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# Lived Experiences of Family Caregivers of Older Adults Living with Dementia: A Qualitative Study

Moeketsane, R., & Hoque, M.

*Department of Public Health, School of Health Care Sciences, Sefako Makgatho Health Sciences University, Pretoria, South Africa*

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***Correspondence to:***
Prof. Muhammad Hoque
muhammad.hoque@smu.ac.za

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**ABSTRACT**

### Introduction

Dementia is a progressive neurodegenerative syndrome that imposes substantial physical, psychological, social, and economic burdens on informal family caregivers. In South Africa, these challenges are compounded by a scarcity of formalized support systems, cultural misconceptions, and limited healthcare resources.

### Purpose

This study examined the lived experiences of family caregivers of older adults living with dementia in Pretoria, South Africa.

### Methods

A qualitative descriptive and contextual design using a phenomenological approach was adopted. In-depth, semi-structured interviews were conducted with 20 purposively selected informal family caregivers of older adults diagnosed with dementia. Data were analyzed manually using Braun and Clarke's thematic analysis framework to generate overarching themes and subthemes.

### Results

Four major themes emerged: (1) *Knowledge, Perceptions, and Pathways to Diagnosis*, capturing initial ignorance, cultural stigma, and diagnostic delays; (2) *Multidimensional Caregiving Demands and Behavioral Challenges*, highlighting 24-hour supervision, physical strain, and neuropsychiatric symptoms; (3) *Psychosocial, Occupational, and Economic Disruption*, describing chronic emotional distress, employment loss, and severe financial strain; and (4) *Coping Mechanisms and Support Systems*, illustrating the reliance on spiritual resilience, family solidarity, and a critical need for institutional respite and healthcare backing.

### Conclusion

Informal dementia caregiving in South Africa involves profound multi-systemic strain balanced by cultural and spiritual resilience. Developing targeted community education campaigns, nurse-led support groups, and structured institutional respite programs is essential to safeguard caregiver well-being and optimize patient care outcomes.

## INTRODUCTION

Dementia is an irreversible and progressive neurodegenerative syndrome characterized by a chronic decline in cognitive ability, memory, behavior, and the capacity to perform independent activities of daily living (World Health Organization [WHO], 2023). It stands as a critical global public health challenge driven by rapidly aging populations, severely impacting affected individuals, their families, and healthcare systems (Livingston et al., 2021). Globally, over 55 million people live with dementia, with more than 10 million new cases diagnosed annually (WHO, 2023). Projections estimate this figure will escalate to 152.8 million by 2050, disproportionately affecting low- and middle-income countries (LMICs) where health and social welfare systems lack adequate resources (Farina et al., 2023). Over 60% of individuals living with dementia currently reside in these resource-constrained settings (WHO, 2023).

Dementia encompasses several etiologies, including Alzheimer's disease, vascular dementia, Lewy body dementia, frontotemporal dementia, and mixed dementias, with Alzheimer's disease accounting for approximately 60% to 70% of all diagnoses (Bergman et al., 2023). As the syndrome progresses through mild, moderate, and severe stages, functional dependence escalates, creating extensive demands on caregivers for personal care, safety monitoring, and healthcare coordination (Goto et al., 2023). In developing regions, these challenges are magnified by structural inequalities, fragile healthcare infrastructure, and limited social welfare safety nets (Al Ghammari et al., 2025).

South Africa mirrors these demographic and systemic pressures, with an estimated 450,000 individuals living with dementia (Farina et al., 2023). Despite this rising prevalence, dementia remains widely misunderstood across many South African communities due to pervasive social stigma, low health literacy, and traditional interpretations attributing symptoms to normal aging or spiritual punishment, such as witchcraft (Zambakari & Zambakari, 2023). These cultural and informational barriers impede timely clinical detection, delay medical interventions, and exacerbate caregiver distress (Adebiyi et al., 2022).

In South Africa and across sub-Saharan Africa, long-term care relies predominantly on informal family caregivers—including spouses, adult children, relatives, and neighbors—who provide unpaid physical, emotional, and logistical support (Mahomed & Pretorius, 2022). These caregivers assist with fundamental activities of daily living, such as bathing, dressing, feeding, toileting, ambulation, and medication management (Brett et al., 2021). Furthermore, caregivers must navigate complex behavioral and psychological symptoms of dementia (BPSD), including verbal and physical aggression, agitation, wandering, hallucinations, sleep disturbances, and emotional lability (Kales et al., 2021). Managing these multifaceted demands frequently precipitates severe physical exhaustion, chronic sleep deprivation, anxiety, depression, and social isolation (Huang et al., 2022).

Despite the documented burdens, caregiving also yields positive psychological dimensions. Research demonstrates that informal caregiving can foster personal growth, emotional bonding, self-efficacy, and a deep sense of fulfillment (Li et al., 2022). In African societies, caregiving is deeply anchored in communal cultural values such as *Ubuntu*, emphasizing solidarity, reciprocity, and family obligation (Zambakari & Zambakari, 2023). While international literature extensively documents caregiver burden, a critical gap persists regarding context-sensitive, qualitative evidence examining how South African family caregivers navigate the interplay between heavy structural burdens, cultural interpretations, and internal coping mechanisms (Mahomed & Pretorius, 2022).

Exploring these lived experiences is vital to uncover unmet supportive care needs, understand adaptive coping strategies, and provide empirical evidence to guide healthcare planners and policy makers (Farina et al., 2023). Therefore, this study investigated the lived experiences of family caregivers of older adults living with dementia in Pretoria, South Africa.

## METHODS

### *Study Design*

A qualitative descriptive and contextual design utilizing a phenomenological approach was adopted to explore and understand the lived experiences of informal family caregivers of older adults living with dementia (Creswell &

Creswell, 2018). This design allowed researchers to capture the subjective realities, emotional nuances, and contextual challenges experienced by participants within their natural socio-cultural environment.

### *Study Setting*

The study was conducted in Pretoria, located within the City of Tshwane Metropolitan Municipality in the Gauteng Province, South Africa. Pretoria serves as a major urban and administrative center characterized by diverse socio-economic strata, multi-ethnic populations, and varied healthcare access points, ranging from primary community clinics to specialized academic hospital complexes. This setting provided a rich multicultural milieu for examining dementia caregiving within South Africa.

### *Target Population and Eligibility Criteria*

The target population comprised informal family caregivers residing in Pretoria. Inclusion criteria required participants to be: (1) informal, unpaid family caregivers (spouses, adult children, or relatives) providing regular physical, emotional, and practical care to an older adult diagnosed with dementia; (2) aged 18 years or older; (3) engaged in caregiving duties for a minimum duration of six months; (4) capable of communicating in English, Afrikaans, or local indigenous languages; and (5) willing to provide written informed consent.

Individuals were excluded if they were formal, paid professional caregivers, had been providing care for less than six months, exhibited severe cognitive or psychiatric impairment that precluded coherent interviewing, or declined to provide informed consent.

### *Sampling and Recruitment*

A purposive sampling technique was employed to recruit participants who possessed direct, rich experiential knowledge of dementia caregiving (Polit & Beck, 2021). Recruitment was facilitated through healthcare professionals, community-based organizations, geriatric outpatient clinics, and local dementia support groups in Pretoria. Recruitment and data collection continued iteratively until data saturation was achieved—the point where subsequent interviews yielded no new codes, properties, or thematic insights (Guest et al., 2020). Saturation was reached at the 20th participant.

### *Data Collection*

Data were collected through face-to-face, semi-structured, in-depth individual interviews conducted by the primary researcher between January and March 2026. An interview guide containing open-ended questions and exploratory probes was developed based on relevant literature (Mahomed & Pretorius, 2022). Sample guiding questions included: "*Can you describe what a typical day is like caring for your relative?*", "*What major challenges do you encounter in your caregiving role?*", and "*How do you cope with the demands of looking after your family member?*"

Interviews were conducted in private, quiet settings chosen by the participants (such as private consultation rooms at participating clinics or quiet areas in community centers) to ensure confidentiality and comfort. Interviews lasted between 45 and 90 minutes. With the explicit permission of each participant, all sessions were audio-recorded. Detailed field notes were maintained during and immediately following each interview to document non-verbal cues, emotional expressions, and environmental context.

### *Trustworthiness*

Rigour and trustworthiness were maintained according to the criteria established by Lincoln and Guba (1985):

- **Credibility:** Ensured through prolonged engagement with participants, peer debriefing with qualitative research experts, and member-checking with three participants to verify the accuracy of transcribed interpretations.
- **Transferability:** Achieved by providing a thick, detailed description of the research methodology, participant demographics, and contextual setting.
- **Dependability:** Maintained through an external audit trail documenting raw audio files, verbatim transcripts, coding frameworks, and reflexive notes.
- **Confirmability:** Established by maintaining reflexivity, ensuring that data interpretations were grounded directly in participants' narratives rather than researcher preconceptions.

### *Data Analysis*

All audio-recorded interviews were transcribed verbatim. Interviews conducted in local languages were professionally translated into English, and back-translated to ensure linguistic equivalence. The primary researcher cross-checked all transcripts against the original audio files to verify accuracy.

Data were analyzed using Braun and Clarke's (2021) six-phase thematic analysis framework: (1) familiarization with the data by reading and re-reading transcripts; (2) generating initial codes systematically across the dataset; (3) searching for potential themes by collating codes into broader overarching categories; (4) reviewing themes against coded extracts and the entire dataset; (5) defining and naming final themes; and (6) producing the scholarly report incorporating compelling verbatim extracts.

### *Ethical Considerations*

Ethical approval was granted by the Sefako Makgatho Health Sciences University Research Ethics Committee (SMUREC/H/123/2026:IR). Institutional permissions were secured from participating clinics and community organizations. Written informed consent was obtained from all participants prior to study commencement. Participants were informed of their right to voluntary participation, confidentiality, anonymity (via alphanumeric pseudonyms), and the unconditional right to withdraw from the study at any point without penalty. All electronic data were stored on a password-protected, encrypted server accessible solely to the research team.

## RESULTS

### *Demographic Characteristics of Participants*

A total of 20 informal family caregivers participated in the study. Participant ages ranged from 28 to 74 years (mean age = 51.4 years). The majority of participants were female (n=16,80%n = 16, 80%n=16,80%), comprising daughters (n=10n = 10n=10), wives (n=4n = 4n=4), and daughters-in-law (n=2n = 2n=2). Male participants (n=4,20%n = 4, 20%n=4,20%) included sons (n=3n = 3n=3) and a husband (n=1n = 1n=1). Caregiving duration ranged from 7 months to over 7 years (mean duration = 3.2 years). Socio-economic backgrounds varied, including unemployed individuals, grant recipients, pensioners, and those engaged in formal or informal employment.

Four major overarching themes and associated subthemes emerged from the thematic analysis, as summarized in **Table 1** below.

**Table 1:**
Summary of Overarching Themes and Subthemes

| Overarching Theme | Subthemes |
|---|---|
| 1. Knowledge, Perceptions, and Pathways to Diagnosis | i. *Low baseline awareness and misattribution to normal aging*<br>ii. *Cultural misconceptions and supernatural attributions*<br>iii. *Diagnostic delays and healthcare dismissal* |
| 2. Multidimensional Caregiving Demands and Behavioral Challenges | i. *Round-the-clock physical care and personal assistance*<br>ii. *Continuous security surveillance and wandering prevention*<br>iii. *Managing neuropsychiatric symptoms of dementia (BPSD)* |
| 3. Psychosocial, Occupational, and Economic Disruption | i. *Emotional distress, anxiety, and caregiver burnout*<br>ii. *Social isolation, stigma, and fractured family dynamics*<br>iii. *Employment disruption, career forfeiture, and financial strain* |
| 4. Coping Mechanisms and Support Systems | i. *Spiritual faith and psychological adaptation*<br>ii. *Informal family networks versus formal institutional gaps*<br>iii. *Expressed needs for specialized respite and counseling* |

### ***Theme 1:*** *Knowledge, Perceptions, and Pathways to Diagnosis*

Participants frequently described a profound lack of awareness regarding dementia prior to assuming caregiving responsibilities, which significantly delayed formal diagnosis and intervention.

#### ***Low Baseline Awareness and Misattribution to Normal Aging***

Many caregivers initially dismissed early cognitive deficits, memory lapses, and behavioral shifts as benign signs of advanced age.

*"At first, we thought it was simply old age because she would always repeat herself and misplace house keys. We did not know it was a disease until she started getting lost in the neighborhood."* **(Participant 4, Female, 48 years)**

***Cultural Misconceptions and Supernatural Attributions***

In alignment with broader community dynamics, participants highlighted how traditional beliefs influenced symptom interpretation, frequently attributing erratic behaviors, hallucinations, or personality changes to witchcraft, curses, or ancestral displeasure.

*"Many people in the community claimed that he was bewitched because he started wandering off at night and talking to people who were not there. Elders in our street suggested we consult traditional healers instead of taking him to a hospital."* **(Participant 11, Female, 62 years)**

***Diagnostic Delays and Healthcare Dismissal***

Caregivers voiced considerable frustration regarding convoluted referral pathways within public health institutions, where primary care personnel frequently dismissed early dementia symptoms as inevitable age-related cognitive decline.

*"We had to go from one local clinic to another for over a year. Nurses kept telling us old people become forgetful, until a doctor at the regional hospital finally examined her properly and gave us the diagnosis of dementia."* **(Participant 2, Male, 55 years)**

**Theme 2:** *Multidimensional Caregiving Demands and Behavioral Challenges*

Caregiving responsibilities escalated progressively, transforming into intensive, round-the-clock duties as the neurodegenerative condition advanced.

***Round-the-Clock Physical Care and Personal Assistance***

Participants reported providing extensive physical assistance for basic activities of daily living, including feeding, bathing, dressing, toileting, and mobility support.

*"I help her do everything now. She cannot bathe herself, eat independently, or even dress properly. Looking after her has become a 24-hour job that absorbs my entire day and night."* **(Participant 7, Female, 42 years)**

***Continuous Security Surveillance and Wandering Prevention***

Constant vigilance was required to mitigate safety hazards, such as wandering, accidental falls, or leaving stoves unattended.

*"You cannot leave him alone for even five minutes because he forgets things and leaves the stove burning or tries to walk out onto the busy main road. Constant surveillance restricts my freedom completely."* **(Participant 15, Male, 67 years)**

***Managing Neuropsychiatric Symptoms of Dementia (BPSD)***

Caregivers identified managing BPSD—such as physical aggression, verbal agitation, severe insomnia, and paranoid delusions—as one of their most physically and emotionally draining responsibilities.

*"Sometimes she becomes intensely violent, screams at midnight, and does not want to cooperate when I try to give her medication. Emotionally and physically, it is really exhausting."* **(Participant 9, Female, 39 years)**

**Theme 3:** *Psychosocial, Occupational, and Economic Disruption*

The relentless demands of caregiving precipitated widespread negative consequences spanning emotional well-being, social connectivity, occupational stability, and personal finances.

***Emotional Distress, Anxiety, and Caregiver Burnout***

Participants reported profound emotional turmoil, including chronic anxiety, depressive symptoms, feelings of helplessness, hopelessness, and grief as they witnessed the gradual cognitive decline of their relatives.

*"Watching your parent slowly lose his mind and fail to recognize you is one of the saddest experiences in life. Sometimes, I find myself crying alone in the kitchen because it is simply too much for a single person."* **(Participant 6, Female, 51 years)**

***Social Isolation, Stigma, and Fractured Family Dynamics***

Stigma surrounding dementia within local communities fostered social withdrawal, while unequal distribution of caregiving duties strained familial relationships.

*"People in our neighborhood would laugh at him because he could not remember things and spoke incoherently. It was humiliating for our family, so I stopped inviting visitors over. Furthermore,*

*my siblings refuse to help, leaving the entire burden on me."* **(Participant 18, Female, 56 years)**

***Employment Disruption, Career Forfeiture, and Financial Strain***

Caregiving entailed substantial out-of-pocket expenditures for adult diapers, specialized nutritional supplements, medications, and transport to medical facilities, frequently culminating in job loss or reduced working hours.

*"Most of my salary is used to buy adult diapers and medication. Eventually, I had to resign from my formal job because there was nobody else to look after my mother during the day."* **(Participant 1, Female, 45 years)**

***Theme 4:*** *Coping Mechanisms and Support Systems*

Despite overwhelming challenges, caregivers demonstrated remarkable resilience through adaptive coping strategies and highlighted critical gaps in institutional support.

***Spiritual Faith and Psychological Acceptance***

Spiritual practices, particularly personal prayer, church fellowship, and internal acceptance, served as vital psychological anchors enabling caregivers to persevere through daily hardships.

*"My prayer life and faith in God help me overcome difficult moments. When I feel like giving up, I pray for strength to endure another day."* **(Participant 12, Female, 64 years)**

***Informal Family Networks versus Formal Institutional Gaps***

While sporadic support was derived from supportive family members and religious communities, participants expressed extreme dissatisfaction with the absence of formal healthcare backing, such as respite care or professional counseling.

*"The local clinics only treat acute physical problems like hypertension or diabetes, but they offer zero psychological or social support for dementia caregivers. A caregiver also requires care because these responsibilities are overwhelming."* **(Participant 14, Female, 59 years)**

## DISCUSSION

This study explored the lived experiences of informal family caregivers of older adults living with dementia in Pretoria, South Africa. The findings reveal that caregivers experience multidimensional challenges that severely impact their psychological, social, economic, and physical well-being. These lived experiences are shaped by low baseline awareness, cultural stigma, escalating caregiving demands, financial strain, and an absence of formalized healthcare support. Despite these severe adversities, caregivers exhibited considerable resilience through spiritual faith, psychological adaptation, and family commitment.

Low dementia awareness emerged as a critical barrier influencing early detection and help-seeking behavior. Many participants initially misattributed cognitive decline, memory deficits, and behavioral changes to normal aging. These findings corroborate previous studies across sub-Saharan Africa demonstrating that limited dementia literacy contributes to delayed clinical diagnoses and prolonged suffering (Farina et al., 2023; Adebiyi et al., 2022). Furthermore, our findings align with Parveen et al. (2022), who emphasized that informal caregivers frequently lack foundational knowledge regarding disease progression and symptom management strategies.

Cultural beliefs and supernatural attributions significantly shaped community perceptions of dementia. Several participants reported that community members attributed dementia symptoms to witchcraft or spiritual punishment. This finding echoes existing regional literature indicating that dementia is frequently misinterpreted through supernatural frameworks in sub-Saharan African settings (Zambakari & Zambakari, 2023). Such misconceptions foster severe social stigma, deter families from seeking orthodox medical care, and induce psychological distress among caregivers (Nguyen & Li, 2022). Consequently, public health interventions must prioritize culturally sensitive community awareness campaigns to demystify dementia as a medical neurodegenerative condition.

The escalating physical and cognitive dependency of care recipients resulted in heavy caregiving burdens. Assisting with activities of daily living, continuous security surveillance to prevent wandering, and managing BPSD were major sources of physical exhaustion. These findings align with longitudinal reviews by Goto et al. (2023) and Brett et al. (2021), confirming that caregiving demands intensify as neurodegenerative pathology progresses. The necessity for round-the-clock supervision severely restricts

caregivers' personal freedom, predisposing them to chronic fatigue and physical morbidity.

Psychologically, caregivers reported high levels of anxiety, depression, emotional exhaustion, and burnout. Witnessing the gradual personality deterioration of a loved one provoked profound grief and feelings of helplessness. These psychological outcomes are well-documented in international and regional literature (Cheng et al., 2021; Garcia-Martin et al., 2023), driven by chronic stress and inadequate institutional psychological support. Conversely, in alignment with Li et al. (2022) and Quinn et al. (2022), caregivers also experienced positive aspects of caregiving, such as a sense of filial duty, moral fulfillment, and reciprocity—values strongly reinforced by the African cultural ethos of *Ubuntu* (Zambakari & Zambakari, 2023).

Social isolation and strained family dynamics were prevalent among participants. The round-the-clock demands of caregiving restricted social participation, leading to loneliness and withdrawal (Silaule et al., 2024). Additionally, disputes regarding unequal burden-sharing among family members exacerbated psychological distress, disproportionately affecting female caregivers. These dynamics reflect Goode's role strain theory and Pearlin's stress process model, where primary stressors (care recipient cognitive impairment) generate secondary role strains (family conflict and constriction of social life) (Pearlin et al., 1990; Biddle, 1986).

Economic strain and occupational disruption constituted major challenges. Caregivers incurred substantial out-of-pocket costs for incontinence products, specialized nutrition, and transport, forcing many to reduce working hours or resign from formal employment. These findings mirror recent economic evaluations in LMICs demonstrating that dementia caregiving precipitates severe financial impoverishment and employment loss (Cui et al., 2025; Al Ghammari et al., 2025).

To cope with these stressors, caregivers relied heavily on spiritual and religious mechanisms, such as prayer and faith, which provided emotional solace and psychological fortitude. Similar coping patterns have been widely observed in African family caregiving contexts (Dilworth-Anderson et al., 2007). However, reliance on informal coping mechanisms does not substitute for structural support. Participants expressed acute dissatisfaction with the public healthcare system's failure to provide respite care, caregiver support groups, or psychological counseling, reflecting systemic deficits in resource-constrained settings (Masoud et al., 2022).

### *Implications for Practice and Policy*

The findings carry significant implications for nursing practice, healthcare policy, and public health programming. Healthcare authorities in South Africa must integrate dementia education into primary healthcare training to enhance early clinical recognition. Furthermore, health authorities should establish nurse-led community support groups, psychoeducational workshops, and accessible respite care facilities to alleviate caregiver burnout. Social welfare policies should also expand financial support mechanisms, such as caregiver grants, to mitigate the severe economic vulnerability experienced by informal families.

### *Limitations*

This study has several limitations. First, the qualitative design and purposive sample of 20 caregivers in an urban South African setting (Pretoria) limit the generalizability of findings to rural populations or broader national contexts. Second, retrospective reporting of caregiving experiences may be subject to recall bias or emotional coloring. Despite these limitations, the study provides rich, context-specific insights into the lived realities of dementia caregivers in South Africa.

## CONCLUSION

This study demonstrates that informal family caregivers of older adults living with dementia in South Africa navigate profound multidimensional burdens encompassing psychological distress, physical exhaustion, social isolation, and severe economic hardship. These challenges are exacerbated by low baseline health literacy, cultural stigmatization, and a severe deficit in formal institutional support. Nevertheless, caregivers display remarkable resilience through spiritual faith and family commitment. Addressing these complex challenges requires comprehensive public health strategies, including community-wide dementia awareness campaigns, formalizing caregiver support programs within primary healthcare clinics, and implementing structured respite and financial assistance policies.

**Use of Artificial Intelligence (AI) Declaration:** The authors declare that a generative AI tool (ChatGPT by OpenAI) was utilized for editorial purposes.

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**Authors' Contributions:**

i. **MR:** Conceptualization, Methodology, Writing – Original Draft, Writing – Review & Editing.
ii. **MH:** Methodology, Formal Analysis, Writing – Review & Editing.

**Data Availability Statement:** The datasets generated and analyzed during the current study are available from the corresponding author upon reasonable request.

**Ethical Approval:** Ethical approval was granted by the Sefako Makgatho Health Sciences University Research Ethics Committee (SMUREC/H/123/2026:IR).

**Informed Consent and Anonymity:** Written informed consent was obtained from all participants prior to study commencement. Participants were informed of their right to voluntary participation, confidentiality, anonymity (via alphanumeric pseudonyms), and the unconditional right to withdraw from the study at any point without penalty.

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