

# CARING FOR LOVED ONES WITH LATE-STAGE DEMENTIA: A FULL-TIME JOURNEY THAT NEEDS MORE SUPPORT

## What Is It Like to Care for a Family Member with Late-Stage Dementia? Insights from Chinese American Families

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### Background

Family caregivers of people with late-stage dementia face intensive demands and limited support, **yet their experiences**—especially within Chinese American communities shaped by cultural values—**remain underexplored**.

### Objective

We aim to better understand how Chinese American families care for loved ones with late-stage dementia.

Specifically, we explore:

- What caregiving is like for family caregivers
- Challenges they face and the support they need
- How caregiving affects their daily lives

### Methods

**Research Design:** A descriptive qualitative design

**Participants, Recruitment, and Sample Size:**

Purposive sampling was used to recruit Chinese American family caregivers through multiple community-based recruitment channels. Sample size will be decided by saturation.

**Inclusion Criteria:** 1) a family caregiver of Chinese ancestry living in the NY/NJ Metropolitan Area. 2) self-identified as the primary caregiver for a family member with late-stage dementia in the community (defined as stage 7 on the Functional Assessment Staging scale). 3) at least 18 years of age. 4) willing and able to be interviewed in English or Chinese.

**Data Collection:** Face-to-face, semi-structured interviews were conducted (five completed, 99-153 minutes)

**Data Analysis:** Conventional content analysis to identify key themes and patterns in caregivers' experiences.

### Findings

#### Participant Characteristics

- **Sample size:** 5 participants (4 women, 1 man), aged 40–79 years
- **Relationship to care recipient:**
  - 3 caring for a parent
  - 2 caring for a spouse
- **Background:** All were first-generation Chinese American immigrants
  - 4 from Mainland China
  - 1 from Hong Kong
- **Dementia stage:** Care recipients were in late-stage dementia (FAST 7a–7c)
- **Hospice care:** None were receiving hospice services
- **Caregiving duration (late stage):** 0.25 to 5 years
- **Daily caregiving time:** 15–24 hours per day

#### Preliminary themes

##### Theme 1: Having no choice but to care

- Strong sense of responsibility and obligation
- Feeling there was no alternative but to provide care

##### Theme 2: Taking it one step at a time

- Coping day by day
- Adjusting to ongoing challenges without long-term planning

##### Theme 3: Overlooked personal needs

- Limited time for self-care
- Difficulty accessing healthcare support
- Dissatisfaction with home care services

##### Theme 4: Caring for achieving peace of mind

- Caregiving to maintain inner peace
- Finding meaning in caregiving

### Conclusions

- This study addresses an important gap by focusing on the experiences of Chinese American families caring for loved ones with late-stage dementia.
- The findings help us better understand the challenges caregivers face and the kinds of support they need.
- The results will guide the development of culturally appropriate, needs-based support programs for family caregivers.

### Discussion

#### Potential Scientific and Public Health Contribution

- Caregiving for late-stage dementia is **often a necessity**, not a choice, influenced by financial and language barriers
- Caregiving is an **ongoing learning process**, requiring adaptation to continuous challenges
- Experiences are shaped by **cultural values** which can both support and burden caregivers
- Caregiving significantly **impacts daily life**, with long hours and limited time for personal needs

#### Potential Impact on Reducing Health Disparities

- Chinese American caregivers face important gaps in support
- Common unmet needs include: self-care; access to healthcare services; satisfaction with home care support
- Culturally appropriate and accessible support services are needed
- Addressing these needs may help reduce disparities and improve well-being for both caregivers and care recipients

### Limitations

- Only family caregivers of Chinese ancestry living in the NY/NJ Metropolitan Area were recruited. Including caregivers from other states may provide a richer understanding of late-stage dementia caregiving experiences.

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