



# The Phenomenology of Dementia Caregiving: A Qualitative Study

Luna Min, OTD; Beth Barstow PhD, OTR/L, SCLV, FAOTA  
Department of Occupational Therapy | University of Alabama at Birmingham  
Alison Walker | South Highland Adult Day Care Center

## Introduction

- Informal caregivers play critical roles for PWD
- An estimated 84% of PWD live at home and collectively receive 82 billion hours of informal care annually (~6 hrs/day)<sup>1</sup>
- Caregiving is recognized as a co-occupation<sup>2</sup>
- Vital to ensure safety for all and understand needs and limitations for continued occupational performance
- Dementia caregiving requires constant and progressive care
- Interventions must be tailored based on the experiences between the caregiver and care recipients<sup>3</sup>
- Current literature explores the effects of caregiving but lacks insight into caregivers perceived lived experiences
- Phenomenology explores what was experienced and how it was experienced<sup>4</sup>
- There is a need to understand beyond what dementia caregiving consists of and examine how caregiving is lived and understood
- **Study Purpose:** To explore how dementia caregivers make sense of their roles, and how the lived experience influences caregiver wellbeing and occupational performance

## Methods

### Research Design

- Qualitative phenomenological design
- Semi-structured interviews (40-50 minutes) conducted via HIPAA-compliant Zoom
- Investigator-developed interview guide of 5 questions addressing:
  - daily responsibilities and routines
  - challenges and coping strategies
  - support systems and resources
  - the impact of caregiving on daily life and identity
- Investigator-develop Qualtrics survey to provide demographic and caregiving-related information

### Population

- Inclusion criteria
  - Primary caregiver for PWD (aged 18 or older)
  - PWD utilizes adult day care center services
  - Access to technological device for interview
  - Fluency in English

### Recruitment

- South Highland Adult Day Care Center (SHACC)
- Potential participants pre-selected by project site mentor/ director at SHACC
- Flyers distributed in-person during pick-up hours

### Data Collection and Analysis

- Audio-recorded interview
- Transcribed verbatim and analyzed using Interpretative Phenomenological Analysis (IPA)

## Results

### Demographics Table:

| Participant | Age | Gender | Relationship to PWD | Duration of Caregiving | Living with PWD? |
|-------------|-----|--------|---------------------|------------------------|------------------|
| 1           | 77  | M      | Spouse              | 1 year                 | Y                |
| 2           | 55  | F      | Sister-in-law       | 3-4 years              | Y                |
| 3           | 82  | M      | Spouse              | 6 years                | Y                |
| 4           | 74  | M      | Spouse              | 2-3 years              | Y                |
| 5           | 48  | M      | Son                 | 6 years                | N                |

### Theme 1: Burden of Daily Care

"It's been a constant spiraling down if we fix one problem, but before we can even get it resolved, something else happens... When I get a strange phone call from a strange number, I kind of assume it's him getting in trouble for something." (Participant 5)

### Theme 2: Adaptation to Role

"I've really cut way back on... personal engagements with other people... I'm not complaining about it, it's just the fact that I've had to make those kinds of adjustments... I've got to take care of this priority." (Participant 1)

### Theme 3: Meaning and Purpose in Caregiving

"We kept our people at home... and took care of them at home... My whole life has been caregiving. Even as frustrating as it is... we know the alternative... It's not good." (Participant 2)

### Theme 4: Support Systems

"I enjoyed [caregiver support groups], it was good to talk to people that had the same problem I did...I quit doing that about 9 months ago... I could probably help somebody, but I don't think anybody could help me." (Participant 3)

## Discussion

### FINDINGS

- Psychological responsibilities may have greater impact on caregiver well-being than physical responsibilities.
- Occupational imbalance occurs with prioritization of care recipients' needs over caregivers' needs.
- Difference in perceived meaning behind caregiving roles based on relational factors (emotional connection vs duty)
- Variability in support needs

### LIMITATIONS

- Small and homogenous sample, recruitment bias, context-specific caregiving situations, researcher interpretation bias

## Conclusion

### IMPLICATIONS

- It is important for OTPs to recognize the diversity in experiences of dementia caregivers to adapt interventions that can promote sustainability in the caregiving role, supporting both the caregiver and PWD

### FUTURE RESEARCH

- Interventions based on transitional stages of dementia
- Cultural and relational influence on caregiver experience
- Effect of OT specific occupational rebalance interventions

## References

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CONTACT INFO: Luna Min: minjh01@uab.edu