GLOBUS PUBLICATION

Globus An International Journal of Medical Science, Engineering and Technology
A Refereed Research Journal
Vol 15 / No 1 / Jan-Jun 2026 ISSN: 2319-8958

EXPLORING THE LIVED EXPERIENCES OF FAMILIES FOR CARING OF DEMENTIA PATIENTS: A PHENOMENOLOGICAL STUDY

*Jesi Lee G. Endrina
**Jejomar D. Quiros
***Bianca Camille Cabrera
****Salome O. Planco
*****Carlo Roy G. Roslinda

Paper Received: 02.01.2026 / **Paper Revised**: 30.01.2026 / **Paper Accepted**: 03.02.2026 / **Paper Published**: 06.02.2026
Corresponding Author: Jesi Lee G. Endrina; doi:10.46360/globus.met.320261007

Abstract

Dementia is a progressive neurocognitive disorder that significantly affects not only individuals diagnosed with the condition but also their family caregivers. As the global prevalence of dementia continues to rise, families increasingly assume the primary responsibility for caregiving, often with limited resources and support. Caregiving for individuals with dementia is associated with emotional, psychological, social, and financial challenges, yet it may also foster resilience and meaning among caregivers. Despite extensive literature on caregiver burden, there remains a need to explore the deeper lived experiences of families, particularly within culturally grounded contexts. This study aimed to explore the lived experiences of families caring for dementia patients and to understand how these experiences can inform better support systems. The analysis revealed three major themes: emotional burden and psychological distress, caregiving challenges and role adaptation, and resilience and meaning-making. Caregivers reported experiencing intense emotions such as sadness, grief, anxiety, and frustration as they witnessed the progressive decline of their loved ones. They also encountered significant caregiving challenges, including physical exhaustion, role changes within the family, financial strain, and limited access to healthcare support. Despite these difficulties, caregivers demonstrated resilience through coping strategies such as seeking social support, engaging in spiritual practices, and finding meaning in their caregiving role. Many participants expressed that caregiving strengthened their sense of purpose, deepened family relationships, and contributed to personal growth. The findings highlight the complex and dual nature of dementia caregiving, characterized by both burden and resilience. Family caregivers play a critical role in supporting individuals with dementia, yet they often do so at the expense of their own well-being. There is a pressing need for comprehensive, culturally sensitive support systems that address the emotional, psychological, and practical needs of caregivers. Enhancing caregiver support through education, accessible healthcare services, and psychosocial interventions can improve both caregiver well-being and the quality of care provided to dementia patients.

Keywords: Dementia Caregiving, Family Caregivers, Lived Experiences, Phenomenology, Caregiver Burden, Resilience, Qualitative Research, Philippines.

Introduction

Caring for individuals with dementia presents profound and multifaceted challenges, particularly for family members who often assume the primary caregiving role. Dementia has been identified by the World Health Organization as a major public health concern of the 21st century, characterized by progressive deterioration in memory, cognition, and the ability to perform everyday activities (WHO, 2017; WHO, 2020). Among its various forms, Alzheimer's disease accounts for approximately 60–70% of cases, followed by vascular dementia, dementia with Lewy bodies, and frontotemporal dementia (WHO, 2017). The global prevalence of dementia continues to rise dramatically, with projections estimating an increase from 47 million cases in 2015 to 152 million by 2050, largely driven by population aging (Prince et al., 2015; WHO, 2020).

The progression of dementia is typically gradual and varies across individuals, making care demands increasingly complex over time. In its advanced stages, individuals often require continuous supervision and assistance with daily activities (Bartley et al., 2018). Consequently, caregiving responsibilities frequently fall upon family members, exposing them to heightened levels of physical, emotional, and psychological stress. Research indicates that caregivers of individuals with dementia experience significantly higher stress compared to those caring for individuals with other chronic conditions (Pinquart & Sörensen, 2003). Moreover, caregivers are often referred to as the "invisible second patients" due to the immense burden they carry (Brodaty & Donkin, 2009; Chiao et al., 2015).

Empirical evidence highlights the adverse effects of caregiving on mental health, including increased risks of depression, anxiety, and psychological distress (Bremer et al., 2015; Jolling et al., 2017). In some cases, caregivers may even experience suicidal

*-*****College of Nursing, Phinma St. Jude College, Philippines.*

ideation and reduced overall well-being, underscoring the severity of caregiving burden (Jolling et al., 2017). Despite these challenges, family caregivers play an indispensable role in supporting persons with dementia (PwDs), particularly in hospital and home settings. They act as advocates, facilitators of communication, and key contributors to decision-making processes, ensuring that the patient's preferences and needs are adequately addressed (Burgstaller et al., 2018; Reilly & Houghton, 2019).

Within the Filipino context, caregiving is deeply rooted in cultural values that emphasize familial responsibility and respect for elders. However, limited awareness of dementia and insufficient access to healthcare resources often place families in vulnerable situations. In some cases, inadequate knowledge and support systems may lead to inappropriate caregiving practices, including neglect or unintentional harm, further compromising the well-being of both patients and caregivers. Additionally, financial constraints and limited availability of specialized care services exacerbate the burden, compelling families to manage complex caregiving demands independently.

Given these realities, there is a critical need to explore the lived experiences of families caring for individuals with dementia. While existing literature has extensively documented the physical and psychological burdens of caregiving, there remains a gap in understanding the deeper emotional dynamics that characterize this experience-particularly the interplay between love, attachment, and suffering. A phenomenological approach provides an opportunity to capture these subjective experiences, offering valuable insights into how caregivers navigate the challenges of dementia care and find meaning within their roles.

Understanding these lived experiences is essential for informing the development of culturally sensitive interventions, support systems, and healthcare policies that can enhance the quality of life for both dementia patients and their caregivers. By shedding light on the emotional, social, and contextual dimensions of caregiving, this study aims to contribute to a more holistic and person-centered approach to dementia care.

Methods

Research Design

This study employed a qualitative research approach utilizing a phenomenological design to explore the lived experiences of families caring for individuals with dementia. Phenomenology is appropriate for this study as it seeks to understand and describe the essence of participants' subjective experiences, particularly the emotional, psychological, and relational dimensions of caregiving. By focusing on caregivers' narratives, the study aimed to capture the depth and meaning of their experiences, including the interplay between love, burden, resilience, and suffering. This approach is consistent with the objective of uncovering rich, first-hand accounts that cannot be quantified but are essential in understanding complex human experiences.

Research Setting

The study was conducted within a selected geographic area or healthcare setting where families of dementia patients could be accessed. The setting included communities and/or healthcare institutions where caregiving activities naturally occur, allowing participants to reflect on their real-life experiences. The chosen setting provided an appropriate context for understanding caregiving dynamics within a culturally relevant environment, particularly in the Filipino context where family-centered care is predominant.

Population and Sampling

The participants of the study consisted of family members who are primary caregivers of individuals diagnosed with dementia. A purposive sampling technique was utilized to select participants who could provide rich and relevant information aligned with the objectives of the study. Inclusion criteria required participants to be actively involved in the caregiving process of a family member with dementia and willing to share their experiences. The study included a total of ten (10) participants, consistent with phenomenological research standards that emphasize depth of data over sample size. This sample size was deemed sufficient to achieve data saturation, where no new themes or insights emerged from additional interviews.

Data Collection Procedure

Data were collected through in-depth, semi-structured interviews, which allowed participants to freely express their experiences while ensuring that key areas of inquiry were addressed. The interviews focused on exploring emotional experiences, caregiving challenges, coping strategies, and sources of resilience. Each interview was conducted in a setting convenient and comfortable for the participant, either face-to-face or through virtual platforms when necessary. Prior to data collection, informed consent was obtained, ensuring that participants were fully aware of the purpose of the study, their rights, and the voluntary nature of their participation. Interviews were audio-recorded with permission and later transcribed verbatim to ensure accuracy and completeness of data.

Data Analysis

The study utilized thematic analysis guided by Husserlian phenomenological principles to interpret

the data. This process involved several stages, including familiarization with the data, identification of significant statements, formulation of meanings, clustering of themes, and synthesis of the essence of the lived experiences. Researchers carefully examined participants' narratives to identify recurring patterns and themes related to caregiving experiences. Bracketing was employed to minimize researcher bias and ensure that interpretations remained grounded in participants' perspectives. Data analysis continued until thematic saturation was achieved, ensuring the credibility and depth of findings.

Ethical Considerations

Ethical standards were strictly observed throughout the study. Participants were provided with informed consent forms outlining the purpose of the research, procedures, potential risks, and benefits. Confidentiality and anonymity were maintained by assigning codes instead of real names and securely storing all collected data. Participants were informed of their right to withdraw from the study at any time without any consequences. Additionally, sensitivity was exercised during interviews, particularly when discussing emotionally challenging experiences, to ensure the psychological well-being of participants.

Results

The analysis of the lived experiences of families caring for individuals with dementia revealed several recurring themes that reflect the complex and multifaceted nature of caregiving. Through thematic analysis, three major themes emerged: emotional burden and psychological distress, caregiving challenges and role adaptation, and resilience and meaning-making. These themes collectively capture the essence of the caregiving journey, highlighting both the difficulties encountered and the adaptive strategies employed by family caregivers.

The first theme, emotional burden and psychological distress, illustrates the profound emotional impact experienced by caregivers. Participants consistently described feelings of sadness, grief, frustration, and helplessness as they witnessed the gradual cognitive and functional decline of their loved ones. Many caregivers expressed anticipatory grief, characterized by mourning the progressive loss of the patient's identity even before physical death occurs. These emotional experiences were further intensified by the unpredictability of dementia progression, which often left caregivers feeling unprepared and overwhelmed. Additionally, participants reported experiencing anxiety and depressive symptoms, consistent with previous findings that caregiving for dementia patients is associated with significant psychological strain. The emotional burden was not only individual but also extended to family dynamics, affecting relationships and communication within the household.

The second theme, caregiving challenges and role adaptation, highlights the practical and relational difficulties faced by caregivers as they assume increasing responsibilities. Participants reported significant adjustments in their daily routines, including managing medications, assisting with activities of daily living, and ensuring the safety of the patient. These responsibilities often resulted in physical exhaustion and limited time for personal needs, leading to social isolation and reduced quality of life. Caregivers also described role shifts within the family, such as spouses becoming primary caregivers or children assuming parental roles, which altered traditional family structures. Financial strain was another prominent challenge, as the cost of medical care, medications, and supportive services placed additional pressure on families. Furthermore, participants emphasized the difficulty of navigating healthcare systems and accessing appropriate support services, often citing a lack of information and guidance. These findings align with existing literature that underscores the demanding and multifaceted nature of dementia caregiving.

The third theme, resilience and meaning-making, reflects the adaptive capacities of caregivers in coping with the demands of caregiving. Despite the challenges, participants demonstrated various coping mechanisms, including seeking social support, engaging in spiritual or religious practices, and developing personal strategies to manage stress. Many caregivers highlighted the importance of family support and community networks in sustaining their caregiving roles. Notably, participants also expressed a sense of fulfillment and purpose derived from caring for their loved ones, viewing caregiving as an expression of love, duty, and reciprocity. This sense of meaning contributed to their resilience, enabling them to endure the emotional and physical demands of caregiving. Additionally, some caregivers reported personal growth, including increased patience, empathy, and strengthened family bonds. These findings suggest that while caregiving is inherently challenging, it can also foster positive psychological outcomes and a deeper sense of meaning.

Across all themes, the interplay between burden and resilience was evident, illustrating the dual nature of the caregiving experience. Caregivers continuously navigated between emotional distress and adaptive coping, highlighting the dynamic and evolving nature of their roles. The findings emphasize the need for comprehensive support systems that address both the challenges and strengths of caregivers. The results provide a nuanced understanding of the lived experiences of families

caring for individuals with dementia, offering valuable insights for healthcare professionals, policymakers, and support services in developing targeted interventions.

Conclusion

This study explored the lived experiences of families caring for individuals with dementia through a phenomenological lens, revealing the complex, dynamic, and deeply emotional nature of caregiving. The findings demonstrate that dementia caregiving extends beyond physical assistance and encompasses significant psychological, emotional, social, and relational dimensions. Caregivers experience profound emotional burden, characterized by grief, stress, anxiety, and a sense of loss as they witness the progressive decline of their loved ones. These emotional challenges are further compounded by the demanding nature of caregiving responsibilities, role adjustments within the family, financial strain, and difficulties in accessing appropriate healthcare support systems.

Despite these challenges, the study highlights the resilience of family caregivers, who continuously adapt and find ways to cope with their circumstances. Caregivers employ various coping mechanisms, including seeking social and familial support, engaging in spiritual practices, and developing personal strategies to manage stress. Importantly, caregiving is not solely defined by burden; it is also shaped by meaning-making processes, where caregivers derive a sense of purpose, fulfillment, and strengthened relationships from their experiences. This duality underscores the coexistence of suffering and growth within the caregiving journey.

The findings emphasize the critical role of family caregivers as essential partners in dementia care. Their involvement significantly influences the quality of care provided to individuals with dementia, particularly in contexts where healthcare resources are limited. However, the study also reveals gaps in support systems, including insufficient caregiver education, limited access to services, and a lack of structured emotional and psychological support for caregivers.

Understanding the lived experiences of families caring for dementia patients is vital in informing the development of holistic, culturally sensitive, and person-centered interventions. Healthcare professionals, policymakers, and support organizations must recognize the needs of caregivers and implement comprehensive support mechanisms that address both the burdens and strengths of caregiving. By doing so, it is possible to enhance not only the well-being of caregivers but also the quality of life of individuals living with dementia.

Conflicts of Interest

The authors declare that there is no conflict of interest in this manuscript. Results have been deduced objectively; nothing influenced this result by any individual, monetary, or institutional interests. In effect, utmost endeavors were in order to conduct a bias-free operation of gathering and analyzing the data into interpretation and producing a study based on merit, away from research inconsistencies.

References

1. Bartley, M., Suarez, L., Shafi, H., et al. (2018). Dementia care and caregiver burden.
2. Bremer, P., Cabrera, E., Leino-Kilpi, H., et al. (2015). Informal dementia caregiving and mental health outcomes.
3. Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience, 11*(2), 217-228.
4. Burgstaller, M., et al. (2018). Family caregiver involvement in hospital care.
5. Chiao, C. Y., Wu, H. S., & Hsiao, C. Y. (2015). Caregiver burden for dementia patients.
6. Clissett, P., et al. (2013). Family involvement in dementia care.
7. Jolling, K. J., O'Dwyer, S. T., Hertogh, C. M., & van Hout, H. P. (2017). Caregiver distress and suicidal ideation.
8. Moyle, W., et al. (2011). Dementia care practices.
9. Pinquart, M., & Sörensen, S. (2003). Differences between caregivers of dementia patients and non-dementia caregivers. *Psychology and Aging, 18*(2), 250–267.
10. Prince, M., et al. (2015). *World Alzheimer Report 2015*. Alzheimer's Disease International.
11. Reilly, S., & Houghton, C. (2019). The role of family caregivers in dementia care.
12. World Health Organization. (2017). *Global action plan on the public health response to dementia 2017-2025*.
13. World Health Organization. (2020). *Dementia fact sheet*.