



## CARING TO BE FORGOTTEN: AN OVERVIEW OF FAMILY RESILIENCE IN ELDERLY DEMENTIA CAREGIVERS

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### Abstrak

Indonesia is entering the aging population period, characterized by an increase in life expectancy and the growing number of elderly individuals. One of the prevalent health issues among the elderly is dementia, which imposes a significant stress burden on caregivers. This study aims to explore family resilience in caregivers of elderly individuals with dementia. A qualitative approach using a case study method was employed. Subjects were selected through purposive sampling, data validity was ensured through source triangulation, and data were analyzed using content analysis. The findings reveal that both families exhibited similar resilience dynamics, characterized by a belief system emphasizing a positive perspective on the situation and reliance on faith in God. Organizational patterns displayed flexibility and the provision of support. The family dynamics of Subject EM were more flexible compared to Subject NR, while the support received by both subjects played a critical role in fostering family resilience. Communication processes were stronger in Subject EM's family compared to Subject NR's, yet communication in both families contributed to the overall resilience dynamics. In conclusion, this study indicates that family resilience is established through a belief system, organizational flexibility, support, and effective communication.

**Keywords:** Caregiver, Dementia, Elderly, Family Resilience

### Introduction

Indonesia has entered a phase characterized by an increase in life expectancy, accompanied by a rise in the elderly population, often referred to as the aging population period. Current data indicates that the elderly population has grown from 18 million in 2010 to 25.9 million in 2019, with projections suggesting it will reach 48.2 million by 2030 (KEMENKES, 2019). This increase poses challenges for the nation, particularly for families caring for the elderly, as aging is often accompanied by degenerative diseases. One such degenerative condition affecting the elderly is dementia.

Data reveals that approximately 1.2 million people in Indonesia suffered from dementia in 2016, alongside other degenerative diseases such as cancer, heart disease, rheumatism, osteoporosis, and cataracts. This number is expected to rise to 2 million by 2030 and 4 million by 2050 (Alzheimer Indonesia, 2019). Additionally, according to the Kyoto Declaration, Indonesia ranks fourth in dementia prevalence and incidence, following China, India, and Japan (Alzheimer's Disease International, 2006). Estimates suggest there were about 556,000 dementia cases in Indonesia in 2015, a figure projected to rise to 2.3 million by 2030 (Prince, Anders, Guerchet, Tzu Wu, & Prina, 2015).

Dementia is a condition that affects brain function, leading to declines in memory, language, cognitive abilities, and problem-solving skills (Wilson et al., 2012). According to the World Health

Organization (2020), dementia ranked seventh among the top ten diseases globally in 2019. Dementia patients experience memory loss, behavioral changes, and physical decline, resulting in dependence on caregivers for daily activities (Bailes, Kelley, & Parker, 2016). Neurological decline and unpredictable conditions often necessitate family involvement in caregiving (Sullivan & Miller, 2015). Elderly individuals with dementia require care and support from caregivers, who bear responsibilities for physical, emotional, financial, and psychological support (Goldberg & Rickler, 2011).

The responsibilities of caregiving for elderly individuals with dementia often lead to stress and fatigue among caregivers. The burden arises because dementia impairs the elderly's ability to recognize and remember their caregivers. This fatigue can result in depression, stress, limited personal time, and self-care challenges (Pena-Longobardo & Oliva-Moreno, 2015). Family caregivers who lack psychological preparedness often feel overwhelmed, fatigued, and despairing, struggling to adapt to caregiving challenges.

Stress, depression, and anxiety among caregivers can lead to difficulties in emotional regulation. The unpredictable nature of caregiving for elderly dementia patients may cause feelings of anger, stemming from caregivers' inability to adapt to changes and a lack of support from their surroundings (Widyastuti, Sahar, & Permatasari, 2012). Acceptance and adaptability can help caregivers navigate the challenges of dementia care. The ability to adapt is closely related to the concept of family resilience.

Family resilience begins with a positive perspective, viewing the family as a collective unit with unique strengths. Warm and strong interactions among family members enhance the family's capacity to care for elderly dementia patients and address caregiving challenges. Resilience refers to the ability to adapt, adjust, and overcome difficult times. Family resilience is defined as the family's capacity to achieve successful adaptation (Marini et al., as cited in Fatimah, 2019). According to Walsh (2016), family resilience is a process whereby the family functions as a unit to overcome, adapt to, and recover from adversity. Three components build family resilience: belief systems, organizational patterns, and communication processes (Walsh, 2016).

Families caring for elderly individuals with dementia face unique challenges and difficulties in the caregiving process. Studies on caregiving experiences for elderly dementia patients reveal varying outcomes. Some studies indicate that caregiving increases family stress and reduces family functioning (Glasdam, Timm, & Vittrup, 2010; Hashimoto et al., 2017; Singh & Dubey, 2016). However, family resilience can enhance resistance to stress. Family resilience is a process enabling families to recover and regain balance after encountering difficult life circumstances. The key components of family resilience include belief systems, organizational patterns, and communication processes.

Based on this background, this study aims to understand the family resilience of caregivers for elderly individuals with dementia. It also explores the formation processes and factors influencing their resilience in facing caregiving challenges. This understanding is expected to provide practical contributions to supporting caregiver families in achieving better psychological well-being and adaptive capacities.

## Research Methodology

This study employed a qualitative case study approach. A case study is used to obtain a comprehensive understanding of a condition that attracts attention, a process occurring, a concrete event, or an individual experience that forms the background of a case (Prihatsanti, Suryanto, & Hendriani, 2018). The case study method was chosen to explore the resilience of families acting as caregivers for elderly individuals with dementia. Data collection was conducted through semi-structured interviews and observations. Semi-structured interviews are interviews in which respondents are required to answer questions prepared by the interviewer (Bastian, Winardi, & Fatmawati, 2018). Credibility was ensured using source triangulation, which involved interviewing significant others of the study subjects. Source triangulation refers to obtaining data and information from different subjects, supplemented by documentary evidence (Purhantara, 2012).

The data analysis method employed in this research was thematic analysis. Thematic analysis (content analysis) is a research technique that emphasizes the consistency of communication content, the meaning of the communication content, the reading of symbols, and the interpretation of symbolic interaction occurring in communication (Bungin, 2017).

Participant selection was carried out using purposive sampling. This technique allows researchers to select participants based on specific criteria relevant to the study (Sugiyono, 2018). The criteria included being female, aged 40–55 years, married, having children, living with their parents, and having a mother diagnosed with dementia. These criteria ensured that participants had experiences relevant to the research topic. From the selection process, two families were chosen as subjects: NR with her significant other U, and EM with her significant other W. Both participants lived with their mothers, who were elderly individuals with dementia. The selection of these participants aimed to provide an in-depth understanding of the situations and dynamics within families caring for elderly members with dementia.

## Results

**Table 1. Research Results**

Aspect	NR Family	EM Family
<b>Subject</b>	NR, a widow with two children, has been taking care of her mother with dementia since late 2019.	EM, a teacher with two children, has been taking care of her mother with dementia for seven years.
<b>Challenges</b>	Physical and emotional fatigue, her mother not recognizing her, and differences of opinion with extended family about caregiving approaches.	Balancing time between work, family, and caregiving, difficulties managing attention to her children, and her mother's hallucinations.
<b>Coping Strategies</b>	Acceptance through spiritual principles, involving a caregiver and domestic assistant, and support from extended family.	Acceptance with a positive outlook, support from extended family, assistance from her husband with household tasks, and open communication in the family.
<b>Family Support</b>	Financial and physical support from the extended family, though there are communication challenges among family members.	Support from her husband, in-laws, and younger sibling. Collaboration in caregiving and household management eases EM's burden.
<b>Positive Perspective</b>	Spiritual belief that God provides strength to face challenges, despite tension in family communication.	Positive outlook with a belief that life will improve after tough times, spiritual support, and openness in family communication.
<b>Resilience Process</b>	Incorporating Javanese cultural values (patience, sincerity, acceptance, and composure) in caregiving.	Maintaining a positive outlook by wholeheartedly and patiently providing care despite her busy schedule.

<b>Family Communication</b>	Communication is hindered by frequent interventions from her children in the caregiving process.	Open communication, with her husband and children understanding each other's roles in caregiving.
<b>Family Flexibility</b>	Limited flexibility in decision-making, causing confusion due to the involvement of many parties.	Sufficient flexibility, with decisions related to treatment delegated to EM, while her husband helps manage the children.
<b>Social Support</b>	Receives financial support and alternating caregiving assistance from the extended family.	Receives support from her husband, younger sibling, and in-laws, who help with caregiving and household tasks.
<b>Positive Meaning</b>	Derives positive meaning by patiently and sincerely caring for her mother with dementia, adhering to Javanese cultural values.	Finds positivity in the situation despite challenges, believing that God provides strength in the caregiving process.
<b>Interview &amp; Observation Findings</b>	Demonstrates high resilience despite tension in family communication and decision-making. Adequate physical and financial support is helpful, but communication needs improvement.	Shows high resilience with strong support from extended family, open communication, and flexibility in role distribution for caregiving.

Based on semi-structured interviews and participatory observations regarding family resilience among caregivers for elderly individuals with dementia, the findings are as follows:

#### 1. NR Family

This study focuses on the experiences of the NR family, a widow with two children, who has been caring for her mother diagnosed with dementia since late 2019. Family resilience was examined through emotional dynamics, family support, and adaptive strategies in coping with the challenges of caring for an elderly person experiencing cognitive decline. NR, a single mother, began living with her mother after her husband passed away. She has two children: the eldest is employed, while the youngest is pursuing higher education. Following her husband's death, NR moved in with her mother, whose memory capacity had significantly deteriorated. For the past four years, NR has been the primary caregiver, often facing challenges such as physical and emotional exhaustion. One of the most difficult aspects of her caregiving experience was when her mother no longer recognized her as her daughter but instead perceived her as a niece.

NR approached this situation with acceptance, relying on the principle of sincerity and the belief that every life trial contains strength bestowed by God. This attitude of acceptance enabled her to provide the best care for her mother. To manage the challenges, NR enlisted the help of a nurse and a domestic helper. Their presence alleviated her daily workload, although she still felt emotionally burdened. Additionally, NR's extended family provided both physical and financial support. They assisted in arranging caregivers, procuring medications, and taking turns caring for NR's mother during specific times, such as weekends or when NR had other commitments. This collective support served as a source of strength for NR in fulfilling her role as a caregiver. However, while the physical support was adequate, communication within the extended family occasionally became a barrier.

NR revealed that differences in opinions and suggestions regarding caregiving often led to tension within the extended family. For instance, disagreements between NR, her siblings, and other relatives about the best methods to handle her mother's situation were frequent. This occasionally left NR feeling unheard in certain aspects, despite the continued provision of other forms of support. Overall, NR demonstrated strong resilience in facing the challenges of being a caregiver. Support from her extended family, assistance from caregivers, and her spiritual beliefs helped NR cope with fatigue and emotional burdens. Nevertheless, communication among family members remained a challenge that needed improvement to enhance the effectiveness of support and foster harmony in caregiving for elderly individuals with dementia.

## 2. Family EM

Additionally, the results of this study were obtained through semi-structured interviews and participatory observation related to the resilience of family caregivers of elderly individuals with dementia. One of the subjects in the study is EM, a university lecturer who lives with her mother, diagnosed with dementia for seven years. EM also has two children, aged 14 and 6. In her daily life, EM faces significant challenges in balancing her work, family, and the responsibility of caring for her mother. The difficulties EM faces are further complicated by her attention to her children, especially the 6-year-old, who sometimes feels neglected due to EM's preoccupation with caregiving. Furthermore, her mother's frequent hallucinations become a source of stress for EM. This situation leads EM to feel that her family does not receive enough attention.

Despite facing numerous pressures, EM strives to come to terms with her situation and maintains a positive outlook. She believes that life will improve after enduring difficult times. Her faith in the presence of God as a companion in her struggles serves as her main source of strength. This belief energizes her to continue her role as a caregiver. Support from her extended family plays a crucial role in helping EM care for her mother. Her husband, parents-in-law, and sibling contribute to the caregiving efforts. On weekends, EM sometimes alternates with her sibling in caring for her mother, providing her with a slight reduction in physical and emotional burdens. The presence of this support system is an essential factor in EM's resilience as a caregiver.

Although small conflicts occasionally arise, particularly with her children, EM demonstrates excellent adaptability in managing these situations. One example of her adaptation is when her husband assists with household tasks, such as picking up the children from school and handling domestic chores. With this collaboration, EM feels the burden is lighter, even though her responsibilities remain substantial. Open communication within EM's family is key to maintaining harmony. EM openly explains her mother's condition to her husband and children, allowing them to understand the challenges they are facing together. This openness fosters a strong familial bond despite the significant challenge of caring for an elderly person with dementia.

## Discussion

Based on the results described previously, the family resilience process experienced by the subjects aligns with Walsh's theory, which states that there are three key processes in the formation of family resilience (Walsh, 2016). Family resilience is a dynamic process involving support, strength, and resources that the family can acquire to enhance resilience. Family belief systems include the way the family interprets difficulties, maintains a positive outlook, and incorporates spirituality to help them face challenging situations (Irene et al., 2021). Recent research also emphasizes the importance of social support in enhancing family resilience. Support from the surrounding environment, such as extended family and community, can serve as external resources to help families cope with difficult situations (Herdiana, 2019).

The first key process is the belief system. The belief system relates to maintaining a positive outlook, assigning meaning to difficulties, and spirituality. Both subjects demonstrate positive beliefs in their perception of events. Although initially facing hardships, both subjects share the belief that what happens is God's will. They share the conviction that despite the challenges, they trust that God will remain by their side, strengthening them throughout the process of caring for their mother with dementia. This is reinforced by interviews with both significant others (U and W), who explain that both subjects consistently involve and rely on God in various aspects of their lives. According to the

significant others, this is reflected in the subjects' religious practices, their prayer habits, and their encouragement for their mother to pray as well. Research shows that spirituality can improve the quality of life for the elderly, which in turn lightens the caregiver's burden (Widari, 2023). Support from significant others, as shown by U and W, also plays a role in strengthening the caregivers' belief system. They explain that both subjects always involve and rely on God in many aspects of life. Such social and spiritual support is crucial for maintaining the emotional and mental balance of caregivers, enabling them to provide optimal care for elderly individuals with dementia (Kusumawaty, 2019).

The positive meaning assigned by NR and EM, according to the significant others, is reflected in their patient care for their mother with dementia and their sincere acceptance of the situation. Javanese cultural values such as patience, gratitude, sincerity, selflessness, acceptance, and relinquishment guide families in developing positive meaning in every event (Azizah & Pudjiati, 2020). For families caring for elderly individuals with dementia, providing positive meaning, acceptance, and sincere acceptance of the situation can help enhance family resilience. Javanese cultural values like patience, gratitude, sincerity, selflessness, acceptance, and relinquishment play a vital role in guiding families to develop positive meaning in every event that occurs (Nashori & Saputro, 2021). For families caring for elderly individuals with dementia, providing positive meaning, acceptance, and sincerity in accepting the situation can contribute to strengthening family resilience. High family resilience plays a role in reducing relapse rates in individuals with mental health disorders (Mastiyas, 2017).

The positive outlook formed by NR and EM through their wholehearted care for their mother is validated by both significant others. NR and EM demonstrate compassionate care, as shown by the medications and attention given despite their busy schedules. A positive outlook helps form a positive mindset, which is an adaptive coping strategy that focuses on positive emotions such as accepting the condition and thinking optimistically about a brighter future (Fuller & Huseth-Zosel, 2020). A positive mindset serves as an adaptive coping mechanism focusing on positive emotions, such as accepting the situation and thinking optimistically about a brighter future. Studies by Fuller and Huseth-Zosel (2020) emphasize that this approach can improve individuals' well-being by promoting acceptance and optimism. Therefore, the loving care provided by NR and EM not only offers physical support but also contributes to the formation of a positive mindset essential for adaptive coping.

Caring for a mother with dementia causes changes in the family dynamics of the subjects. In NR's case, flexibility is less effective. According to the significant other (U), decision-making in NR's family often causes confusion due to the involvement of the extended family. Meanwhile, in EM's family, flexibility is quite good. This is reflected in the significant other (W) stating that role-sharing in caring for children can be done by the husband, and decision-making in the mother's treatment process is entrusted to EM. According to Kamariyah and Nurlinawati (2020), a lack of flexibility in decision-making often exacerbates the condition, as it sometimes requires waiting for the decisions of many parties, experiencing confusion, conflicting opinions, and fear of the consequences to be faced. Therefore, good flexibility is necessary, as it helps all family members understand and know what is expected of each one.

The support provided to the subjects helps in building family resilience. NR receives support for medical expenses, and other family members help by taking turns accompanying the mother. According to U, the subject's siblings regularly send financial aid monthly and accompany the mother during holidays. Meanwhile, EM receives support from her husband, siblings, and in-laws in caring for her mother. Significant other (W) explains that on holidays, EM's sibling comes or picks up the mother to take her home, and the husband supports by doing household chores that EM cannot perform. The availability of resources, both financial and social support, can enhance family resilience (Nies & McEwen, 2018). Research by Kurniawan and Kusumawati (2024) shows a significant positive relationship between social support and family resilience during economic crises;

the more social support received, the higher the family resilience. Similarly, research by Pinasti, Wibhowo, and Novi (2023) found that family social support positively correlates with resilience.

Communication is a crucial process in the formation of family resilience. For families caring for elderly individuals with dementia, effective communication must be established. Families are expected to accept and understand the condition of elderly individuals with dementia and maintain good communication and openness. In NR's case, communication is not very effective, due to the numerous interventions from all the children in the mother's care. According to U, the lack of good communication is due to each party feeling their suggestions must be heard. This is caused by the numerous interventions from all children in the care of the mother, where each party feels their suggestions must be heard, thus hindering effective communication (Hamka et al., 2023). In contrast, EM demonstrates more effective communication. W states that in decision-making, EM sometimes consults her sibling and seeks the best solution for their mother. Good communication can help families solve problems collaboratively when facing a crisis situation. Effective communication allows families to collaboratively solve problems in crisis situations, as revealed in research showing that strategies to enhance caregiver resilience involve personal, family, social background, social support, and education factors (Wulandari et al., 2020).

The family plays a crucial role in caring for elderly individuals with dementia, particularly in making effective decisions, providing support during difficult times, and taking responsibility for the care and financial aspects of the patient. According to research by Kamariyah and Nurlinawati (2020), families are vital in the companion and care process for patients, which includes effective decision-making, supporting patients through difficult days, and taking responsibility for both the care and financial aspects. Effective family communication helps minimize conflicts, which in turn enhances family resilience in facing the challenges of caring for elderly individuals with dementia. Research shows that families with effective communication can reduce stress and improve their emotional well-being. Additionally, the family's role as the primary caregiver involves various aspects, including meeting the physical, emotional, and social needs of the elderly, all of which contribute to the quality of care provided (Wulandari et al., 2020).

The findings of this study encompass the results obtained from field data collection using various techniques such as questionnaires, surveys, documents, interviews, observations, and other methods. The data presented has undergone processing to ensure that the information conveyed is not raw data. All the data obtained is processed and presented in a format that is easy for readers to understand, either in the form of tables, figures, or descriptions. In presenting the results, the processed data is explained with detailed explanations to facilitate understanding. The findings cover various variables relevant to the topic being discussed and are presented clearly so that readers can identify patterns or findings emerging from the analysis conducted. This data presentation aims to provide a clear overview of the observed conditions in this study. The findings from this data analysis reflect significant information that can provide insights into the research topic. Each result is organized with attention to relevant aspects and can contribute to a better understanding of the issues being investigated. A more in-depth discussion of these findings will be presented in the following chapter.

## Conclusion

Based on the research conducted, it can be concluded that both subjects align with Walsh's theory, which posits that family resilience involves three dynamic and essential processes. These processes include the strengths and resources accessible to the family, which help reinforce its resilience. Both subjects, NR and EM, exhibit a relatively strong family resilience, as they have undergone the crucial processes necessary to build this resilience. In the case of NR, family resilience is fostered through a robust belief system. This subject is able to accept their circumstances more positively and attribute them to divine power. However, challenges remain in aspects such as family communication and organizational patterns, including a lack of flexibility and ineffective communication, which may hinder further resilience development. Meanwhile, for subject EM, family resilience is similarly supported by a belief system that provides positive meaning to the circumstances faced. EM demonstrates a reliance on divine intervention to navigate difficult situations. Unlike NR, in terms of communication and organizational patterns, subject EM shows greater flexibility in family roles and clearer communication, which contributes to strengthening family resilience. Both subjects possess adequate resources to care for elderly individuals with dementia, which plays a significant role in reinforcing their family resilience. This support enables them to better navigate the challenges of caregiving, although there are still areas requiring improvement, particularly in communication and flexibility.

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