Journal of Population and Social Studies (JPSS)

Family Interactions Among Family Caregivers and Other Family Members of Older Adults with Dementia (OAWD) in Indonesia: A Phenomenological Analysis

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Submitted: 30 October 2024. Accepted: 13 June 2025. Published: 4 July 2025
Volume 34, 2026. pp. 402–419. http://doi.org/10.25133/JPSSv342026.021

Abstract

Previous studies emphasize the effects of dementia on families, particularly those providing care. However, understanding of how caregiving influences the relationships between family caregivers and other relatives is limited, especially in the context of caring for older adults with dementia (OAWD) in Indonesia. The objective of this study is to explore the experiences of family caregivers of OAWD and other family members who face challenges and to understand the mechanisms of adaptation in family interactions within the context of caregiving for OAWD in Indonesia. This study employed a phenomenological research design involving in-depth interviews with thirty respondents: 15 family caregivers and 15 family members from one family relationship. Thematic analysis identified patterns from respondents' perspectives. Family caregiver interactions and adaptations can be categorized into six themes. Findings highlight the significance of family interactions, strengthening ties, and adaptability in managing demanding roles. Caregivers and family members experience changes in interactions across diverse dementia care settings at home. It emphasizes the need for intervention support for families, as endorsed by policy and caregiver groups, aiming to enhance the care-life balance. This support is crucial for meeting the requirements of families with dementia care needs at home.

Keywords

Dementia; family caregiver; family interaction; Indonesia; phenomenology

Background

Dementia currently affects approximately 55 million people worldwide, a figure projected to rise due to an aging population (Yuan et al., 2023). As the region's demographic landscape shifts towards a more senior population, the role of family caregivers in dementia management is expected to become increasingly vital (Xiao et al., 2014). In the coming years, the primary responsibility for caring for elderly individuals in Southeast Asia will primarily rest with family members (Kua, 2010). The growing number of older adults in Southeast Asia is leading to an increase in dementia cases, presenting significant challenges for both healthcare systems and families (Heese, 2015; Ng, 2010). Family caregivers in this region often face considerable difficulties, including limited training opportunities, financial pressures, and the emotional burden of watching their loved ones decline (Kua, 2010; Ng, 2010). This situation is especially evident in Indonesia, where there is a rapidly aging population and minimal formal support for families, particularly those caring for elderly individuals with dementia (OAWD). The need for financial support, healthcare, and institutional care is urgent, and addressing these challenges is essential (Turana et al., 2019).

Few studies attempt to inform the increase in the number of individuals affected by dementia, particularly in Indonesia. According to Prince (2015), the estimated number of dementia cases in Indonesia is projected to increase from around 1.9 million in 2030 to nearly 4 million in 2050. Differences in dementia diagnosis methods, as well as demographic, socioeconomic, and risk factors, may cause variations in the prevalence of dementia (Ong et al., 2021). Moreover, dementia as a disorder poses many challenges to health professionals throughout the entire care pathway, from early diagnosis to end-of-life (Igarashi et al., 2020). Formal providers may be involved for a short period and engaged to supplement or supplant the care provided by families and caregiving family members, either in a residential facility or at home (Qualls, 2016; Silverstein & Giarrusso, 2010). Thus, government recognition of the consequences of dementia is substantial in providing dementia care services and enabling the community to support older adults living with dementia (OAWD), including their family and caregivers.

Long-term care needs in older adults often arise from impairments in physical or cognitive abilities, particularly those experienced by individuals with dementia (Brodaty & Donkin, 2009; Chen & Lin, 2022). Notably, the caregiving role becomes increasingly demanding as the disease progresses over time (Huang et al., 2015). This role is often assumed by a close relative of the patient (typically a spouse or child) who is wholly dedicated to the provision of care. In low- and middle-income countries, such as Indonesia, where access to professional care is limited to a small proportion of cases due to its high cost and lack of coverage by public or private insurance, care is frequently shared among several family members (Hazzan et al., 2022; Park et al., 2022; Riffin et al., 2019). Moreover, the impact of caregiving on the negative and positive aspects of caregiving experiences is individualized and varies, depending on the diverse family and contextual characteristics. Family caregiving within the framework of routine family care, with associated costs and benefits across the lifespan (Qualls, 2016). Caregiving roles can change family priorities, lifestyles, and routines, potentially decreasing their quality of life (QoL) (Alqhtani et al., 2021; Irfan et al., 2017). Consequently, the cumulative demand for care by family carers may lead to community and government support to meet their various needs.

Despite the prevalence of informal caregiving, particularly among family caregivers, it is more common for a single person to take care of a dependent relative within the family, resulting in an overloaded task and potentially altering the family's functional dynamics. To better understand the caregiving experience among family caregivers, it is essential to recognize the structure of families, e.g., multiple generations or blended families, the type of relationship, and the provision of support. Dykstra and Komter (2012) stated that interdependencies between generations in families in aging societies primarily affect older persons, their economic situation, health, mobility, social integration, family support, and care. Understanding interdependencies between different generations in families, as noted by Mehta (2016), the relationships have multi-directional patterns of exchange that affect the quality of intergenerational relations, i.e., objective indicators have often been used to measure the closeness of the relationship, such as the frequency of contact or the geographical distance between parents and their children. The subjective criteria of relationship quality focus on the subjective perception and evaluation of the relationship between parents and children by each partner. Therefore, changing family structures necessitates studying family caregivers, especially those living with OAWD, to explore daily interactions and support practices within families.

While informal caregiving is common, especially among family members, there is still much to learn about how dementia caregiving impacts family life. Bengtson (2001) noted that the characteristics of family structure have fostered greater intergenerational reliance on fulfilling family roles, including caring for dependent elders, which can lead to adverse effects due to prolonged shared lives across generations. One under-researched area is the reciprocal influence between parents and children during dementia caregiving, particularly regarding the experiences and interactions of family caregivers in an Indonesian setting. Changes such as the shift from extended to nuclear families, increased migration, urbanization, heightened use of elder care facilities, and new views on filial responsibilities illustrate significant shifts in family dynamics and structure concerning Indonesian elder caregiving (Qibthiyyah & Utomo, 2016).

Furthermore, rising divorce rates, changing marital trends, and smaller households have led to an increasing number of elderly individuals living apart from their children, relying on non-cohabiting support, and experiencing a gradual decline in the quality and consistency of familial care (Qibthiyyah & Utomo, 2016; Schröder-Butterfill, 2004). Thus, a deeper understanding of the experiences of family caregivers for individuals with dementia may drive research focused on the current landscape, knowledge, and crucial elements required to tackle the evolving needs of Indonesian families caring for loved ones with dementia at home.

This study examines the lived experiences of family interaction between the family caregiver of the OAWD and other family members, focusing on both positive and negative influences on dementia caregiving within the Indonesian family context. Addressing the limited understanding of family caregivers' experiences, the sociopolitical and cultural limited resources and support they face in Indonesia will affect the ability of families to provide care for their family members during illness, particularly dementia. Examining how family caregivers of OAWD and other family members experience the challenges and adaptation in family interaction within the context of providing caregiving to OAWD at home is essential to understanding their experience, particularly in the phenomenological analysis and practical implications in improving family interaction among family caregivers and other family members of the OAWD in Indonesian cultural context.

Theoretical framework

A framework for understanding family interactions among family caregivers of the OAWD and other family members was developed based on the theory of the Social Construction of Reality by Berger and Luckmann (1991), which views everyday life as an intersubjective reality within the social interaction experience. The fact that everyday life, shared with others, occurs face-to-face and is viewed as a distinct social interaction experience, separate from other situations. Moreover, the phenomenology of Berger and Luckmann primarily aims to re-establish the social construction of reality; namely, subjectivity is comprehended as a phenomenon constructed collectively from interaction. The concept of intersubjectivity is understood as the meeting, by the subject, with another consciousness that continues to constitute it and is not limited to a face-to-face encounter. However, it expands in all dimensions of social life (García, 2015). Following this, family interaction collectively constructs realities through socialization, internalization, and externalization, which includes how family caregivers of the OAWD and other family members create, maintain, and share understanding in daily caregiving activities at home.

The second analytical foundation is family interaction, which signifies that the engagement among family members shapes their relationships. Additionally, these interactions help create a mental model of family life, highlighting the interdependence and collective nature of families across generations (Fitzpatrick, 2004; Fitzpatrick & Ritchie, 1994; Zhang & Jean Yeung, 2012). In this context, each family member develops their perceptions, shaping their reality based on both internal and external experiences derived from interactions with others. Several explanations exist regarding the interactions between older and younger generations, particularly concerning chronic illnesses such as dementia, which can affect the health of all family members (Ashida & Schafer, 2015; Barnes et al., 2020; Binda et al., 2018). McCauley et al. (2021) also noted that family caregivers often feel unsupported by other family members, complicating their adjustment to caregiving demands. Therefore, it is essential to examine the relationship between family interaction and family caregiving in the context of dementia.

Indonesian family context

Cultural factors significantly influence caregiving dynamics. Involving family in care plans and providing support for caregivers is crucial for effective coordination (Wang et al., 2019). These cultural values impact experiences across different ethnic groups, shaping obligations, responsibilities, and decision-making processes (Tran et al., 2023). Beard and Kunharibowo (2001) emphasized that co-residence is the prevalent arrangement, benefiting both elderly parents and their adult children in Indonesia. Keasberry (2001) noted that a substantial number of older adults in Yogyakarta, a province with a large elderly population, reside near their children, thereby ensuring caregiver accessibility. Likewise, Johar and Maruyama (2011) and Setiyani and Windsor (2019) observed that elderly parents tend to choose to live with their children, particularly their daughters, for support. This situation increases the demands of informal caregiving as there are more older individuals compared to younger ones, particularly those who are disabled and elderly individuals living longer. Consequently, long-term family support for elderly care in Indonesia is rooted in filial piety and caregiving norms among family members.

Methods

Study design, research site, and process of recruitment

This study conducted a qualitative investigation using a phenomenological research design. Phenomenology, as a qualitative research approach, offers profound insights into the lived experiences of individuals, enabling researchers to grasp the meanings and perceptions that influence someone else's reality (Pascal et al., 2010). By focusing on participants' subjective experiences, phenomenology aims to uncover the significance that individuals ascribe to their lives (Groenewald, 2004). This methodology is particularly advantageous for exploring family dynamics involving caregivers and relatives of older adults with dementia, where understanding daily complexities, emotional challenges, and adaptive strategies is crucial for grasping the caregiving experience. Moreover, by focusing on the lived experiences of caregivers, this approach provides a comprehensive perspective on the emotional, social, and practical challenges they face (Nowell et al., 2017). Therefore, this method offers researchers valuable insights into participants' perspectives.

The selection of a research site in Yogyakarta Province, which has a high percentage of older adults—15.52%—is compared with other provinces. Rural and urban areas were selected based on consultations with local officials and health cadres, who informed the principal investigator about the health status, lifestyles, and awareness affecting dementia prevalence among older adults (BPS-Statistics Indonesia, 2021). This research involves fieldwork in two areas: rural families in Kulon Progo, Bantul, and Gunungkidul Regencies, as well as urban families in Sleman Regency and Yogyakarta City.

The recruitment process began by distributing information through posters, letters, and messages via social media, WhatsApp, email, and telephone to local organizations in the Yogyakarta region, including the Alzheimer Indonesia (ALZI) community and the Older People's Forum under the Provincial Health Office and the National Population and Family Planning Agency (BKKBN). The researcher is identifying and addressing potential barriers that may prevent respondents from participating in this research by outlining the study objectives, detailing the study risks and benefits, and reviewing formal MUSSIRB-designed consent materials with respondents before requesting their consent via phone, WhatsApp text, or in person.

Families with OAWD residing at home with a clinical diagnosis of dementia, indicating any subtype and various stages, and living together at home with their family caregivers, were invited to participate. Additionally, family members in one household or a nuclear family are often involved in the caregiving and support of the family caregiver of the OAWD. Another inclusion criterion for the sampling is that the respondent is 18 years or above, lives in urban or rural areas in Yogyakarta, and can provide informed consent to the researcher when conducting home visits for a one-on-one interview, as well as complete the interview. The exclusion criterion involved respondents who had relocated, were ill, could not continue their caregiver roles, or could not be interviewed. The potential respondents who agreed and were willing to participate in the research proceeded with a one-on-one interview, followed by follow-up correspondence, such as participant information and informed consent. The researcher then confirmed eligibility and arranged a suitable time for the interview.

Given that sample size is a consideration for data saturation, the researcher implemented recruitment strategies aimed at recruiting 15 family caregivers and 15 family member dyads within a single family or household. Potential respondents received a letter stating the study's intentions and modalities of privacy and confidentiality. Maintaining respondents' personal information ensures consistency throughout the research process, from recruitment to data collection and the final report. This study was approved by the Mahidol University Social Sciences Institutional Review Board with Certificate of Approval No. MUSSIRB 2023/037.

Data collection and analysis

Data collection was conducted in two phases. The first phase, the recruitment process, emphasizes obtaining a sufficient proportion of respondents who meet the inclusion criteria and can participate in the entire research process. The second phase, the interview stage, begins with the respondent providing informed consent before proceeding to the interview phase. The interview length for a single session is 60 minutes, using an interview guide. Considering the family interview, specifically the family caregiver of the OAWD and their family members during family interactions in their caregiving role at home, a conflict of interest may arise due to the family dynamics of the entire family. Accordingly, the interview process has been divided into four sets of interviews: two with family caregivers and two with family members who meet the inclusion criteria.

All those interviews were conducted separately, and the researcher chose the time and place as a research procedure to address a potential conflict of interest during the one-on-one interviews. From the choice of data collection, interviews were recorded and transcribed for later coding and analysis. Due to the data being collected in Indonesian, the principal investigator produced a precise English translation for the benefit of other researchers. This translation aims to reflect the structure and format of the Indonesian language while also considering the relevant cultural nuances. The principal investigator verified the accuracy of each transcript. The principal investigator conducted interviews until a consensus was reached with other researchers that data saturation had been achieved. Data collection occurred from April to September 2023. As Indonesia moves from the COVID-19 pandemic to an endemic phase, data collection must be flexible and adaptable. The principal investigator emphasizes the need to understand caregiver experiences and challenges by providing communication through mobile phones and WhatsApp to obtain informed consent before scheduling one-on-one interviews. Ethical considerations and data privacy remain crucial in this process. This approach enables researchers to gather real-time data about respondents while complying with social distancing guidelines.

The researcher employed thematic analysis to highlight and interpret broader constructs within a complex social context. Thematic analysis, as employed by Sundler et al. (2019) in phenomenological research, was used to identify meaningful patterns within the descriptions and narratives of the data regarding the informant's lived experiences. This analysis begins by identifying themes; the authors emphasized that the selected extracts should provide a vivid and compelling account of the arguments associated with each theme. The principal investigator identifies themes by continuously reading and re-reading each respondent's transcript. The researcher continued to compare the emerging meanings from the codes and categories that could support an interpretation of respondents' experiences of family caregiving for the OAWD at home (Braun & Clarke, 2006). The research team concentrated on validating the identified themes and subthemes. To ensure the trustworthiness of the data, we adhered to the guidelines set by Sundler et al. (2019) by maintaining an extensive codebook that documented categories, themes, subthemes, and the decisions made during ongoing analysis. We achieved data triangulation through coding audits, detailed reviews, and a collective agreement among the team on the findings and themes.

Results

The respondent's characteristics

In this research, fifteen families participated in a qualitative study consisting of two interviews with family caregivers and two interviews with family members. All families are integrated into regional and national socioeconomic structures and continue to rely on local trade, agriculture, and service sectors as their primary sources of income. Several families differ in the extent of their family support networks, particularly in terms of migration, which provides financial support to help families with limited funds during the provision of long-term care for older adults with dementia at home. Findings were combined for family caregivers and family members' dyads, where similar themes emerged in the data. The characteristics of the respondents are shown in Table 1 as follows:

Table 1: Characteristics of the Respondents (*N* = 15)

	Characteristics of Family Caregiver *N* (%)	**Characteristics of Family Member** *N* (%)
Gender		
Male	4 (27%)	2 (13%)
Female	11 (73%)	13 (87%)
Age in years, mean (SD)	54.3 (13.4) Range (29–84)	39.26 (10.7) Range (24–70)
Between 19–25 years old	-	1 (7%)
Between 26–35 years old	1 (6.67%)	6 (40 %)
Between 36–45 years old	4 (27%)	3 (20%)
Between 46–55 years old	3 (20%)	4 (26%)
Between 56–75 years old	6 (40%)	1 (7%)
Between 76–85 years old	1 (6.67%)	-
Marital Status		
Never married	2 (13%)	1 (7%)
Married	13 (87%)	14 (93%)
Education		
Primary	2 (13%)	-
High School	3 (20%)	4 (27%)
Diploma	2 (13%)	2 (13%)
Bachelor Graduate	8 (53%)	9 (60%)
Occupation		
Full Housewife	9 (60%)	7 (46%)
Retired Staff	3 (20%)	-
NGO or private staff	-	5 (33%)
Government staff	1 (6.67%)	1 (7%)
Food seller and farmer	1 (6.67%)	-
Honorary Teacher	1 (6.67%)	-
State-owned enterprise	-	1 (7%)
Part-timer	-	1 (7%)

	Characteristics of Family Caregiver *N* (%)	Characteristics of Family Member *N* (%)
Place of Residence		
Rural	9 (60%)	9 (60%)
Urban	6 (40%)	6 (40%)
Relationship to the OAWD		
Husband	2 (13%)	-
Wife	5 (33%)	-
Son/Daughter	4 (27%)	11 (73%)
Son/Daughter-in-law	4 (27%)	3 (20%)
Grandchildren	-	1 (6.67%)

Note: A family caregiver provides full-time care for an older adult with dementia (OAWD), while a family member supports the caregiver. They are different individuals within the same family.

Given these demographics, it is not surprising that many individuals find themselves caring for an older adult family member across various family structures, such as spouse caregivers, parent-child relationships, adult children, relatives, or grandchildren. Generally, wives serve as caregivers for older adults with dementia (OAWD), while sons or daughters support the primary caregiver in caring for the OAWD at home. Caregivers are predominantly female in both areas (11 females overall). On average, family caregivers are 54 years old, while family members are 39 years old. Both family caregivers and family members appear to be married and educated, with most having completed bachelor's degrees. Among various occupations, 60% of family caregivers and 46% of family members are full-time homemakers.

The data revealed six key themes: defining knowledge and duty of care, enhancing effective communication, various forms of mutual support, combining decision-making processes, utilizing support groups, and securing financial assistance. In the respondent's statement, the family caregiver's initials are 'R,' and the family member's initials are 'M'.

Theme 1: Defining knowledge and duty of care

Before the dementia diagnosis, caregivers had mistaken the early symptoms of dementia for several different anomalies, such as depression and dementia being a normal outcome of aging. As a family member (M11) and family caregiver (R14) shared:

> *"When my father was first sick, I was shocked and did not understand at all that he was sick. I do not know exactly what the initial cause was. I was not strong enough to deal with the changing conditions at that time."*
>
> (M11, Daughter, 33 years old)

> *"When my father got sick in the first phase, I did not understand his behavioral changes. My mother, who was sometimes impatient, would talk to him in a high tone. That happens quite often, and I sometimes felt confused about how to respond to these situations."*
>
> (R14, Daughter, 24 years old)

This study revealed that family caregivers gained a deeper understanding of dementia and caregiving for older adults with dementia (OAWD) after assuming their roles as full-time caregivers, as reflected in:

> *"After seven years of treating OAWD, we are now at the stage of observing changes in the condition and continuing efforts to slow its progression. At the very beginning, I was perplexed because I had no idea that my husband had Alzheimer's."*
>
> (R1, Wife, 44 years old)

Furthermore, family caregivers and members report that caregiving for the OAWD is undertaken without question due to the embedded norms and values within the family, including those rooted in religious teachings, such as the obligation of children to be devoted to their parents and care for a sick spouse as a form of worship. This responsibility represents an internalized behavior for the respondents, as family members (M13) and family caregivers (R3) explained:

> *"As an only child, taking care of my father is my responsibility and a form of worship. After my mother died, my father's condition declined. I try to fill my wife's role when I have a day off, especially when my father needs to shower. However, my wife is his daughter-in-law, so some tasks do not seem appropriate for her. Now, we also have a trained male part-time caregiver who assists my father."*
>
> (M13, Son, 49 years old)

> *"I decided to take care of my wife because, at that time, after she had an operation, she needed attention. I did this consciously and sincerely because she raised our three children very well. If I view it as an act of worship, hopefully, I will receive good things in my life, too."*
>
> (R3, Husband, 72 years old)

Respondents have attempted to familiarize themselves with the signs of dementia so that they can respond respectfully and caringly. This effort requires routine assistance from other family members. Determining family norms and values, as well as acceptable interactions and involvement patterns in caregiving tasks, necessitates integration within the family.

Theme 2: Enhancing effective communication

Caregivers shared experiences about their family's communication. Many individuals felt guilty and had low self-esteem, which hindered effective communication with their relatives. Some also reported interpersonal communication failures. Busy lives often limit family members' time for meaningful conversations, leading to a breakdown in communication and interaction. The following statements illustrate this:

> *"I do not want to burden my children with my issues since they have their responsibilities. If it's not important, I don't mention it. They understand, especially when I appear to be struggling."*
>
> (R11, Wife, 62 years old)

> *"My children and I sometimes misunderstand one another. Even my son, who lives nearby, has to find time to visit. We rely on cellphones and a family WhatsApp group; communication is slow because everyone is busy."*
>
> (R3, Husband, 72 years old)

> *"I have five siblings, but it seems they either don't think about my mother or don't live near our parents. When my mother was hospitalized, I often felt alone and repeatedly visited the hospital by myself. My wife reached out to my siblings, but they didn't respond."*
>
> (M15, Son, 47 years old)

These statements indicate that each of them willingly accepted the fluctuations that accompany caregiving and generally upheld the importance of communication, even as they faced barriers within the family by adapting to various situations.

Theme 3: Various forms of mutual support

In such situations, a few female caregivers stated that their daily routine work makes them physically and mentally tired. Several respondents also said that if they could still handle their OAWD conditions, they asked for assistance from outside family members for household needs, such as helping clean the home environment, as described by the following statements:

> *"I felt reluctant and afraid of troubling my parents. Finally, I found the courage to share my story and ask for help. I could reach out if I were tired, knowing they were ready to give or seek help. It comforts and strengthens me to this day."*
>
> (R1, Wife, 44 years old)

> *"I adjusted to my exhausting daily work and motherhood. After discussing with my husband, we decided to invite an assistant to handle house cleaning, allowing me to focus on other activities, like helping my children with their studies."*
>
> (R13, Daughter-in-law, 43 years old)

Meanwhile, they also described how the lack of support and care within the family contributes to negative interactions with husbands, children, and other family members. They strive to build mutual understanding, as supported by the following statements:

> *"...just be grateful we can share honestly about our difficulties. Sometimes, I can't understand my brother's condition as the primary caregiver for our father (OAWD), and we get angry with each other. However, I always call or come directly when he needs help to take care of our father."*
>
> (M11, Daughter, 33 years old)

These statements suggest that a lack of support or care among family members often leads to conflict and misunderstandings, which in turn create tension and strain their relationships.

Theme 4: Combining decision-making processes

Family caregivers reported different experiences related to decision-making and involving family members in decisions regarding the long-term treatment of OAWD at home. Treatments for OAWD are often complicated, involving diagnoses of cognitive impairment, frailty, and comorbidities. One caregiver mentioned:

> *"We negotiate, for instance, if my wife's control time is up and there is medication available. We agree that a qualified medical professional should prescribe the medicine. The same goes for the memory doctor; certain simulations can help delay the disease."*
>
> (R2, Husband, 72 years old)

Family members' willingness to be involved in decision-making with family caregivers varies, and each experience carries the risk of conflict among family caregivers and family members, potentially undermining the goals of shared decision-making. Moreover, younger siblings sometimes seek advice from their older siblings, especially regarding the care of their parents. One family member shared:

> *"Mother's care costs about 8 to 9 million rupiah monthly. I separate accounts to access funds from relatives who send money for her needs. I inform and consult my older siblings on crucial decisions regarding her treatment."*
>
> (M5, Daughter, 48 years old)

The experiences of these respondents indicated that they valued the involvement of family members in decision-making, which includes participation and collaboration in addressing needs and providing support related to the caregiving process at home.

Theme 5: Utilizing support groups

Transcripts indicate that numerous individuals find support groups helpful in alleviating stress as caregivers. During the pandemic, social media support groups have become increasingly popular, offering caregivers a space to share experiences, express feelings, and access information to enhance their understanding, unwind, and come to terms with their circumstances, as shown in the following statement:

> *"I'm grateful for my daughter, who helps when I am struggling with her mom (OAWD). I relieve my fatigue by playing computer games and participating in the WhatsApp chat group from ALZI, which shares valuable information about dementia, including events with specialists and meetings for caregivers. Sometimes, I took my wife to those meetings if her condition allowed it."*
>
> (R3, Husband, 72 years old)

Family caregivers and relatives share their experiences to foster optimism, showing that the present circumstances are an improvement from the past and that numerous challenges faced by OAWD can be tackled.

Theme 6: Securing Financial Assistance

Various concerns expressed by caregivers hindered their ability to care for older adults with dementia (OAWD). The economic situations of caregivers vary; those with sufficient funds can cover the daily needs of OAWD, including routine medications and physiotherapy. Families with limited treatment budgets try to utilize health insurance, and when that is insufficient, they share the financial burden among family members. Often, children contribute financially to their parents' living and treatment expenses, especially since they are unable to work or retire, as supported by the following family caregiver and family member statement:

> *"My children show initiative. For instance, when my son sends packages, he includes vitamins, occasional medicine, and essential oils for my husband (OAWD) and me. I'm grateful that my children, despite having their own families, still think of me and their father."*
>
> (R11, Wife, 62 years old)

> *"I support my father regarding my grandmother's health care. My parents rely on income from market sales and our home shop. After COVID-19, it has been challenging, but I can work at a clinic to help pay for grandma's medicine and health insurance registration."*
>
> (M7, Daughter, 29 years old)

The experiences of these respondents indicated that both family caregivers and members share the responsibility for funding medical care and addressing the daily living needs of the OAWD while also supporting caregivers in fulfilling those needs.

Discussion

The findings highlight the various challenges and adaptations in family interaction experiences when providing care for older adults with dementia at home. Most families in this study had established rules and strategies to manage different roles and tasks while caring for the OAWD. However, during the COVID-19 pandemic, respondents noted that many of these rules and strategies were modified to meet the needs of family caregivers and other members in managing the distribution of caregiving tasks and commitments. It is essential to understand how family interaction experiences among caregivers and other family members develop processes and foster intersubjectivity by creating interactions centered on mutual intention, shared focus, and emotions related to dementia caregiving at home. Interactions between family caregivers and relatives support long-term adaptations, including a shared understanding of dementia caregiving. Respondents observed that family dynamics felt strained due to perceived differences in support, both in time and effort. Furthermore, findings emphasize caregivers' awareness of their burden, which encompasses the challenges and negative dynamics they experience, reflecting the reciprocal nature of daily interactions in dementia caregiving.

As research unfolds, family institutions evolve, with caregivers assuming an increasing responsibility for OAWD. This discussion examines how this shift influences family dynamics. Findings indicate that caregiving for OAWD at home is often burdensome, affecting both the individual's life and the well-being of their family. Challenges arise from complex interactions between caregivers and family members, highlighting that care varies depending on the circumstances. Care tasks encompass daily living activities (ADLs), such as bathing and feeding, as well as instrumental activities of daily living (IADLs), including shopping, transportation, and managing finances. Emotional and instrumental support for caregivers encompasses various activities, even as family members hold differing views on illness, striving to find a balance that suits each individual. Therefore, addressing these challenges is crucial for delivering personalized support and alleviating the burden on caregivers and family members.

The findings also suggest that becoming a caregiver often leads to the formation of a new identity, which significantly impacts family interactions. As caregivers adopt this role, their sense of self and family dynamics can undergo significant changes (Cooper, 2021). Caregivers may face role conflict, particularly when balancing caregiving responsibilities with employment or caring for children, which can have a significant impact on families, both emotionally and financially. Caregiving is individualized, with unique pressures, obligations, expectations, and circumstances shaping roles and caregiver identity (Daley et al., 2018). This identity shift can alter communication, leading to disagreements and misunderstandings (Moore & Gillespie, 2014). Understanding these changes is crucial to recognizing the diverse and evolving needs of caregivers and family members throughout their journey. Interviews with respondents reveal that caregiving responsibilities primarily fall to spouses, daughters, and daughters-in-law, while sons and grandchildren handle the remaining tasks.

The interviews also suggest that entrenched cultural values, particularly in Javanese culture, influence family norms by emphasizing family unity and mutual support while fostering loyalty, obligations, and responsibilities among family members. These norms, internalized as a collective understanding within the family, govern its functioning and decision-making processes, thereby impacting family dynamics and caregiving roles. These insights support previous research by Kristanti et al. (2019), which suggested that caregiving duties are influenced by cultural values rooted in family norms in specific cultures, acknowledging the socialization processes that drive actions, processes, and outcomes for both caregivers and the entire family.

Few respondents reported effective communication among family members during the long-term treatment of OAWD, leading to positive interactions and support in caregiving. Examples showed that family caregivers managed tasks and daily life well due to this conducive communication, fostering positive ties. They also utilized online applications like WhatsApp for video calls, facilitating real-time interaction. Respondents noted that social media aids prompt information sharing, helping family caregivers update on OAWD’s status, including eating habits, medication adherence, and interactions with distant relatives. This highlights ongoing communication that fosters a shared understanding of OAWD needs and collaborative caregiving efforts. Numerous studies support the idea that family communication allows members to express their needs and resolve common issues (Fitzpatrick, 2004; Zhang & Jean Yeung, 2012).

Moreover, effective communication among family members fosters practical problem-solving, strengthens emotional bonds, and enhances intimacy. This process shapes their relationships and allows them to develop a mental framework of family life, emphasizing interdependence and the family’s collective nature across generations (Friedemann & Buckwalter, 2014; Galvin & Braithwaite, 2014). Examining family communication from a phenomenological perspective highlights caregiving as a relational activity that develops within familial settings, where family caregivers and other members work together and negotiate care practices. This intersubjective communication experience enables individuals to engage in daily life with greater awareness and attention, particularly in their daily routine activities, which ultimately presents others as they truly are. This experience also acknowledges the dynamic communication between family caregivers and other family members by creating a shared understanding of the OAWDs’ needs and engaging in a collaborative effort that contributes to problem-solving strategies, shaping a unique process of family interactions.

The results of this study suggest that, although the family caregiver and other family members also experienced negative interactions, they value feelings of togetherness facilitated by common trust, which can help family members adapt positively to stressful OAWD caregiving situations. It is suggested that family caregivers and other family members collectively share complicated feelings and maintain connectedness despite heightened negative interactions within the family. For instance, they utilize family meetings or gatherings to enhance positive communication through leisure activities, i.e., eating together, leading to improved everyday family support. Numerous qualitative studies carried out in diverse contexts (Grevenstein et al., 2019; Stevenson et al., 2022) have demonstrated that when a family member is ill, it strengthens the bonds within the family and that family support is crucial in mitigating the negative impact of stress because the illness affects the entire family as a whole, especially in collectivist cultures. Families also enhance well-being by encouraging a sense of involvement and connection (Thomas et al., 2017). Therefore, it may contribute to a better understanding and promote dialogue that can enhance mutually supportive family interactions.

Returning to Berger and Luckmann's (1991) theoretical framework enables us to understand intersubjectivity in mutually supportive family interactions, where family caregivers and other members coordinate on dementia caregiving tasks. They create a process to communicate and develop a shared understanding of their experiences while providing care for the OAWD. They also share a purpose related to dementia caregiving as part of their mutual understanding by paying attention to everyday challenges in OAWD behavior and the progression of the disease. Furthermore, caregivers describe a dynamic where the needs of care recipients advance to a point that exceeds the caregiver's control and abilities. This realization seems to mark a turning point when caregivers may acknowledge their limitations in meeting the OAWD needs.

Additionally, caregivers often describe coping with escalating needs by taking on more responsibilities until they can no longer function effectively and require support from other family members. Collaboration between family caregivers and other relatives, built on trust, fosters a sense of togetherness that promotes positive family interactions and relationships. Thus, nurturing, supportive family interactions influence positive adaptation, care needs, and family functioning during caregiving for older adults with dementia at home.

Conclusion

This study highlights the perspectives of family caregivers and family members on the challenges they face in their daily interactions and the adaptations they make in caring for individuals with dementia at home. Challenges associated with changes in the family communications between family caregivers and family members influence the management of caregiving tasks, including shared roles and responsibilities. The findings of adaptations in family interactions within the family address ways to enable supportive involvement in the family, utilizing resources that can facilitate family members' positive adaptation to stressful and demanding OAWD caregiving situations within the overall caregiving experience.

Moreover, it is an essential recommendation for policies to take into account the dynamics of family interactions and provide a platform for initiating support for families with parents or relatives who have special health needs, particularly dementia. The implementation needs to consider partnerships between the government and stakeholders, including local authorities and local organizations, such as the ALZI Community and the Older Peoples' Forum, in mainstreaming family and older adults into national policy, strengthening governance, and enhancing institutional capacity for the wider public and political actors in Indonesia.

Although this research provides considerable insight into the perspectives of family caregivers and family members on their roles as caregivers of the OAWD and their daily experiences of interaction with other family members, the limitations should be addressed. This limitation suggests a risk of selection bias, as the duration of living with and providing care for an individual with dementia, as well as the stage of the disease, may also influence the experiences reported by respondents. Research designs that employ phenomenology rely on subjective experiences, which complicates the generalization of findings to broader Indonesian populations. To address this limitation, future research should adopt a nationwide quantitative approach to deepen understanding of this topic.

Future research must validate the findings from this study in clinical settings. For instance, will therapy enhance family interaction and caregiving, benefiting both individuals with dementia and their caregivers? This research could help map interventions in health social practices by considering family dynamics when designing family-based strategies to improve interaction quality across diverse populations, locations, and ethnicities in Indonesia. Such studies should be integrated with existing elderly care policies to address the care needs and well-being of older adults and their families in various Indonesian cultures.

Acknowledgments

The author(s) received financial support for the research of this article partially from the Faculty of Graduate Studies, Mahidol University. In addition, the authors would also like to thank the respondents for their voluntary participation in this research.

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