Original Article

# Structural Model of Family Caregiver for Elderly with Dementia


## Abstract

**Background:** The number of older people with dementia was continuously increasing globally. Unfortunately, many of them had received inappropriate medical treatment to overcome the dementia they suffered. This current research aimed to analyze the factors that affected family-based caregiver empowerment. **Materials and Methods:** An analytic observational method with a cross-sectional approach was applied. The population was all families with dementia elderly in East Java, Indonesia, in 2021, who met the inclusion and exclusion criteria. The sample size was determined to be 100 respondents. **Results:** The results showed that the factors (i.e., elderly factors, family factors, health service factors, family's filial value, family assessment, and the need for care) had significant effects directly or indirectly on the family's ability to do home care. **Conclusions:** Factors that influenced directly (i.e., elderly factors, family factors, family assessment, and care needs) and indirectly (i.e., health service factors) were essential in constructing a structural model of family care for the elderly with dementia.


**Keywords:** *Dementia, elderly, empowerment, family caregiver*


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## Introduction

The number of dementia cases among the elderly has steadily increased worldwide.[1,2] Dementia is a cognitive decline commonly observed in individuals over 60.[3] It is a degenerative disease that necessitates long-term care. Home care becomes a crucial priority to ensure that older individuals can remain in a familiar environment.[2] Unfortunately, many people mistakenly believe that dementia is a normal part of aging, resulting in inappropriate medical treatment for affected individuals.

Family-based home care is considered a suitable approach in Indonesia due to the country's cultural support for such care practices. The family plays a pivotal role in providing care for the elderly and is integral to decision-making and care strategies based on cultural values. Families can provide essential support systems for housebound dementia patients who require prolonged care.[4] Research by Alholidi *et al*.[5] indicates a significant correlation between family support and the elderly's independence in daily activities.

Home care services can be provided by both formal (e.g., nurses) and informal (e.g., family members and friends) sectors. However, most home care is provided by nursing staff from local health clinics or hospitals in Indonesia. Therefore, developing informal home care provided by family members themselves becomes crucial. Alholidi *et al*.[5] assert that one of the primary functions of the family is to provide health care, which includes preventing health problems and caring for sick family members. The empowerment of families in providing care can be achieved by considering various factors such as family connection, support, community resources, filial values, and caregiver outcomes.[6] By analyzing these factors, this study aimed to understand the elements that influence family-based caregiver empowerment, which in turn can help families navigate the challenges associated with dementia care and unlock their hidden capacities and potentials.[5]

## Materials and Methods

The research was conducted in Surabaya City, Indonesia, in 2021. An analytic observational method with the cross-sectional approach was applied in this research. Data collection was conducted to obtain the description of elderly factors, family factors, health service factors, care



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needs, basic family values, and family assessments that may have affected families as caregivers in doing home care for dementia elderly. The population in this study was all families with dementia elderly in East Java, Indonesia. The inclusion criteria were being registered in the elderly health center/posyandu, being diagnosed with dementia through Mini-Mental Stage Examination (MMSE), and living with other family members (extended family type).

In this research, the rule of thumb method was employed to calculate the required sample size. This method utilized structural equation modeling–partial least square (SEM-PLS) to determine the sample size while considering statistical power and effect size adjusted to the sample size of the SEM-PLS model. For each estimation, the recommended number of respondents using the maximum-likelihood method was approximately 100–150 respondents or around 5–10 times the number of observed variables.

In this study, a total of 20 parameters were estimated. Therefore, the sample size needed was the highest at around 20 times (5–10) the number of respondents, which was approximately 100–200 respondents. However, considering the limited number of families with elderly dementia in the area, it was decided to use 100 respondents recorded at Puskesmas in East Java, Indonesia. The sample was taken through the cluster random sampling technique in four health centers in the areas of West, East, North, and South Surabaya, with 25 respondents in each Puskesmas, so the total respondents were 100 people.

A standardized questionnaire was utilized to collect data according to the characteristics of the respondents. For data related to elderly factors, such as age, gender, education, income, and medical history, a closed-ended questionnaire was employed. Additionally, the emotional level of the respondents was assessed using the Emotional Regulation Questionnaire (ERQ), while their spiritual level was measured through the Daily Spiritual Experience Scale (DSES). Data regarding family factors, encompassing sociocultural aspects and the family environment, were gathered using Friedman's 5 criteria. Furthermore, the Family Coping Index (FCI) was utilized to collect data on individual coping, and the Assessment of Family Interaction (AFI) was employed to gather data on family relationships and interactions.

The data on healthcare factors were collected through a questionnaire compiled based on Levesque's theory.[7] The data on basic family value factors were collected using the Filial Value Scale (FVS), while data on family assessment factors were collected using the Revised Caregiving Appraisal Scale (RCAS). The data on the factor of caregiving needs were collected using the Caregiver Needs Assessment for Dementia (CNA-D), and the data on the family's ability to do home care were collected using Caregiver Outcomes (CGO).

All instruments were tested for validity using convergent validity, where an instrument was said to be valid if it had a loading factor and the average variance extracted (AVE) of more than 0.5. The test results found that all instruments had a loading factor of more than 0.5, which was declared valid. Meanwhile, to test the reliability of the instruments, construct reliability tests were applied with Cronbach's alpha and composite reliability calculations, where if the composite reliability was more than 0.7 and the Cronbach alpha was more than 0.6, then the construct was declared reliable. The test results indicated that each variable had a Cronbach alpha value greater than 0.6 and a composite reliability value of more than 0.7. Thus, all instruments were declared reliable.

The collected data were analyzed in two ways: descriptive analysis and inferential analysis. Descriptive analysis was used to describe the respondents' characteristics and research variables by calculating the mean, maximum–minimum value, and standard deviation. Meanwhile, the inferential analysis was a variation, component-based structural equation model called the SEM-PLS structural equation model. SEM-PLS analysis was carried out using SmartPLS software, which included a measurement model (outer model), structural model (inner model), and hypothesis testing. The next step was to analyze and link variables to develop a model and develop a home care model based on a family caregiver.

### Ethical considerations

The ethical considerations in the current study followed the Helsinki Declaration. All participants agreed and gave their consent to participate in the research. The research was already approved by the ethical committee of Universitas Airlangga under the number 00045-8794-2020.

## Results

The demographic analysis results of the respondents [Table 1] showed that most of the respondents were more than 50 years old (47%), while the gender composition was balanced. Regarding the educational background, the respondents' level of education was mostly senior high school (50%), and most of them worked as entrepreneurs (67%) with an average income following the regional minimum wage.

The test results [Table 2] show that the elderly factors significantly affected the family's filial values. It meant that the better the elderly factors, the better the family's filial values would be. The test results also indicated that elderly factors significantly affected the caregiver's demands. It meant that the better the elderly factors, the more caregiver's demands would be. Meanwhile, the test results pointed out that the elderly factor significantly affected the ability of families to do home care. It meant that the better the elderly factors, the more families' ability to do home care. The test results indicated that family factors significantly affected the family's filial value. It meant that the better the family factors, the higher the family's filial values.

The test results also indicated that family factors did not significantly affect the caregiver's demands. Meanwhile, the test results pointed out that family factor significantly affected the families' ability to do home care. It meant that the better the family factors, the better the families' ability to do home care.

The test results of the effect of the healthcare factor on the basic values (filial values) of the family showed a significant influence. It meant that the better the healthcare factor, the more the family's basic value (filial value) would be. In addition, the test results of the effect of the health care factor on caregiver demands showed significant results. It meant that the better the healthcare factor, the more caregiver demands would be. In contrast, the test of the effect of the healthcare factor on the family's ability to conduct home care showed no significant results.

**Table 1: Demographic characteristics of respondents (family) (*n*=100)**

| Indicator | Category | n (%) |
|---|---|---|
| Age | ≤ 35 years | 15 (15) |
| | 36–40 years | 8 (8) |
| | 41–45 years | 15 (15) |
| | 46–50 years | 15 (15) |
| | >50 years | 47 (47) |
| | Total | 100 (100) |
| Gender | Male | 45 (45) |
| | Female | 55 (55) |
| | Total | 100 (100) |
| Education | Non schooled | 3 (3) |
| | Elementary school | 11 (11) |
| | Junior high school | 10 (10) |
| | Senior high school | 50 (50) |
| | College | 26 (26) |
| | Total | 100 (100) |
| Occupation | Farmer | 1 (1) |
| | Entrepreneurs | 67 (67) |
| | Civil servants | 4 (4) |
| | Jobless/housewife | 28 (28) |
| | Total | 100 (100) |
| Income | < Regional minimum wage | 33 (33) |
| | =Regional minimum wage | 57 (57) |
| | > Regional minimum wage | 10 (10) |
| | Total | 100 (100) |

Source: Primary data, 2021

Based on the test results above, a significant model construct can be seen in Figure 1. The figure indicated that X1 (elderly factor), which consisted of three indicators (i.e., age, gender, and emotion), had a direct influence on X4 (filial values), caregiver demands, and the family's ability to do home care. Besides, X2 (family factor)—consisting of the indicators of family sociocultural condition, family environment, family structure and function, family stress, family coping, and relationships/interactions in the family—had a direct influence on basic family values (filial value), care needs/caregiver's demands, and the ability of the family to do home care.

Meanwhile, X3 (health service factor)—consisting of access, health workers, facilities, and infrastructure—directly influenced the basic family values/filial values and caregiving needs/caregiver's demands but did not directly influence the family's ability to do home care.

Other factors that influenced the family's ability to perform home care included X4 (basic family values), X5 (family appraisal), and X6 (caregiver demands). Filial value indirectly influenced the family's ability to do home care through family appraisal. Meanwhile, caregiving/caregiver's demands had the most significant/dominant influence on the family's ability to do home care.

## Discussion

First, the results showed that the elderly factors (i.e., age, gender, education, health, and emotional conditions) significantly affected the family's filial values, caregiver demands, and family abilities. As Wang, Xing, Yan, Sun,

**Table 2: Hypothesis testing on caregiver empowerment-based home care in East Java, 2021**

| Effect | Original sample (O) | T statistics (O/St. Dev\|) | *p* |
|---|---|---|---|
| Elderly factors (X1)* -> family's filial values (X4) | 0.19 | 2.42 | 0.016 |
| Elderly factor (X1) -> caregiver demands (X6) | 0.37 | 4.50 | 0.000 |
| Elderly factor (X1) -> family's ability to do home care (Y1) | 0.25 | 3.41 | 0.001 |
| Family factor (X2) -> family's filial values (X4) | 0.31 | 3.11 | 0.002 |
| Family factor (X2) -> caregiver demands (X6) | 0.14 | 1.74 | 0.083 |
| Family factor (X2) -> family's ability to do home care (Y1) | 0.24 | 2.61 | 0.009 |
| Healthcare factors (X3) ->family's filial values (X4) | 0.32 | 3.20 | 0.001 |
| Healthcare factors (X3) -> caregiver demands (X6) | 0.39 | 4.70 | 0.000 |
| Healthcare factors (X3) -> family's ability to do home care (Y1)** | -0.07 | 0.80 | 0.422 |
| Family's filial values (X4) -> family appraisal (X5) | 0.56 | 6.94 | 0.001 |
| Family appraisal (X5) -> family's ability to do home care (Y1) | 0.20 | 2.04 | 0.042 |
| Caregiver demands (X6) -> family's ability to do home care (Y1) | 0.45 | 5.56 | 0.000 |

Note: *X=independent variable (influencing factor). **Y=dependent variable (influenced factor)

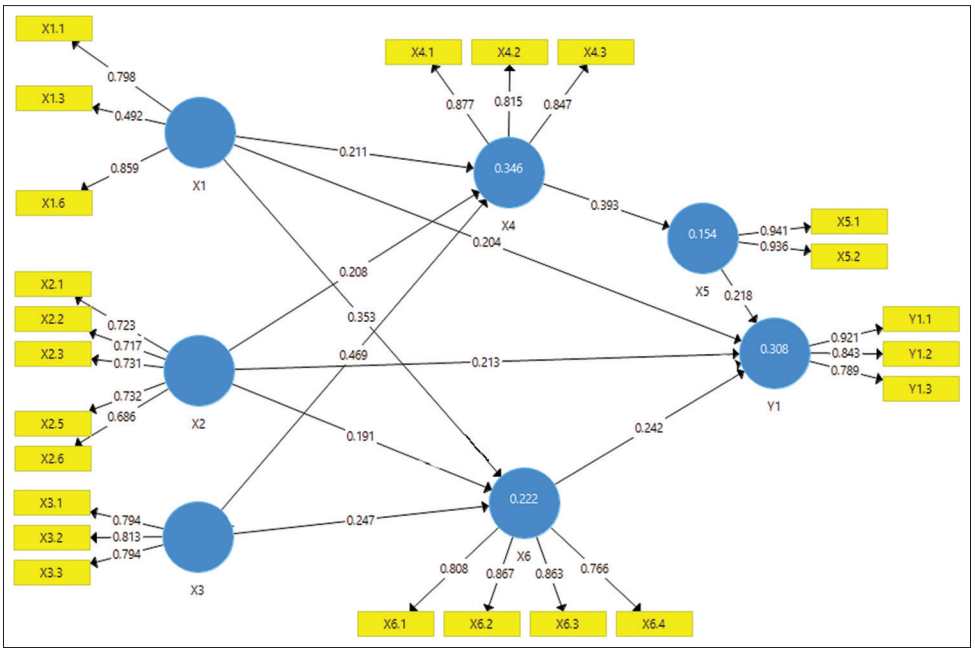


**Figure 1: Construct of inner model significant pathways in caregiver empowerment-based home care in East Java, 2021**

Zhang, and Huang[8] revealed, 45.4% of 1003 respondents indicated a willingness to be treated at an elderly care institution.

Second, it was found that family factors significantly affected the families' filial values and the families' ability to do home care for the elderly. Sun and Wand's[9] study explained that families, especially in the Asian region, possess a cultural value where a child is always required to devote themselves to his/her parents and provide long-term care as a form of informal support.

Third, the healthcare factors significantly affected the family's basic values and parenting needs. It meant that the better the health care factors, the higher the basic value of the family and the need for caregiving. Research by Rondhianto, Nursalam, Kusnanto, and Melaniani[10] concluded that the factors of health workers, especially nurses, directly affected the family's basic values and indirectly affected the patient's ability to self-manage diabetes mellitus. The disease required care and attention to prevent complications, so support from health workers and health facilities (as well as family support) was urgently needed.

Fourth, the filial value of the family had a significant effect on family appraisal. The filial value was the basic indicator of the formation of family empowerment to develop the family's ability to provide care for their members. Research by Arief, Nursalam, and Rachmawati[11] mentioned that family values supported family assessment in facing problems, especially health problems. With good familial values, the problem did not become a stressor but rather a challenge to face, solve, and find a solution. This increased the ability of families to provide respect and care to children with leukemia.

The result was also in line with the research by Zulka, Yusuf, Nihayati, Nugrahani, Kholidah, and Lestari, D.I.,[4] explaining that the basic value of the family became the basis for conducting an assessment and supported the care of family members with schizophrenia. Excellent family value significantly affected the family's assessment in providing care to the sick family members, enhancing the family experience to do good care.[12]

The result showed that family appraisal significantly affected the family's ability to do home care. It meant that the better the family appraisal, the better the ability of the family to do home care. Arief, Nursalam, and Rachmawati[11] defined family appraisal as the role of the family in assessing and treating diseases suffered by family members. A positive family appraisal could foster family empowerment to do home care for pediatric patients with leukemia.

Women played a significant role in family care in Asian countries, including Indonesia. The Asian culture required female members of a family (i.e., the wife, daughter—especially the first daughter, granddaughter) to take care of older family members, including their grandparents. In addition, women were considered more flexible in caring for their family members. It was easier for them to establish familiarity and closeness with those they cared for. However, some studies indicated that women were more susceptible to stress and depression, which could affect the provision of care to the elderly.[13]

Overall, the results suggested that the family's filial values, including knowledge, stigma, and interaction relationships in the family, significantly affected the family appraisal in caring for family members.[14] The caring concept was an integration of the family appraisal concept explaining

that caring arose from a healthy interpersonal relationship between the family, a caregiver, and the patient. Caring was expressed through honesty, sincerity, respect, understanding, wisdom, reciprocity, and incorporating elements, which enabled effective communication through conversation and listening,[4,15]

Caregiver demands significantly affected the families' ability to perform home care. According to Dorlan,[14] in the decade lasting from 2018 to 2028, the home care industry was required to meet the needs of about 4.7 million home care jobs. The forecasted figure, slightly higher than previously projected, was a pressure faced by almost all home care providers in the USA. That is, home caregiving was indispensable for patients.[16]

Based on their health conditions, some elderly needed more, even longer, care and attention from caregivers to support recovery and manage chronic and advanced conditions. Services the elderly may have needed included care, treatment management, and cognitive stimulation of activities. This represented a steady increase in demand for special care for older people and increased caregiver demand. It was partly due to increased awareness of the importance of elderly caregiving, chronic diseases that required long-term care, the increasing elderly population, and difficulty in hiring people due to the pandemic. Thus, it required community empowerment and awareness about the importance of professional care for the elderly. Family support for home care was needed amid the pandemic, as more vulnerable people and care recipients were encouraged to stay at home for a long time.

The limitation of this research was the population number. It would have given a more comprehensive picture of the feasibility of family members as home care providers for dementia elderly.

## Conclusion

It was concluded that the elderly, family, healthcare, and family filial value factors had an indirect effect on the family's ability to provide home care. Meanwhile, the variables that directly influenced the family's ability to do home care included the elderly, family, family assessment, and caregiver's demands factors. Of the factors that had a direct influence, the caregiver's demands had the most significant influence on the family's ability to do home care. The care of the elderly with dementia required long-term care, meaning that it required continuous care. It required family members to act as caregivers and carry out self-development in the home caring for the elderly with dementia. Thus, it was expected that they would be able to improve the health status of the elderly in particular and be beneficial in supporting the development of state health in general.

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### Conflicts of interest

Nothing to declare.

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