimes unplanned, but it is a noble job because there is an element of appreciating life (Muharyani, 2010). Management of the elderly with dementia must also be done by treating symptoms and healing with medical treatment (Chyani & Hastuti, 2021). Assistance provided by caregivers, such as assistance in carrying out the activity of daily living (ADL) and efforts to help the elderly from exposure caused by the environment and their deviant behaviour.

The main task of caregivers is to help and accompany the elderly in daily self-care—the duration of working more than 40 hours a week, 27 days a month. However, caregivers admit that the income/salary received by caregivers is not balanced with the tasks they have to do daily; it is still far from the regional minimum wage standards in DKI Jakarta Province (Pergub No 103 of 2020). The absence of other job options makes caregivers try to accept these conditions. One example of behaviour that often occurs in elderly dementia is described by caregivers as follows:

"Often angry, sometimes slamming anything, talk nonsense, do not know what to say, when they talk does not make sense, and sometimes poop in bed. Grumpy, I have been hit, punched, and held breasts. Usually grumbles, bitchy when spoken to spoke rudely, sometimes they words offended them, accusing me of taking money, even though they forgot where to put it, they word hurt me."

The caregiver's statement is part of the triggers of the stress experienced. Work stress can impact individuals, organizations, and even society. For individuals, work stress harms workers' physical and mental health, decreases performance, causes a lack of career development, and loss of enthusiasm (Rangkuti et al., 2022). The most significant difficulty that caregivers face when accompanying the elderly with dementia is how they communicate with each other. Caregivers have difficulty understanding what the elderly convey, and the elderly also have difficulty understanding what the caregiver conveys. These conditions can cause psychological pressure. Therefore mental health efforts must be carried out for every individual, family, and community with a preventive promotive approach (UU No 18 of 2014, Ministry of Health RI).

The existence of communication and other problems between the elderly with dementia and caregivers who accompany them need to find a solution by the nursing home's management. P1 and P2 (as key informants), who have worked for 24 years and 30 years, stated that:

"Accepting caregivers at the nursing home is one of the efforts to empower the surrounding community. As the number of elderly people who need assistance (including elderly people with dementia) tends to increase, nursing homes are opening partnerships with various parties, for example, universities, to contribute and to providing training to caregivers with relevant knowledge of the older person."

Through document studies, data was obtained that elderly residents of the nursing home came and chose to stay after fulfilling the requirements set by the nursing home, including those who guaranteed financial sustainability for living expenses, including providing caregiver salaries for people with dementia. The welfare of the elderly is very important to the fulfilment of their needs of the elderly (Triwanti et al., 2014). Standards or minimum criteria regarding nursing homes

and services have not been specifically regulated in regulations (Permensos No 18 Concerning Organization and Work Procedures of Social Rehabilitation, 2018).

Nursing Homes for the elderly that are organized by the community with various advantages in providing services and shortcomings need to be appreciated by the state because they have played a role in seeking the welfare of the elderly as stipulated in state laws.

CONCLUSIONS

Based on the research results, it can be concluded as follows:

1. The PWD who live in a nursing home is on their initiative and their families. They experience dependence in performing ADL and IADL and have a medical history of comorbidities.
2. The level of dependence experienced is in the moderate to severe category, which indicates the need for long-term care.
3. Caregivers accompanying the elderly with dementia do not have a health education background, requiring special training to gain knowledge about dementia and the skills to provide professional assistance.
4. Caregivers need adequate compensation for labour, time off, and health insurance.
5. Nursing home managers need to work with other institutions to design system-based services for the elderly with dementia.

From the five written points, the main conclusion obtained from this research is that elderly dementia will get worse if they do not receive adequate treatment, and caregivers will become stressed and have the potential to experience emotional mental disorders if they are not trained and given an understanding of techniques to accompany elderly dementia. Welfare in the form of a salary beyond the UMR must be implemented because accompanying PWD can be classified as extraordinary service.

Suggestions for further research are developing services for the elderly with dementia by utilizing digital technology (application development) that can be used easily by caregivers in providing reports to nursing home managers and families of the elderly with dementia.

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