

ELDERLY SHELTER FORMAL CAREGIVERS' LIVED EXPERIENCES WORKING WITH DEMENTIA PATIENTS

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Abstract

Elderly with chronic conditions require specialized care and attention. With this, a caregiver is required to provide care and support. This qualitative research investigates the lived experiences of formal caregivers of dementia patients in an elderly shelter in Rizal, Philippines. With the growing prevalence of dementia, understanding the caregivers' perspectives is essential for improving care quality. Employing a phenomenological approach, the study explores caregivers' perceptions of their roles and responsibilities, challenges, and coping strategies. Several related studies reveal significant emotional and psychological stressors, including burnout and the impact of limited institutional support. The study underscores the importance of caregivers' well-being and the quality of care provided to dementia patients. By highlighting these, the study aims to provide insights about dementia research in the Philippines and contribute to new knowledge in the medical field to make way for possible projects and innovations the healthcare professionals may develop.

Keywords: Formal Caregivers, Dementia, Experiences.

Introduction

Alzheimer's disease is a type of dementia that has affected around 50 million people worldwide, with a projected rise in incidence in Asia Pacific (Tri et al., 2023). Dementia is a neurocognitive condition marked by a decline in cognitive ability beyond expected from biological aging. It disrupts daily functioning and social autonomy, severely affecting an individual's ability to perform daily activities, creating a pressing need for support systems, especially in countries like the Philippines. The Philippines is one of the low- and middle-income countries (LMIC) where almost 60% of dementia patients currently reside (Anlacan et al., 2024). Dementia requires particular care and attention for elderly because some can no longer function alone. Therefore, a caregiver is needed to support a range of tasks, particularly formal caregivers. According to Arsenault et al. (2021), there is a shift toward person-centered care (PCC) that caregivers use in an elderly shelter, which prioritizes individuals' unique needs and preferences. This method involves senior citizens in care choices and activities to improve their quality of life. Those who use this approach are formal caregivers who can help share their lived experiences and perceptions of duty in dementia care. Acton et al. (2024) stated that they are trained professionals who take care and support people with a wide range of needs, including cognitive disabilities and dementia.

To understand trends in caregivers' experiences within elderly shelters, it is vital to recognize their emotional and psychological hurdles. Research by

Lee et al. (2022) shows that caregivers frequently endure stress and burnout, affecting their well-being and care quality. The shift to person-centered care benefits both the elderly and caregivers, giving them purpose and fulfillment. However, this care requires proper training and resources, which many facilities lack. Caregivers' experiences vary based on institutional support, staff numbers, and workplace culture (Johnson et al., 2023). Understanding these factors can improve caregivers' experiences and care for dementia patients. Ongoing support and recognition are essential for a sustainable environment. Dementia affects an increasing number of people globally, and it is expected to double every 20 years (Tsai et al., 2021). Arsenault et al. (2022) highlight challenges in primary care for dementia, including symptom identification, knowledge gaps, and diagnosis uncertainty. Caregivers with severe forms, like neuropsychiatric symptoms (NPS), face negative factors like physical and mental illnesses, reduced function, dependence, low education, and increased workload, affecting their health. Research on dementia caregivers' burden is limited, despite efforts to understand the challenges they face (Tsai et al., 2021).

The World Health Organization (2023) predicts a significant rise in dementia, affecting 55 million people globally. Over 50% of these live in nursing homes and Residential Aged Care Facilities (RACFs) (Dementia Australia, 2023; Freedman et al., 2021). In Australia, the cost of dementia care in RACFs was \$4 billion in 2022 (Brown et al., 2022). Formal caregivers play a crucial role in providing clinical, emotional, and social support, but caregiving is linked to high stress and low job satisfaction (Costello et al., 2019). These outcomes impact the well-being of both caregivers and patients (Rajamohan et al., 2019). The WHO's Global Action Plan aims to double dementia research output from 2017 to 2025, addressing low productivity in regions like the Philippines, where only 1.1% of published articles focus on dementia (Anlacan et al., 2024). Santos' (2023) study emphasizes the family caregivers' role in maintaining patients' identity and calls for further research on formal caregivers' experiences in Rizal, Philippines.

Knowing the underlying issues, the objective of this study is to know how they perceive their duty, utilize their experiences, determine difficulties they experience, and apply strategies. Overall, it aims to address the problem statement and its underlying probing questions, potentially leading to valuable findings after conducting the study.

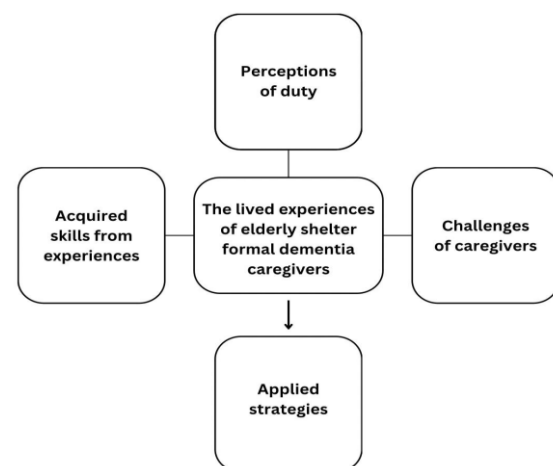
The study's findings could enhance medical research by revealing caregivers' experiences in elderly shelters with dementia patients. Healthcare providers can better understand caregivers'

challenges and strategies, enabling the provision of support activities. The university's Vision, Mission, and Goals aim to improve the quality of life for elderly dementia patients by acknowledging caregivers' contributions and addressing their challenges. This can improve the health and quality of life for dementia patients and contribute to the Sustainable Development Goals.

Conceptual Framework

The study's conceptual paradigm is illustrated in the diagram below, with the lived experiences of elderly shelter dementia workers at its center - the focus of the study we aim to understand. Surrounding this are four key concepts - perceptions of duty, acquired skills from experiences, challenges of caregivers, and applied strategies - that help characterize the dementia workers' experiences. Collectively, these perspectives from dementia caregivers may offer a detailed account of their experiences interacting with dementia patients in an elderly shelter.

Figure 1: The Conceptual Structure of the Study



This study described how caregivers view their tasks as duties that may also lead to describing the application of skills they have acquired through their experiences. It may also inspire them to share the challenges they faced and the strategies they use for managing dementia patients in an elderly shelter.

Statement of The Problem

This study dived into the lived experiences of caregivers in an elderly shelter who assist elderly patients with Dementia. It seeks to provide answers to the following questions:

Central Question: How may the elderly shelter workers' experiences with Dementia patients be described?

Probing Questions

1. How do caregivers perceive their roles and responsibilities in assisting elderly patients with Dementia?
2. What challenges do caregivers experience working with patients who have dementia?
3. How do caregivers utilize these experiences to enhance their caregiving abilities?
4. What strategies are utilized by caregivers in handling elderly patients with dementia?

Scope and Delimitation

The study aims to understand the approach to dementia care by examining the formal caregivers' experiences in elderly care. The study focuses on formal caregivers' experiences, perceptions, skills, challenges, and strategies in assisting elderly dementia patients, highlighting their roles, responsibilities, and strategies.

The study interviewed 14 caregivers in an elderly shelter in Rizal, Philippines, who provide personalized support to dementia patients. The research, conducted in the SY 2024-2025, aims to enhance their quality of life and safety.

Methodology

Research Design

The study utilized qualitative research to explore the experiences of official caregivers in assisting elderly shelter residents with dementia, aiming to understand their lived experiences through in-depth narratives and context (Braun & Clarke, 2021).

The researchers used a phenomenological approach to study caregivers' experiences in fields like psychology, medicine, education, and everyday life (Manen, 2023). This enhances their methodological focus and understanding of human behavior (Ayton, 2023).

Participants/Respondents of the Study

The study interviewed 14 formal caregivers as key informants, who actively care for elderly dementia patients, with the number potentially changing based on availability through sampling.

The researchers utilized a purposive sampling. According to Andrade (2021), this sampling technique is the selection of individuals based on specific qualities that align with research goals. The primary informants were the formal caregivers of dementia. The study focuses on the lived experiences of dementia patients' hands-on caretakers, highlighting the quality of care they provide and the challenges they face (Fertalova et al., 2022). The focus is on highlighting the experiences of those working at an elderly shelter, excluding family caregivers. Family caregivers often lack training and structured methodologies for

dementia care, compared to professionally trained professionals (Hailu et al., 2024).

Instrument/s of the Study

The researchers used a structured interview protocol to gather in-depth insights into the experiences of formal caregivers in an elderly shelter for dementia patients (George & Merkus, 2022). The following protocol is followed:

- The researchers conducted the structured interview with the dementia formal caregivers.
- The interview questions were reviewed with the dementia formal caregivers by the researchers and ensured that the interview will be voluntary.
- The formal caregivers were interviewed in brief, audio-recorded sessions lasting less than ten minutes each.
- To make sure the proponents follow the terms of their participation agreement, the proponents discussed data confidentiality.

Data Collection and Analysis

The study's objective is to explore the lived experiences of formal dementia caregivers in an elderly shelter. The researchers gathered data by making use of the following processes:

1. *Selection of Key Informants.* The participants of this study involved 14 dementia caregivers, this sample is selected using a purposive sampling technique.
2. *Choosing a Method for Gathering Data.* The proponents created 4-item open-ended interview questions that are conducted through a structured interview.
3. *Assent to Carry Out an Interview.* The Questionnaire is validated by the research adviser and shelter facilitator.
4. *Adhering to Ethical Guidelines.* The researchers adhered to ethical guidelines in conducting the research, respecting the rights and privacy of the participants at all times and ensuring that the interview is audio recorded and transcribed.
5. *Data Analysis.* The researchers made use of Colaizzi's Phenomenological Method, a type of thematic analysis to interpret the gathered data.

This research's data analysis is qualitative, which underwent thematic analysis. Dawadi (2020), defined thematic analysis as a systematic method for systematically analyzing and interpreting complex data sets by repeatedly identifying key themes. Thematic analysis is a method employed by researchers to identify recurring patterns in data, utilizing Colaizzi's Phenomenological Method for systematic exploration. According to Praveena and Sasikumar (2021), define Colaizzi's

Phenomenological Method as a descriptive method for interpreting data.

This study utilized Colaizzi's Phenomenological Method to explore the perceptions and experiences of caregivers of dementia patients. The study's conclusions are derived from Colaizzi's approach, which categorizes responses based on shared content. The proponents aimed to identify and categorize recurring patterns in the collected data for a better comprehension and identification of themes.

Ethical Considerations

The study adhered to the University's Ethical Guidelines, adhering to the capsule and overall completed paper before conducting the study, in which follows:

1. The researchers effectively discussed the study's nature and provided participants with an understanding of its purpose.
2. The researchers made sure that the key informants chosen were based on the relevance of the field they are in.
3. Researchers ensured data confidentiality by including potential risks in their study and adhering to the Data Privacy Act.
4. The researchers informed the participants of the benefits or contributions of the study.
5. The researchers adhered to data safekeeping to ensure the protection of information, particularly confidentiality and anonymity of key informants.
6. The researchers asked permission to record interviews with the key informants.
7. The researchers requested authorization to use standardized equipment.
8. Key informants had the right to terminate participation without a need of an explanation.
9. Key informants have the right to refuse to answer sensitive questions if they feel that the question makes them feel uncomfortable.
10. Key informants had the right to be informed about the study results.
11. Key informants had the right to ask questions regarding the study.
12. The researchers adhered to the proper safekeeping and disposal of our collected data.
13. The researchers addressed potential conflicts of interest that could potentially compromise the integrity of the research.

Results and Discussion

SOP 1: How do caregivers perceive their roles and responsibilities in assisting elderly patients with Dementia?

Emergent Theme 1: Dementia caregivers' perceptions of duty in assisting elderly patients

The above shows how elderly dementia caregivers perceive their roles. Mainly,

- (1) caregivers view their work as a second family,
- (2) caregivers are a vital source of support,
- (3) caregivers carry heavy responsibilities, and
- (4) a lack of practical experience and knowledge makes care difficult.

Overall, caregivers see themselves as providers of daily support and care, offering comfort as a stand-in family, and recognize the need for practical training to provide accurate care.

Caregivers are viewed as the second family of dementia patients as they create an environment that feels like home, providing support and primary source of care, aligns with the study of Rahman et al. (2019). Similar study to Yu et al. (2023), that caregivers are the source of wellness and support of patients, providing strength for their health and well-being development. Caregivers provide immeasurable assistance for a wide range of needs from providing healthcare to providing personal care, corresponding with the study of Gitlin (2024). Lack of knowledge and experience for dementia caregivers may lead to stress and inefficient care, in sync with the study of Ung et al. (2022).

SOP 2: What challenges do caregivers experience working with patients who have dementia?

Emergent Theme 2: On the challenges caregivers experience working with people who have dementia

This shown unfolds 5 sub-themes. Mainly:

- (1) dementia patients may hurt themselves,
- (2) handling patients that are aggressive
- (3) patients have difficulties expressing their needs,
- (4) emotional attachment of caregivers when they part ways with the patient, and
- (5) caregivers feel underappreciated by their patients towards care.

Overall, these challenges in caring for dementia patients display self-harm, aggression to others, open communication, attachment to patients, and patient's lack of appreciation.

Similar to the study of Acton (2024), the degenerative nature of dementia may aggravate these issues, increasing anger or violence as the illness worsens, they have the tendency to self-harm. Patients may also exhibit aggression in communicating their desires and emotions, which makes it difficult for caregivers to comprehend and meet the requirements of the patient (Paudel et al., 2023).

The study's findings correspond with the study of Falzarano et al. (2023) that the functional need of the care recipient can cause a deep emotional

attachment, making the loss even more difficult for the caregiver. Lastly, the analysis of the study syncs with the study of Reckrey et al. (2024) that patients who are experiencing cognitive decline may not completely comprehend and appreciate the function of caregivers or the services being offered to them.

SOP 3: How do caregivers utilize these experiences to enhance their caregiving abilities?

Emergent Theme 3: The acquired experiences of elderly shelter caregivers in caring for dementia patients

The emerged from 6 sub-themes. Mainly:

- (1) caregivers become more skilled over time,
- (2) patience and flexibility are key to caregiving,
- (3) caregivers rely on careful observation to understand patient needs,
- (4) effective communication and humor nurture connections with patients,
- (5) caregivers find fulfillment in supporting dementia patients, and
- (6) caregivers improve their methods through reflection on experience.

Overall, the elderly shelter caregivers use their hands-on experience to refine their skills, adapt to patients' needs, and provide more compassionate, effective care. Through continuous learning, they enhance their ability to handle challenges and build stronger connections with patients.

Caregivers improve their skills and confidence over time (Bédard et al., 2019), becoming more patient and flexible in managing unpredictable behaviors (Chao et al., 2020). They rely on careful observation to understand patient's needs (Reuben et al., 2021), and use communication strategies like humor to connect with patients (Kallio et al., 2021). Supporting daily tasks helps maintain patients' dignity and sense of purpose (Brown et al., 2020), while reflection on past experiences enhances caregiving practices (Mody et al., 2022). Overall, the findings mirror Scales et al. (2020), showing that caregivers evolve into more skilled and compassionate providers through experience and emotional connection.

SOP 4: What strategies are utilized by caregivers in handling elderly patients with dementia?

Emergent Theme 4:

This shown emerged from 4 sub-themes. Mainly:

- (1) setting restrictions not to get too attached with patients to prevent emotional impact when parting ways,
- (2) listening to patients' problems and providing assurance,

- (3) collaborating with other caregivers by sharing signals to understand each other, and
- (4) diverting the attention of patients by music engagement and physical activities.

Overall, caregivers use strategies like striving to empathize with their patients' perspectives, offering assurance and active listening, collaboration with other caregivers, and utilizing physical activities as both entertainment as well as exercise to ensure their physical health.

This study aligns with the study of Estrada (2021) that patients with dementia can communicate more effectively when you listen to them. By meeting their psychological need for relatedness, caregivers better comprehend their experiences and offer the right kind of support, which in turn improves the patients' emotional health. The analysis coincides with the study of Verve Senior Living (2023) that over-attachment of caregiver to its patient could lead to affecting them negatively when they part ways and could influence their emotional health.

The outcomes about distraction coincides with Vikas et al. (2023) that higher participation in tailored music treatments was linked to lower levels of depressed behavior. This suggests that in order to keep older patients engaged and enhance their mental health, caregivers may promote involvement in a variety of activities, such as entertainment and physical activity. Lastly, sharing caregiving techniques among caregivers is vital for improving the quality of care. It allows caregivers to learn from each other's experiences, adapt successful strategies, and enhance their overall effectiveness in managing care (Layne et al., 2023).

Limitation of The Study

This study focused on dementia caregivers in an elderly shelter in Rizal, Philippines, but its findings could be applicable to other shelters if further research is conducted. Therefore, its findings can not be generalized.

Conclusion

Based on the study's results, the following conclusions were drawn:

1. Elderly dementia caregivers see their roles and responsibilities as a second family to the elderly patients because they give vital support with their health and personal care, but it acquires heavy responsibilities that become heavier when a caregiver lacks practical experience and knowledge.
2. Caregivers encounter challenges in monitoring several patients at once due to the possibility of patients committing self-harm or showing aggression to others.

Emotionally, they feel unappreciated by their patients due to their case of cognitive decline; ultimately, caregivers also experience grief when patients pass.

3. Caregivers' experiences led them to develop skills to be empathic in giving care and support among their dementia patients. These skills were only acquired through time and continuous learning from the various cases of dementia that they handled. Over time, caregivers become more flexible in providing the best response for their patients' needs.
4. The strategies utilized by the caregivers handling elderly dementia patients include not getting too attached to avoid the emotional impact of patient loss. However, getting attached is inevitable because this is one of the effects of connecting with patients to effectively respond to their needs. Lastly, listening to them to provide assurance, collaborating with other caregivers, and using music and physical activities to divert the patient's attention.

Recommendations

Based on the conclusions drawn from the findings, the following recommendations are presented:

1. To ensure the welfare of both the caregiver and patient, the caregiver should be oriented more on how to address/control the elderly dementia patients' episodes. Therefore, they ought to get assistance from senior caregivers on how to handle their patients on a specific patient act.
2. Shelter facilitators may consider having an implementation to prevent the hazards of patients doing self-harm and aggression to others. They may also facilitate programs to elevate caregivers' feelings of being unappreciated and emotional detachment from patients.
3. Shelter facilitators should enhance caregivers' empathy, promote self-reflection, and provide time for self-care.
4. Future research may focus on having coping mechanisms for the emotional detachment of caregivers. Furthermore, listening, assuring, using music, and physical therapy to assist can maintain the well-being of patients.
5. The scope of future research may explore more than one elderly shelter to gain insights on the experiences of caregivers dealing with elderly dementia patients from multiple shelters.

Practical Implications of The Study

Elderly dementia caregivers can improve their well-being by seeking emotional support, establishing an

adaptive communication plan, and utilizing shelters for recognition programs. Caregivers should also create personalized care plans incorporating humor, patience, and self-reflection to ensure the best response to patients' needs, addressing their varying viewpoints and promoting overall well-being.

Theoretical Implication

The study aligns with the Self-Determination Theory of Huang et al. (2023), suggesting that caring for dementia patients improves engagement, emotional health, and cognitive outcomes. Caregivers can provide a supportive atmosphere, engage patients in rewarding activities, and empower them by enhancing care practices and patient well-being.

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.

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