

EXPERIENCES OF MILD-MODERATE DEMENTIA ELDERLY IN GETTING CARE AT HOME

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Abstract

Dementia is a progressive decline in cognitive abilities characterized by memory loss that affects everyday abilities. As a result of this decline, elderly people with dementia problems are often considered unable to communicate the changes they experience. The purpose of this paper is to find out whether the meaning of cognitive and psychosocial changes perceived by the elderly with dementia through a phenomenological study of ten elderly people with mild-moderate dementia. The method of analysis and presentation of descriptive phenomenology data in this study used a structured and specific analysis method developed by Moustakas by modifying the Stevick-Colaizzi-Keen method. The results of this study show that elderly people with mild to moderate dementia have the ability to share their experiences in dealing with changes due to dementia. The changes perceived by the elderly towards dementia they experience consist of a decrease in cognitive function and a decrease in psychosocial function. The decrease in cognitive function is felt by the elderly with dementia through frequent difficulties in remembering information, decreased ability to manage finances, and decreased intelligence. Decreased psychosocial function is felt by elderly dementia through behavioral changes, skill changes, and decreased communication skills. The conclusion of this study is the ability of elderly people with dementia to share their experiences related to changes when experiencing mild to moderate dementia indicates that the elderly in LTC institutions have been educated enough about their ability to see signs and symptoms of dementia in the early stages. Suggestions for LTC institution organizers are periodic screening of dementia independence and screening for consideration in providing services to the elderly with dementia.

Keywords : Cognitif; Dementia; Eldely; Experience; Psychosocial

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INTRODUCTION

The number of elderly people has increased from year to year in almost all countries in the world. The World Health Organization (2017) states that the proportion of the world's population over 60 years will almost double from 12% to 22% from 2015 to 2050. Not much different from the number of elderly people in the world, the percentage of elderly people in Indonesia will increase by around doubled (1971-2017) in the past five decades, namely 8.97 percent (23.4 million people) in 2017 (Central Statistics Agency, 2017). The high number of elderly people cannot be separated from the increasing age of hope in Indonesia itself, the increasing number of elderly people is making this country *facetruple burden* that is, in addition to increasing birth rates and the burden of disease (infectious and non-communicable), there will also be an increase in the number of dependents of the productive age group on the unproductive age group (Ministry of Health of the Republic of Indonesia, 2014). One of the health problems of the elderly is dementia.

The incidence of dementia in the elderly is a health problem that occurs quite often in the elderly. In 2015 there were around 46.8 million people worldwide living with dementia, then this increased to 50 million people in 2018, and it is estimated that this will increase threefold to 152 million people in 2050

(Patterson, 2018). Most of the increase in the number of people with dementia is in low to middle income countries. In 2015, the number of elderly people with dementia in the Asia Pacific region was around 23,279,000 people (Alzheimer's Disease International, 2014). For Indonesia, based on data from Alzheimer's Disease International (2014), the number of dementia sufferers recorded in Indonesia was 1,033,000 people or around 0.4% of the total population in Indonesia in that year. This number places Indonesia in 4th position (after China, India and Japan) with the highest number of dementia sufferers in the Asia-Pacific region.

The incidence of dementia in Indonesia is like an iceberg phenomenon, only a small portion of the total number of dementia sufferers recorded. Based on data from Alzheimer's Disease International (2014), the number of dementia sufferers recorded in Indonesia was 1,033,000 people or around 0.4% of the total population in Indonesia in that year. This number places Indonesia in 4th position (after China, India and Japan) with the highest number of dementia sufferers in the Asia-Pacific region. The three provinces in Indonesia with the highest number of dementia sufferers include DKI Jakarta, West Java and Central Java with a total prevalence of the three reaching 38.9% with around 4% declared to be suffering from severe dementia (Ministry of Health Republic of Indonesia, 2015). Apart from that, Wreksoatmodjo (2014) in his research stated that 37.8% of elderly people in Jakarta have poor cognitive function. These data show that the prevalence of dementia sufferers in DKI Jakarta is higher compared to other provinces in Indonesia.

Dementia is a chronic or progressive syndrome in which there is damage to cognitive function that affects memory, thinking, orientation, understanding, calculation, learning capacity, language and judgment which is accompanied or preceded by a decrease in emotional control, social behavior and motivation (World Health Organization , 2017). The theoretical model of functional consequences of dementia was developed by Miller (2012). This theory explains that elderly people experience functional consequences caused by age-related changes and other risk factors. Based on this description, dementia is a syndrome of progressive cognitive dysfunction that can disrupt a person's function due to a decrease in memory, thinking, orientation, understanding, calculation, learning capacity, language and judgment which is accompanied or preceded by a decrease in emotional control and social behavior. , and motivation.

The problem of dementia has quite a variety of impacts on every elderly person who experiences it. In general, Qiu and Fratiglioni (2018) explained that the result of dementia is a clinical syndrome related to brain disorders characterized by a decline in cognitive function that is severe enough to interfere with the sufferer's social function and daily activities. In general, the signs and symptoms of elderly people experiencing dementia include memory loss which affects daily abilities; difficulty performing daily tasks; problems with language; disorientation in time and space; interference in decision making; problems with abstract thinking; forgetting where to store things; changes in feelings and behavior; personality changes; and loss of initiative (Jeffrey Model Foundation, 2014).

Elderly people with dementia experience a progressive and chronic accumulation of damage at the personal and social level that often threatens the elderly person's sense of security and autonomy. Living with dementia can be understood as an ongoing and highly disruptive experience, older adults with dementia enter a period of life that is highly uncertain, unpredictable and ambiguous. Seniors with dementia have to face all kinds of losses that profoundly change their relationships with others and the world around them. As the disease progresses, social relationships continually shift and must be reorganized repeatedly to accommodate new realities (van Wijngaarden et al., 2019).

Dementia is divided into three stages, namely early, middle and late. Dementia in the mild to moderate category is in the early to mid stages of dementia. In the early stages of dementia, people with dementia actively confront their cognitive decline, adjust to cognitive loss, and are able to take an active role in discussing values and preferences for future care (Cotter et al., 2017). At this stage, people with dementia retain many of their functional abilities and require minimal assistance, including with communication skills. Dementia sufferers at this stage have insight into the changes they feel, are able to talk about their experiences of living with perceived dementia problems, and are able to plan and direct their future care (Alzheimer Society of Canada, 2018). In the middle stages of dementia, signs and symptoms of cognitive impairment become more obvious and abilities become more limited. Some dementia sufferers at this stage can still share some of their experiences of life as a dementia sufferer even though their memory and cognitive abilities are getting worse. Elderly with *middle stage* can still participate in daily life by carrying out some instructions that are easy to understand.

Elderly people with mild to moderate dementia are often considered incapable of feeling the changes caused by the dementia they are experiencing, so caregivers often ignore the elderly's ability to make care decisions according to the changes felt by the elderly person with dementia. Bolt et al. (2022) stated that elderly people with dementia at the beginning of their diagnosis were able to express what they felt, including saying that their life still had value and meaning; the elderly feel that they are unique individuals as themselves; the elderly put their trust in others; the elderly feel that the future worries them; and seniors accept and embrace what is happening in their lives. In addition, elderly people are able to talk about their life experiences when they receive a diagnosis of dementia, show their awareness of the difficulties caused by dementia, and explain the negative perceptions of other people towards elderly people with dementia (Johnson, 2016). Mistakes in nurses' and caregivers' understanding of the perspective of elderly people with dementia are often seen as something that usually happens and will improve on its own. Based on this background, the researcher intends to carry out further research regarding the experiences of elderly people with mild-moderate dementia in receiving care in the family as an effort to find out the meaning and significance of the changes and responses felt by these elderly people through a descriptive phenomenological study.

RESEARCH METHODS

The research design used by researchers in this study is a qualitative research design using a descriptive phenomenological approach. Descriptive phenomenology is qualitative research that focuses on descriptions of informants' experiences of a phenomenon (Creswell, 2014). The phenomenon examined in this research is the ability of elderly people with dementia living in families in DKI Jakarta to talk about the changes they have experienced. The sampling technique used is *purposive sampling* to get elderly participants with mild-moderate dementia who live with their families in Cianjur Regency. The method for analyzing and presenting descriptive phenomenological data uses a structured and specific analysis method developed by Moustakas (1994) by modifying the Stevick-Colaizzi-Keen method (Creswell, 2014).

RESULTS

This research involved ten elderly informants with dementia who live in families in the Cianjur Regency area. The ten informants were selected according to the inclusion criteria in this study. Research saturation was reached by the tenth informant, which was marked by repetition of answers and answers to research questions. In this study, informants varied according to age, namely the youngest elderly aged

60 years and the oldest elderly aged 72 years who lived in Cianjur Regency. The ten elderly people with dementia consisted of 7 people who were female and 3 other people who were male; 8 elderly people have junior high school education and 2 other people have high school education; 3 elderly people suffer from moderate dementia and 7 other people suffer from mild dementia. Using in-depth interviews, researchers identified the changes experienced by elderly people with mild-moderate dementia into three themes, namely difficulty remembering information, decreased ability to manage finances, and decreased intelligence.

Difficulty Recalling Information

Symptoms of difficulty remembering information were conveyed by research participants, including difficulty remembering names, difficulty remembering the location of items, difficulty remembering time and place, and difficulty remembering important information. Difficulty remembering names occurred when research participants got to know new people, but several elderly people said that participants could also forget the names of old people they previously remembered, such as the names of nieces, nephews, cousins, and so on. The following are statements from participants who have symptoms of difficulty remembering names

"Often the names of friends, even though they are often seen, if they are acquaintances they like to forget their names, for example acquaintances who are left behind for a while like to forget" (I2)

"People's names, that's even more so, especially nephews and nieces, because there are a lot of them... who is who... it has been explained but I forgot again. Moreover, full name, it can't be me" (I3)

"Sometimes when we chat we forget who we are talking to" (I10)

The category of difficulty remembering where items are is another symptom felt by 5 research participants. Research participants experienced forgetting the location of items commonly used daily, such as wallets, combs, and so on. The following is a participant's statement explaining that difficulty remembering the location of items is a symptom of decreased cognitive function:

"Well, where do I put it? It feels like yesterday I put it here, but where does it go? Well, that's often the case. Just forgetting" (I4)

"If I want to get something, I forget it when I go to my room, then I remember when I come out" (I6)

"If I want to take something, I forget it when I go to my room, then I remember when I come out" (I9)

Difficulty remembering time and place was also another symptom reported by 2 participants as part of the signs and symptoms of decreased cognitive function. Statements from research participants who stated that they had difficulty remembering times and places in their daily lives as a result of decreased cognitive function in dementia, included:

"There are also people who like to forget, for example "Grandma, Friday or Saturday, come here and play"" (I1)

"For example, I also like to forget the names of places, maybe it's because of health factors, if only I remember first" (I10)

Difficulty remembering important information is another symptom experienced by elderly people with dementia. These symptoms were reported by 3 research participants, including:

"Yes, I often forget (important information)" (I2)

"My child's birthday has been forgotten for up to a month" (I6)

"My memory is a bit lacking, so what is it called, for example, what are you talking about, I keep forgetting, I forget a lot" (I7)

Decreased Ability to Manage Finances

Participants conveyed a decline in their ability to manage finances through their experiences regarding a decline in carrying out financial transactions and a decline in their ability to calculate. The decline in carrying out financial transactions was conveyed by 2 participants.

Three significant statements from participants explaining the decline in carrying out financial transactions, namely:

"(decline in) numeracy, especially those related to (financial) income" (I2)

"Money problem? Oh that's not at all" (I3)

"I leave everything to my nephew, I'm too stupid, sometimes when I need money, I just call my nephew" (I3)

Meanwhile, 2 participants conveyed the decline in numeracy skills, namely:

"(decline in) counting" (I2)

"Moreover, I can no longer do my calculations. I can just leave it to Miss IN (caregiver) to count the groceries" (I3)

Decreased Intelligence

Symptoms of decreased intelligence are supported by one statement made by the participant, namely feeling stupid. Feelings of feeling stupid were conveyed by 2 participants, namely:

"But now I've become stupid" (I1)

"So stupid" (I1)

"Yeah, his brain isn't working anymore" (I3)

DISCUSSION

Decreased cognitive function is an early symptom of dementia. The results of this study indicate that elderly people with mild to moderate dementia have the ability to talk about their experiences in dealing with the early symptoms of dementia, including difficulties remembering information, decreased financial abilities, and decreased intelligence. Research conducted by Cotter et al. (2017) stated that in the early stages of dementia, elderly people with dementia are able to adjust to the loss of cognitive function and share their experiences of decreased cognitive function with others. The results of this research are in line with the results of research conducted by researchers. According to the researchers' analysis, the ability to report early symptoms of decreased cognitive function experienced by elderly people with mild-moderate dementia is an indication that elderly people with dementia are adapting to the conditions of decreased cognitive function they experience, including difficulty remembering information, difficulty managing finances, and decreased intelligence.

Difficulty Recalling Information

The condition of decreased cognitive function experienced by elderly people with mild-moderate dementia in the results of research conducted by researchers is part of the characteristics of the nursing diagnosis of memory impairment. Based on NANDA reference-*International* 2018-2020, decreased

cognitive function in nursing diagnoses of memory impairment is characterized by the inability to remember some information or attitude skills (Herdman & Kamitsuru, 2017). The theory of memory impairment presented in *NANDA-International* 2018-2020 is in line with the results of research conducted by researchers which stated that elderly people with mild-moderate dementia experience difficulty remembering information and difficulty performing certain behavioral skills.

In the early stages of dementia, a senior realizes that his body can no longer manage his daily life because he can no longer remember and keep track of things like he used to. Research conducted by Thoft and Ward (2022) states that memory problems affect daily life, most elderly people with moderate dementia explained that events from the past require a lot of energy to remember and it is not always possible to evoke these memories, it is easier for them to describe episodes from their childhood and young adult lives, e.g. about school, sports, work, and their hobbies.

Easily forgetting new information is one of the main characteristics of dementia, followed by impaired independence in defecation and urination, wandering far from home, going out naked, and even picking up rubbish in more severe symptoms (Svennevig & Landmark, 2019)

Signs and symptoms of decreased cognitive function that emerged in the results of research conducted by researchers indicate difficulty in remembering information and difficulty remembering time. Some elderly people in the early phase of dementia show the following complaints: elderly people forget meetings with important clients and transfer money to the wrong bank account; seniors experience increasing difficulty remembering commitments to their families and misplacing items, which is noticed by their family members (Sasaki et al., 2020). Other research that is in line with research conducted by researchers is research conducted by Hugo and Ganguli (2014) which states that the domains of cognitive function that decline in elderly people with dementia are complex attention, executive function, learning and memory processes, language, perceptual function- motor or visuospatial, as well as changes in social cognition.

The results of research on the decline in cognitive function of elderly people with mild-moderate dementia show that there is difficulty remembering information consisting of difficulty remembering names, the location of items, and orientation to place and time. Research conducted by Sharp (2017) through a phenomenological study stated that elderly people with mild to moderate dementia explained their experience of being unable to remember new information that suddenly occurred in their daily lives as an effect of the dementia problem they were experiencing. The results of this research are in line with the results of research conducted by researchers.

Difficulty Managing Finances

Another decline in cognitive function felt by research participants was difficulty in managing finances and a decrease in numeracy skills. Elderly people with mild to moderate dementia in this study reported a decline in their ability to carry out financial transactions and numeracy by handing over all financial management to family members and experiencing a decline in income. The results of this study are in line with research conducted by Robinson, Tang, and Taylor (2015) which explains that a decrease in numeracy skills and a decrease in the ability to manage finances is an indication of a decline in cognitive function in elderly people with dementia, known as *acalculia*. This concept is in line with research conducted by researchers where elderly people with dementia experienced a decrease in their ability to calculate, including a decrease in their ability to manage finances.

Elderly people report that financial deficits are first identified by family members while elderly people with dementia tend not to realize it directly before being told by those closest to them about their declining financial capabilities (Gill et al., 2019).

Difficulty in managing finances as part of the result of decreased cognitive function occurs in participants with mild-moderate dementia. These difficulties include the inability to use an ATM, calculate income and expenses, and the limited amount of money that elderly people have. Research conducted by Frank and Forbes (2017) states that elderly people with dementia experience problems in managing their finances and need professional help to manage their finances. The results of this research are in line with the results of research conducted by researchers. Based on the researcher's analysis, elderly people with dementia described their experience of decreasing their ability to calculate and manage finances so that these elderly people decided to hand over their financial management to professionals (family, *caregiver*, or notary).

Decreased Intelligence

Apart from a decrease in the ability to manage finances and calculate, another decrease in cognitive function felt by participants in this study was a decrease in intelligence. The ability of elderly people with dementia to realize a decrease in intelligence is one of the experiences of research participants mentioned by the majority of participants in this study. Cheng (2016) in his research stated that elderly people with dementia experience a decline in intelligence which can be accurately measured through *premorbid intelligence* (IQ) as an effort to measure the decline in cognitive function in elderly people with dementia. However, there is no specific IQ value for people with dementia, intelligence assessment in elderly people with dementia focuses on assessing spoken and written language, object recognition, problem solving, attention and executive function (Ulugut & Pijnenburg, 2023). In general, in health services, a decrease in IQ in elderly people with dementia is identified through IQ measurement questionnaires which are able to assess the ability of elderly people in word reading tasks, lexical decision tasks, word description tasks, as well as visuospatial reasoning tasks and demographic similarities (Overman et al., 2021)

In the early stages of a dementia diagnosis, the decline in intelligence is felt by the elderly. In a one-year observational study in the early stages of dementia, it was found that there was a relationship between cognitive reserve and *premorbid intelligence* (IQ) on the worsening cognitive status of dementia patients (Quattropani et al., 2021). This is in line with the statements made by participants in this study where in the first year of dementia diagnosis, the elderly were able to describe a decline in intelligence and residual intelligence which they felt was still persistent. Through a phenomenological study of elderly people with mild to moderate dementia, Johnson (2016) stated that elderly people with mild to moderate dementia were able to talk about their experiences of a decline in intelligence leading to stupidity that they experienced since suffering from dementia. Elderly people with mild to moderate dementia are able to tell about their experiences of decreased cognitive function which is characterized by a decrease in intelligence to the point of feeling like an idiot after experiencing dementia, which ultimately worsens the condition of the dementia itself.

Based on the explanation above, researchers can see that elderly people with mild to moderate dementia are able to describe and recognize the changes in cognitive function they experience as early symptoms of dementia in the elderly. The early symptoms of dementia that elderly people can recognize and then receive further treatment can help elderly people with mild-moderate dementia from falling into severe dementia.

CONCLUSION

Elderly people with mild to moderate dementia have the ability to talk about their experiences in dealing with changes due to dementia. The changes experienced by elderly people regarding their mild-moderate dementia consist of difficulty remembering information, decreased ability to manage finances, and decreased intelligence. The conclusion of this study is that the ability of elderly people with dementia to share their experiences regarding the changes they feel when experiencing mild to moderate dementia indicates that elderly people in the early stages of their diagnosis have the ability to see the signs and symptoms of dementia in the early stages. Suggestions for elderly health providers in families (one of which is community health centers) are to carry out regular independence screening and dementia screening as considerations in providing services for elderly people with dementia in the family.

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