



# Systematic Literature Review on Challenges against the Care of the Elderly with Dementia

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## KEYWORDS

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## ABSTRACT:

Elderly people aged 60 years and above and diagnosed with dementia need careful care from their family members or caregivers. The caregivers of the elderly with dementia face many challenges that must be overcome. This paper aims to discuss the conceptual definition of dementia and the challenges faced by caregivers when looking after the elderly with dementia. The secondary analysis method is used in this paper to find out the definition of the concept of dementia and the various challenges faced by caregivers from various sources in a secondary approach. The results of the study obtained from previous studies found four challenges faced by caregivers in caring for the elderly with dementia, namely limited communication, pressure on caregivers, the role of women in parental care and financial burden. The implication is that the role of a caregiver who takes care of the elderly with dementia can cause internal conflict on the caregiver himself due to the decline in cognitive function among dementia patients.

## 1. Introduction

Based on the Malaysian Demographic Statistics Report for the first quarter (2021), the population aged 65 and above has increased from 2.26 million to 2.37 million for the same period. The expected number of elderly people in Malaysia will be more than double from 1970 to 2020, from 5.4 percent to 11.1. Percent and expected to reach 19.8 percent in 2040. Therefore, Malaysia is expected to become an aging country like Japan by 2030 (Department of Statistics Malaysia, 2018; Ai Jing and Harifah, 2022). This aging process has become a global phenomenon that also happens in Malaysia. It is a phenomenon that exists in developing and developing countries, especially in developing countries (Ai Jing and Harifah, 2022). Aging is the process of accumulated structural and functional changes in organisms as a result of the passage of time. This process is a long process that occurs throughout an individual's life not only due to age

and genetics but by the interaction between environmental conditions and personal events and behavior. These changes cause fertility and physiological functions to decrease until the last time they are in this world (Ulises et al., 2016; Fernandez-Ballesteros, 2013). Expectations obtained from the United Nations show that the number of elderly people in Malaysia will reach 15 percent of the total population (Noraini et al., 2015). This is due to the increase in the number of elderly people who are affected by medical aid facilities, nutritional and health care awareness, increasingly sophisticated treatment methods and increased advances in medical technology (Abdul Aziz et al., 2002).

Suridah and Rahimah (2018) explained that the increase in the life expectancy of the elderly causes them to need to be taken care of after for a long period of time. The number of frail and sick elderly is rising, which increases the demand for care,



whether it is formal or informal. In Malaysia, most people still choose to do informal elderly care because they still uphold strong values where the elderly is taken care by their family. Even the elderly still depend on their family members when they fall ill (Suridah and Rahimah, 2018). This is because the elderly will experience a lack of physical ability such as hearing, vision, memory loss, urinary incontinence and joint pain (Said, 2017; Bravo et al., 2012; Barca et al., 2011; Saraswat et al., 2020) ; De Luca et al., 2019). One of the most common memory loss diseases among the elderly is dementia. In addition, dementia is a disease that causes patients to lose progressive brain nerve cells that are important for normal thinking, action and brain function. Studies that have been conducted show that a total of 300,000 Malaysians have been diagnosed with dementia and half of them have Alzheimer's type dementia in the age category of 65 years and above (Institute of Gerontology, Universiti Putra Malaysia, 2012). Among the famous figures who are suffering from dementia are the former 5th Prime Minister of Malaysia, Tun Abdullah Ahmad Badawi, and the famous male actor in the West, Bruce Willis.

Caring for the elderly with dementia is different from caring for the elderly without dementia. The challenges, experiences and needs of caring for elderly people with dementia are different when compared to caring for elderly people without dementia (Ory et al., 1999; Sequeira, 2003). Based on the study of Rohana et al. (2017), primary caregivers adapt themselves in care by staying calm, surrendering to God, acting to solve problems, and avoiding care situations. Adaptation to avoid caregiving situations is the most widely used method by primary caregivers in the care of dementia patients to reduce stress and ease the burden they bear. The main caregiver's way of adapting themselves in the care situation is still less effective in reducing the stress and burden of care. They still need help and support from family and friends when elderly caregiving is taxing them (Rohana et al., 2017).

Although studies on the elderly and their relationship with dementia are done in various aspects such as Rohana et al. (2017) who looked at the adaptation of primary carers in the care of dementia patients; Roshanim (2018) analyzed the economic burden for people with dementia and health care costs in Malaysia and Khadijah, Noraini and Ponnusamy (2019) conducted a study of anxiety and depression with the quality of life of the elderly.

Therefore, this study aims to discuss about the challenges of caring for the elderly with dementia.

## Research Objective

Dementia is a disease that is detected in men and women aged 60 years and above. It is caused by the death of cells in the brain that affects the cognitive function of individuals who suffer from it. In general, this study was conducted with the aim of analyzing elderly people suffering from brain degeneration and describing the challenges of caring for elderly people suffering from dementia. Specifically, this study was conducted based on the following objectives, namely:

- (1) Identify the conceptual definition of dementia and,
- (2) Analyze the challenges faced in caring for the elderly with dementia

## 2. Research Method

The data required in academic research can be collected either in the field or not in the field from various sources (Sekaran and Bougie, 2013). The research method used to collect data in this study is secondary data. Secondary data is a review of information obtained from journals, books, documents and past research for a new research (Noraini, 2013). Since the discussion in this paper is focusing on the discussion of the previous studies results analysis on the challenges of caring for the elderly with dementia, all the discussions in this paper use the secondary analysis method. Secondary analysis, also known as a literature review, uses existing information collected by previous researchers to meet the needs of their study. The need to use this literature review is to document the research in this paper adding to the existing literature. The literature that was identified and analysed based on the compatibility factor with the theme of this paper, was applied and analysed again. Since empirical research has not been done, the theme of this paper is more about preliminary findings.

## 3. Literature Review

The problem of disability among the elderly is increasing due to increasing age and health problems (Farhah Hanun and Denise, 2017). This causes elderly people with health disabilities to demand special care to continue their daily lives (Aishah and Katiman, 2012). This study was conducted to analyze the challenges of caring for elderly people with dementia. Until now, there have been many



researchers who have focused on the elderly in various aspects of their studies. Khadijah, Noraini and Ponnusamy (2019) examined the relationship between anxiety and depression with the quality of life of elderly people with dementia. Their study was conducted to identify the relationship between anxiety and depression and the quality of life of elderly people with dementia in care institutions. Their study also suggests reminiscence group therapy in reducing anxiety and depression among residents in elderly care institutions. The findings of the study show that there is a non-significant relationship between the quality of life and the level of anxiety while the relationship between the quality of life and the level of depression of elderly people with dementia is significant. The use of reminiscence group therapy as one of the effective interventions in helping to improve the quality of life and reduce anxiety and depression among the elderly in care institutions (Khadijah, Noraini and Ponnusamy, 2019).

The emphasis on challenges in providing services to the elderly was studied by Nur Hanis, Mardhiah and Khadijah (2019). The main purpose of their study is to explore the challenges of gerontology social work apprentices in providing services to chronic elderly patients at Rumah Ehsan, Kuala Kubu Bharu, Selangor. The findings of the study are divided into two parts, namely SKM level 3 apprentices and elderly carers. SKM apprentices find their main challenges are finance, facilities, management, and training to handle chronically unwell elderly people. While the involvement of gerontology apprentices can help ease the burden of care among health care assistants. Caregivers can also share communication skills, listening skills and so on from gerontology social work apprentices (Nur Hanis, Mardhiah and Khadijah, 2019). Sharifah Rohayah, Muhammad Wafi and Sofia Haminah's study (2020) explores the relevance of the elderly in the pandemic era. Their study aims to analyze the impact of the MCO on the resilience of the elderly in Penang from the aspect of adapting to the MCO situation while also reviewing the support system available to them. The results of the study found that close social relationships and access to activities related to the environment are important elements in the survival of the elderly during the MCO (Sharifah Rohayah, Muhammad Wafi and Sofia Haminah, 2020). In addition, Nurul Hudani, Habibie and Puteri Hayati (2020) studied the intergenerational relationship of psychological and social support in the care of the elderly in Kota Kinabalu, Sabah. Their study aims to describe the views of adult children or elderly caregivers on

intergenerational aspects, psychological and social support in elderly care. The results of the study show that noble values in society such as respecting the elderly are still held by children who play a role as the younger generation. Because of the attitude of respect for the elderly, it further creates a sense of responsibility and love among the adult children to take care of their parents, thus showing a good intergenerational relationship. Research findings also report that adult caregivers need social support and psychological support in the process of caring for their elders (Nurul Hudani, Habibie and Puteri Hayati, 2020). Arina, Eka Riyanti and Tiara (2021) in their study explored the subjective well-being of adult daughter caregivers of parents with dementia. The results of the study found that the dynamic of caregivers' well-being is linked to their attitude in accepting the role of caregiver to parents with dementia (Arina, Eka Riyanti and Tiara, 2021). Therefore, many questions have been studied and become the focus of researchers regarding the issue of the elderly. Examples are the relationship between anxiety and depression and quality of life in care institutions, challenges in providing services to the elderly, the impact of the MCO on the resilience of the elderly, the intergenerational relationship of psychological and social support in care and the subjective well-being of caregivers of adult daughters. Therefore, it is very appropriate that this study is conducted to analyse the challenges faced in the care of elderly people with dementia.

## 4. Results and Discussion

### Definition of Dementia

Dementia is a disorder of brain function. This disease involves a group of symptoms that include deterioration of memory function, difficulty in thinking, communicating, solving problems and behavioral and emotional changes (Asrenee and Rozanizam, 2019). While according to Khadijah, Noraini and Ponnusamy (2017), dementia is a syndrome that disrupts cognitive functions in terms of memory, communication, perception, and association with people around them (Yafee et al., 2013; Christine and Linda, 2011). Deterioration of memory in general causes the active life of the elderly to be limited. This limited life will contribute to feelings of boredom and stress because they must be at home alone (Agnis et al., 2017). Dementia is also considered to be a disease that is usually suffered by the elderly aged 60 years and above (Khadijah, Noraini and Ponnusamy, 2019). Dementia also affects individuals as they gradually lose their abilities and their relatives and other



supporters. This is because they have to deal with seeing family members or friends getting sick and their health deteriorating. At the same time, people with dementia need to respond to their needs such as increasing dependence on family members and changes in behavior that require care in health and social aspects (Livingston et al., 2017).

According to Wilson et al. (2012), dementia is a symptom characterized by a decline in memory function, language, problem solving and cognitive abilities. Dementia patients will experience changes in behavior and condition continuously until they are bedridden and completely dependent on caregivers to perform daily activities (Bailes, Kelley and Parker, 2016). This chronic neurological health condition has a long recovery time and is difficult to predict. So people with dementia need family members or other people to take care of them (Sullivan and Miller, 2015).

Family members who are caregivers act as individuals who provide moral, emotional, financial support and informal care and do not have proper training to treat dementia patients (Goldberg and Rickler, 2011). Thus, in the context of this paper, dementia can be concluded as a state of decline in brain function experienced by the elderly aged 60 years and above. This group will experience a decline in memory, difficulty in thinking and making decisions so that they need the help of others or family members to manage their daily needs.

## Challenges to the Care of the Elderly with Dementia

Caregivers of elderly people with dementia confront a variety of challenges. Previous studies have shown that elderly people with dementia often experience symptoms of depression and anxiety, i.e. they feel angry easily (Tay, Subramaniam and Oei, 2018). Situations such as depression and anxiety become the biggest challenges for caregivers consisting of children and other close family members to deal with the needs of the elderly. It is caused by the elderly being easily sensitive followed by their behaviour also changing to be like children and showing a rebellious attitude and doing forbidden things (Noraini et al., 2015).

### a. Limited Communication

The most significant aging change is the limited communication process due to chronic health problems such as stroke, dementia or alzheimer's. It causes a serious decline in thinking memory and communication among the elderly, and they need

full-time care. With various changes occurring, the phenomenon of communication among the elderly is a very important issue for formal and informal caregivers in improving the well-being and quality of life of the elderly. Communication means the process of creating, processing and exchanging information between individuals, groups and social organizations which is the basis of human daily life (Khadijah and Maizatul Haizan, 2017). The main purpose of communication is to create continuous and dynamic communication, change or change knowledge, attitudes and behavior in line with values and interests in interaction (Sobkowiak, 1998). Communication is divided into three categories, namely, verbal, non-verbal and written. Verbal communication is very important to informal, professional caregivers (social and health care). If verbal communication is not clear, then it can hinder the service delivery system in complying with the wishes of the elderly (Arnett and Douglas, 2007). The clarity of verbal communication is influenced by semantic clarity including the use of the same accent as them so that the targeted goal is achieved (Oluga, 2010).

In addition to verbal communication, non-verbal communication is also no less important to the elderly. Non-verbal communication is such as body language, appearance, facial expressions or facial movements, touch, language, gaze, and body posture (Sharples, 2007). Non-verbal communication needs to be made in tandem with verbal communication so that it can be used to reinforce what is said verbally (Maizatul Haizan and Noor Afzaliza, 2017). For example, if we are discussing a serious matter but our facial expression is less serious, then the people around us will have less faith in what is being said. When verbal and non-verbal communication is uneven, then people will trust the non-verbal. The prominence of facial expressions accompanied by body movements that come from a sincere heart by informal and formal caregivers in serving the elderly. This is because the sincerity can be felt by the recipient of the message and further increases the satisfaction of communication between the giver and recipient of the message effectively (Khadijah and Maizatul Haizan, 2017).

Effective communication is the basis for achieving clear information from the deliverer (informal caregiver, social or health worker) to the receiver (elderly) in an effort to create a message that is clear, easily accepted and understood by the elderly so as not to cause misunderstandings. Receiving the message clearly and effectively is important to





change one's attitude and behavior in accordance with what the sender of the message wants (Khadijah and Maizatul Haizal, 2017). The aging process also affects the inability to communicate. Therefore, caregivers need to modify communication techniques among the elderly, especially those at high risk due to pathological-psychological changes so that communication becomes more difficult. For example, elderly people suffering from stroke, dementia and parkinson's disease (Khadijah and Maizatul Haizal, 2017).

## **b. Pressure on Caregivers**

Caring for sick elderly for a long period of time has an impact on caregivers, especially informal caregivers. Caring responsibilities for a long period of time can be a burden for informal carers to balance between daily responsibilities and also towards the elderly. For that, caring for the elderly for a long period of time can cause stress and dilemmas for informal caregivers, thus having a negative effect on the physical and mental health of informal caregivers. This long-term care situation receives less public attention because it is considered a private matter and is done informally in the caregiver's home (Suridah and Rahimah, 2018).

Grifith and Bunrayong (2016) also stated that caring for elderly people with dementia will cause caregivers to be stressed. Grifith and Bunrayong's research were conducted to delve into the problems faced by caregivers. The results of their study found that caregivers face difficulties during daily care because the task of taking the elderly to the toilet is the most difficult task. This situation occurs because most elderly people with dementia do not tell that they want to go to the toilet, thus making it difficult for caregivers to clean themselves and the clothes of the elderly involved. In addition, caregivers also stated that the frequency of lifting the elderly caused them back pain when caring for the elderly alone and without assistance from others. Caregivers are also faced with problems because elderly people with dementia will experience poor memory, for example easily forgetting important things such as eating or taking medicine. In order to overcome problems when caring for the elderly, caregivers need support from trained professionals, family members and other community members (Suridah and Rahimah, 2018).

## **c. The Role of Women in Parental Care**

There is a study that found that women play an important role in caring for elderly parents (Suridah and Rahimah, 2018). Analysis done by Khadijah and

Rahim (2010) found that women are more involved in elderly care because elderly parents also expect help and support from daughters. The types of care provided by daughters are practical care (eg washing clothes, preparing food and cleaning the house), personal help (eg talking about problems and giving advice) and material help (eg financial and gifts).

According to Garcia and Bazo (2001), usually daughters will bear the heavy responsibility of caring for their parents not only psychologically but also physically. For example, in Spain daughters are the main carers of the elderly. Caregiving assistance received from other family members such as other siblings is at a minimal level. This situation causes daughters to often feel burdened and neglected. In the family context, all family members need to provide support and help without having to feel burdened, selfish, low self-esteem, dependency, and feelings of shame (Nurul Hudani et al., 2019). Several past studies also prove that women are the main caregivers of the elderly (Heok and Yong 1994; Low, Payne and Roderick, 1999; Zainuddin, Arokiasamy and Poi, 2003; Choo et al., 2003; Cox, 2003; Kuuppelomaki et al., 2004; Fatimah, 2006). Good care requires a deep emotional bond and commitment, and that function is performed by women (Galliano, 2003). This situation is related to the socialization process that women go through, that is, they have been socialized to perform the role of nurturing, caring, giving love and emotional support (Fatimang, Rahmah and Fatimah, 2009).

In addition to bearing the burden of care, women also have a role to take care of their own families and work. This phenomenon can have implications for the career and family of the women involved and even affect the development of the country (Suridah and Rahimah, 2018). These people do not have enough time or resources to divide their responsibilities fairly and equitably. Extreme commitment and involving a load of demands and role conflict create stress that is difficult to deal with. When the demands of other social roles collide with the responsibility of caring for parents, they often experience a situation closely related to role limitations. Role limitation is the burden of role demands that refers to limited time, energy, and personal resources in an effort to shoulder all the responsibilities that rest on an individual's shoulders. In general, middle-aged women often face various responsibilities to take care of several layers of other generations in the family (Khadijah and Rahim, 2010).



#### d. Financial Burden

Financial burden is an important resource, especially in the aspect of care when the caregiver's income can be affected by the daily expenses that need to be allocated to meet the care needs of children and the elderly (Fast, Williamson and Keating, 1999; Hayman et al., 2001; White -Means and Rubin, 2004). However, for caregivers who experience economic problems who often experience an imbalance in the provision of care needs to the elderly and children (Norulhuda et al., 2014). According to Andrew (2007), caregivers who care for two generations simultaneously tend to face financial problems and time constraints to provide basic needs such as food, shelter, security to ensure the well-being of family life. For low-income caregivers, they are more at risk of facing financial-related problems than caregivers with high incomes. This is because income exceeds expenses causing them to have to save and divide the caregiver's income for home expenses, education, health and self-management (Norulhuda et al., 2014).

Caregivers of the elderly also have higher care and support challenges from a financial aspect, especially when the elderly cared for have a chronic illness (Koh and MacDonald, 2006). They require high expenses to manage and provide the daily needs of the family (Acton and Kang, 2001; Aoun et al., 2005; Hickenbottom et al., 2002; Langa et al., 2004; Panda and Coleman, 2001). In addition, daily expenses to support family and elderly parents also affect the finances of caregivers (Hayman et al., 2001; WhiteMeans and Rubin, 2004) and they need to prioritize basic needs in spending (Ahmad, 2012). Usually, caregivers who take care of families and elderly parents must pay their own expenses related to transportation costs, medical supplies, household appliances and other household needs (Decima Research, 2002; Hollander, Liu and Chappell, 2009).

#### Conclusions and Further Research

The whole discussion shows that limited communication factors, pressure on caregivers, women's role in parental care and financial burden are challenges to the care of elderly people with dementia. This ongoing caregiving commitment can pose its own challenges to caregivers.

This is because they do not have enough time or resources to divide responsibilities fairly and equitably. This high commitment and burden of role demands and role conflict often creates stress that is difficult to deal with. When the demands of other

social roles collide with the responsibility of caring for parents, they often experience a situation closely related to role limitations (Khadijah and Rahim, 2010). Thus, caregivers will face problems in communicating with dementia patients due to the deterioration of brain memory functions such as doing something repeatedly. The situation puts pressure on caregivers who do not have the appropriate skills and training in caring for elderly people with dementia. However, for women who act as caregivers, they are considered capable of taking care of the needs of the elderly because daughters provide more care than sons.

Suggestions for further research that can be considered need to study strategies to overcome the challenges faced by caregivers who care for elderly people with dementia. Strategies to overcome the challenges faced by caregivers need to be given attention so that the elderly cared for receive the best care. In addition, there is a need for a more detailed study on the issue of care for elderly people with dementia who are in care canter under the supervision of government, private or non-government bodies.

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