

## Niece and Nephew Dementia Caregivers: Family Relationships and Care Dynamics

Karen A. Roberto, Ph.D.\*, Jyoti Savla, Ph.D.

Virginia Tech

Karen A. Roberto, Ph.D., Center for Gerontology and Institute for Society, Culture and Environment, Virginia Tech, Blacksburg, VA, USA [kroberto@vt.edu](mailto:kroberto@vt.edu)  
<https://orcid.org/0000-0003-1153-1811>

\*Corresponding Author

Jyoti Savla, Ph.D., Center for Gerontology and Department of Human Development and Family Science, Virginia Tech, Blacksburg, VA, USA [jsavla@vt.edu](mailto:jsavla@vt.edu)  
<https://orcid.org/0000-0001-7142-3770>

Reference: Roberto, K.A., & Savla, J. (2025). Niece and Nephew Dementia Caregivers: Family Relationships and Care Dynamics, *The Gerontologist*, gnaf154, <https://doi.org/10.1093/geront/gnaf154>

## Abstract

**Background and Objectives:** The dementia caregiving literature has largely ignored extended family caregivers who play a vital role in sustaining community living for older adults living with dementia. Guided by a life course perspective and grounded in a stress-coping framework, we focus attention on the caregiving experiences of nieces/nephews who have assumed the role of primary caregiver for their aunts/uncles, a topic that has received limited attention in the research literature.

**Research Design and Methods:** Employing a mixed-methods design, we conducted interviews with 20 niece and 5 nephew primary caregivers ( $M_{age} = 55$  yrs;  $R = 38-67$ ). Interviews were analyzed following principles of the life history approach to understand how family history and dynamics shaped care responsibilities and practices; correlation analyses assessed associations with caregiver outcomes.

**Results:** Interactions in childhood provided the foundation for establishing relationships with aunts/uncles. Two-thirds of the nieces/nephews never expected to be their relative's caregiver, but rather either gradually "fell into it" or abruptly assumed the role because of "family circumstances." Caregivers relied primarily on their own family for help with care tasks; aunts'/uncles' family members and paid services provided targeted assistance. Nieces/nephews who relied on family support to assist with care experienced more caregiver burden and faced greater family strain.

**Discussion and Implications:** The nieces/nephews embraced their caregiver roles and were committed to ensuring their aunts/uncles received the care they needed. Findings contribute new knowledge about the complexity of extended family relationships and realities of dementia care amidst the transformations occurring in family life today.

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

**Keywords:** caregiving, extended family; family helpers; paid services

Downloaded from <https://academic.oup.com/gerontologist/advance-article/doi/10.1093/geronl/gnaf154/8162695> by GSA Society Access user on 10 July 2025

1  
2  
3 With the aging of the American population, the prevalence of Alzheimer's diseases and  
4 related dementia (referred to as dementia hereafter) is rising significantly, placing increased  
5 demands on family caregivers, traditionally spouses and adult children (National Alliance for  
6 Caregiving, 2017). Changing family structures resulting from a host of demographic and societal  
7 trends including declining birthrates, rising divorce, declining remarriage rates, and increasing  
8 ubiquity of women in the workforce are reducing the availability of these traditional family  
9 caregivers (Roberto & Blieszner, 2015). As spouses and adult children (i.e., immediate family  
10 members) become less available to provide care, extended kin, including adult grandchildren,  
11 siblings, and nieces/nephews are likely to play a vital role in sustaining community living for  
12 older adults living with dementia; thus, pointing to the importance of understanding extended  
13 family caregiving. This study aims to contribute to the family caregiving literature by focusing  
14 attention on the experiences of nieces/nephews who have assumed the role of primary caregiver  
15 for their aunts/uncles living with dementia.  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31

### 32 33 **Traditional Family Caregivers** 34

35 Spouses and adult children – typically women – account for more than one-half of  
36 dementia caregivers (National Alliance for Caregiving, 2017). Their responsibilities include  
37 helping their relatives with household activities, providing transportation, managing finances and  
38 medications, arranging health care and other services, and assisting with personal activities of  
39 daily living. A combination of individual, relational, and social factors influence the reasons  
40 given for assuming the caregiver role. While family members often perceive that they have no  
41 choice but to take on the role of caregiver for their relatives living with dementia (Alzheimer's  
42 Association, 2024) they are frequently motivated to do so out of love, reciprocity, duty, and  
43 obligation (Greenword & Smith, 2019). Family relationships and dynamics also influence who  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 provides care. Spouses often viewed caregiving as part of their marital commitment (Shiff et al.,  
4  
5 2025). For couples who shared responsibilities throughout their marriage, as one partner's  
6  
7 cognitive abilities decline, the other takes on more daily responsibilities than they had once held  
8  
9 (Roberto et al., 2013). Adult children, daughters, biological children, and children with fewer  
10  
11 competing demands (e.g., unpartnered, no minor children) were more likely to provide care for  
12  
13 their parents compared with their respective counterparts (Lin & Wolf, 2020). Parental pre-  
14  
15 caregiving expectations and shared values predicted which adult siblings provided care for their  
16  
17 mother (Pillemer & Suiter, 2014). Cultural beliefs and societal expectations also underly family  
18  
19 care arrangements (Zarzycki et al, 2023). For example, minority and rural caregivers often  
20  
21 deferred to their relatives' preferences for family care rather than seeking assistance from formal  
22  
23 services (Parker & Fabius, 2022; Roberto et al., 2022). While most family members find  
24  
25 dementia caregiving rewarding (National Poll on Health Aging, 2017), they also frequently  
26  
27 report high levels of burden and stress (Schulz & Eden, 2016) and other adverse mental health  
28  
29 outcomes (Ma et al., 2018).  
30  
31  
32  
33  
34

### 35 **Extended Family Caregivers**

36  
37 Most family caregiving studies, regardless of sample size or design, include a relatively  
38  
39 small number of extended family caregivers. As a result, investigators tend to either exclude  
40  
41 other relatives from primary analyses or combine them into a broad "other" caregiver category.  
42  
43 For example, Nichols' et al (2011) comparison of "typical" (spouse, children) and "atypical"  
44  
45 (child-in-law, sibling, nephew/niece, grandchild) dementia caregivers found that caregivers other  
46  
47 than spouses were more likely to provide care for women and unmarried relatives and atypical  
48  
49 caregivers had fewer competing family demands and commitments (i.e., unmarried, childless),  
50  
51 but did not specify similarities or differences among the atypical caregivers.  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 Similarly, analyses of national datasets such as the National Health and Aging Trends  
4 Study (NHATS) and National Study of Caregiving (NSOC) frequently group extended family  
5 caregivers into an “other relative” category and rarely present finding by specific extended kin  
6 relationship (see <https://www.nhats.org/publications>). For example, Wolff and colleagues (2016)  
7 used NHATS and NSOC data to develop a national profile of family and unpaid caregivers who  
8 assist older adults with health care activities such as care coordination and medication  
9 management. They reported that extended family members comprised 16.7% of the caregiver  
10 sample who provided substantial help with health care activities. Compared to spousal  
11 caregivers, extended family caregivers and adult child caregivers were just as likely to report  
12 physical difficulties, and reduced participation in valued activities because of caregiving. Travers  
13 and colleagues (2023), also using NSOC data, distinguished spouses, adult children, and other  
14 relatives/non-relatives based on their use of supportive services. They found that extended family  
15 caregivers were significantly less likely to utilize formal services compared to kin caregivers,  
16 suggesting potential unmet needs among these caregivers.  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34

35 More recently, a mixed-methods analysis of dementia caregiving data from  
36 NHATS/NSOC and primary caregivers in rural Appalachia examined the responsibilities of  
37 extended family caregivers and the impact of caregiving on their health and well-being (Roberto  
38 & Savla, 2022). Assisting with household activities was common across caregiver groups in both  
39 datasets (i.e., siblings, grandchild, niece/nephew, and stepkin) with only a small percentage of  
40 caregivers relying on paid services to assist with the care of their relatives. In addition, study  
41 participants found the role of caregiving emotionally and physically draining, particularly when  
42 they reported strained relationships with the person living with dementia and had little support  
43 from informal or formal sources. While these analyses render a preliminary understanding of the  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 scope of care activities of extended family caregivers, detailed information about caregiver  
4 characteristics, caregiver experiences by relationship type, and older care recipients' functional  
5 status remain notably scarce, underscoring the need for more targeted research.  
6  
7

### 8 9 10 **Niece/Nephew Dementia Caregivers**

11  
12 Nieces/nephews often have lifelong relationships with their aunts/uncles shaped by  
13 shared generational ties that position them as potential dementia family caregivers. Milardo's  
14 (2010) landmark study of these "forgotten kin" found that parents who maintain close ties with  
15 their siblings provide opportunities for their children's relationships with their aunts/uncles to  
16 develop, whereas when relationships were peripheral or challenging, nieces/nephews were less  
17 likely to develop meaningful bonds. In some families, aunts/uncles acted as a second parent.  
18  
19 How this role is enacted depended on many factors, including the sibling relationship,  
20 geographic proximity, and siblings' age, marital status, and social class (Davis-Sowers, 2012;  
21 Kiraly et al., 2021; Pashos & McBurney, 2008). From the perspective of young adult  
22 nieces/nephews, family relationships, careers and family obligations, and family responsibilities  
23 and care norms influenced closeness to their aunts/uncles (Milardo, 2010). However, little is  
24 known about how these relationships evolve as both generations age and aunts/uncles experience  
25 cognitive decline.  
26  
27

28  
29 National estimates suggest that among dementia family caregivers, approximately 4% are  
30 nieces/nephews (National Alliance for Caregiving, 2017). Yet, their presence in the caregiving  
31 literature is noticeable absent. When they are included in study samples, detailed information  
32 about niece/nephew experiences as caregivers is not always evident without a full read of the  
33 publication. For example, in the study cited above (Roberto & Savla, 2022), three of the nine  
34 rural extended kin caregivers were middle-aged nieces who provided their relatives with help  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 with various instrumental and personal care tasks, and relied on other family members (e.g.,  
4 spouse, sibling) for assistance with the care of their care. Although no significant differences  
5 were found among different types of extended family caregivers and caregiving difficulties, 25%  
6 of nieces/nephews in the quantitative sample reported physical difficulties related to providing  
7 care compared with just 10% of siblings and 7% of stepkin. Overall, many of the nieces/nephews  
8 in this study reported physical strain and anxiety symptoms, paralleling reports in the literature  
9 about the experiences of adult child caregivers (Bastawrous, et al., 2015). However, they were  
10 not necessarily their relative's primary caregiver; a gap we address in the current study.

### 21 **Theoretical Framework and Research Questions**

22  
23  
24 A life course perspective informed our understanding of caregiving families. This  
25 theoretical perspective draws attention to the complexity of life pathways, relationships, and  
26 broader social and cultural factors, coupling the older person's life and dementia trajectory with  
27 their nieces'/nephews' lives and developmental trajectory. Specifically, the principle of "linked  
28 lives," which emphasizes relational interconnectedness and embeddedness (Elder, 1998) is  
29 particularly relevant for examining how nieces/nephews become primary caregivers for their  
30 aunts/uncles. Throughout the life course, nieces'/nephews' lives are embedded within family  
31 networks shaped by these relationships and influenced by the social contexts and structures in  
32 which they live. Thus, we anticipated that assuming the primary caregiver role would be  
33 influenced not only by practical factors such as the nieces'/nephews' availability, proximity to,  
34 and the care needs of their aunts/uncles, but also by their engagement and emotional closeness  
35 shared with their aunts/uncles throughout their life.

36  
37  
38 While caregiving relationships often involve positive experiences about caregiving and  
39 meaningful connections with their relatives (Quinn et al., 2019), the stress associated with  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

dementia caregiving is pervasive and often increases as the disease progresses (van den Kieboom et al., 2020). To understand caregiving stress and its consequences, we drew upon Pearlin's Stress Process Model, which conceptualizes caregiving outcomes (e.g., burden, guilt, role captivity) as resulting from the interplay among background and context variables (e.g., gender; living arrangements), primary caregiving-specific stressors (e.g., care needs; behavioral symptoms), and non-caregiving secondary stressors (e.g., general family conflicts and strain).

Guided by the life course perspective and grounded in the stress process framework, our specific research questions asked: (1) How do past and present family relationships and dynamics influence nieces' and nephews' caregiving responsibilities and practices? and (2) What are the relationships between caregiving-specific stressors, non-caregiving stressors, and caregiver outcomes among niece/nephew primary caregivers?

### Methods

The niece/nephew data came from our telephone-based, mixed-methods study of extended family members who serve as a primary caregiver for a relative living with dementia. The aim of the larger study is to interview extended family members to learn about their paths to dementia caregiving, how they manage their care responsibilities, and the resultant effects on their well-being and that of the person living with dementia. Data collection began in 2021 and is on-going. The Virginia Tech Institutional Review Board approved the study (#20-742).

### Study Sample

The 20 niece and 5 nephew primary caregivers ranged in age from 38 to 67 ( $M_{age} = 55.44$  years;  $SD = 8.68$ ); most caregivers ( $n = 16$ ) identified as White. Ten caregivers relied on informal helpers, typically another family member, to assist them with the personal care (activities of daily living; PADLs) of their aunts/uncles. Four caregivers relied on paid services

1  
2  
3 to help their relatives with PADLs. The caregivers reported caring for their relatives for an  
4  
5 average of 3.62 years ( $SD = 3.94$ ,  $R = 0.12$ – $20$ ). The 19 aunts and 6 uncles ranged in age from  
6  
7 56 to 97 ( $Mage = 79$ ,  $SD = 10.64$ ); 8 lived with the caregiver. They had an average of about 10  
8  
9 memory and behavioral expressions of dementia ( $SD = 4.25$ ,  $R = 3$ – $18$ ) and 2.68 personal care  
10  
11 limitations ( $SD = 2.04$ ,  $R = 0$ – $6$ ). Table 1 provides additional sample demographics.  
12  
13

## 14 15 **Recruitment**

16  
17 Caregivers were recruited from Virginia, Kentucky, Maryland, North Carolina,  
18  
19 Tennessee, and West Virginia. These states share many demographic characteristics, most  
20  
21 notably a high percentage of adults aged 65+, a significant minority population, and a mix of  
22  
23 metropolitan and non-metropolitan areas. Following recommendations for sampling hard-to-  
24  
25 reach and low-prevalence populations (King et al., 2014; Shaghghi et al., 2011), we used a  
26  
27 variety of agency-based (e.g., Health Care System, Area Agencies on Aging) and location-  
28  
29 sampling (e.g., churches and education/support programs for dementia caregivers; food banks)  
30  
31 recruitment approaches. Other recruitment strategies included employing a recruitment firm  
32  
33 specializing in dementia studies, posting on Alzheimer's Association TrialMatch, presenting  
34  
35 about the study on radio shows, in local newspapers and newsletters, and on social networking  
36  
37 services (e.g., Facebook, Nextdoor), and advertising through libraries, community colleges, and  
38  
39 other community entities.  
40  
41  
42  
43

44  
45 Potential participants were identified either through an agency/organization or they self-  
46  
47 identified by completing a secure interest form accessed from the project's website. Project staff  
48  
49 contacted them to provide information about the study, answer questions, confirm their interest  
50  
51 and eligibility, and arrange the day/time for the telephone interview. Prior to the start of data  
52  
53 collection, the caregivers received written information about the study, a detailed consent form,  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 visual aids for the telephone interview and they provided verbal consent to participate in the  
4  
5 study.  
6

7  
8 Caregiver inclusion criteria includes being aged 18 or older; primarily responsible for the  
9  
10 hands-on care and/or overall management of care for their relative who lives in the community  
11  
12 (i.e., not service-enriched housing or care facilities); has face-to-face contact with the relative at  
13  
14 least 3 days a week or co-resides with them; speaks/reads English; and has no difficulty  
15  
16 talking/hearing on the telephone. In addition, caregivers responded to three items from the  
17  
18 *Clinical Dementia Rating* (Hughes et al., 1982) to provide an overall assessment of their  
19  
20 relatives' abilities in three domains: Memory, Personal Care, and Judgement/Problem Solving.  
21  
22 Only caregivers who reported that their relative exhibited at least mild to moderate memory loss  
23  
24 and moderate/severe difficulties in managing finances or routine household tasks were eligible  
25  
26 for the study. Of the 40 nieces and 10 nephews who received information or inquired about  
27  
28 participating in the study, 36 met the screening criteria and 34 agreed to be interviewed. Nine of  
29  
30 the 34 who initially agreed to participate later declined. The primary reasons for not participating  
31  
32 were lack of interest and not having the time. The analytical sample is comprised of 17 nieces  
33  
34 caring for aunts, 3 nieces caring for uncles, 4 nephews caring for aunts, and 1 nephew caring for  
35  
36 an uncle.  
37  
38  
39  
40  
41

## 42 **Interviews and Measures**

43  
44  
45 Using a concurrent nested Qual + Quan study design (Tashakkori et al., 2002), data from  
46  
47 the qualitative portion of the interview provided the context for the care situation (e.g.,  
48  
49 relationship dynamics; role acquisition/responsibilities; family expectations). The interview also  
50  
51 complemented and aided in interpreting the quantitative interview data (e.g., force-choice items;  
52  
53 structured scales) by providing more nuanced insights about the relationship between the  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 caregivers and their relatives and their caregiving experiences. Measures were taken to ensure  
4 data quality and reliability, including recording interviews (with consent). Interviews lasted  
5 approximately 60-70 minutes with the audio-recorded qualitative portion averaging 23 minutes  
6 ( $R = 12-41$  min). The audio-recordings were transcribed professionally, followed by verification  
7 by a research team member who compared each transcript with the recording. Caregiver  
8 compensation was a \$30.00 gift card.

9  
10 The qualitative portion of the interview solicited biographical accounts of the caregivers'  
11 past and present relationship with their aunts/uncles and caregiving trajectory and experiences.  
12 We used semi-structured interview questions (with probes) to gather their personal stories to  
13 bring to light relationships with aunts/uncles and their perspectives and experiences as primary  
14 dementia caregivers (see Supplementary Material).

15  
16 The quantitative items included in the current analysis focused on demographic  
17 characteristics, potential primary and secondary stressors, and caregiving outcomes. To assess  
18 caregiving-related primary stressors, caregivers identified the occurrence (yes/no) of **behavior**  
19 **symptoms of dementia** (Teri et al., 1992;  $\alpha = .90$ ), help needed with **personal activities of daily**  
20 **living** (PADL; ability to eat, dress, groom themselves, bathe/shower, use the toilet, get/in/out of  
21 bed; Katz & Akpom, 1976;  $\alpha = .86$ ) and **instrumental activities of daily living** (IADL; take  
22 medications, do housework, shop for food, prepare food, do laundry, use transportation, handle  
23 money; Lawton & Brody, 1970;  $\alpha = .70$ ). Caregivers also reported the sources of assistance for  
24 PADL tasks, specifically identifying whether help was provided by other informal helpers (e.g.,  
25 family and friends) or paid caregivers.

26  
27 **Family strain**, reflecting a secondary stressor, was measured using a 4-item measure that  
28 asked about the caregiver's relationship with family members in general: made too many  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 demands on them, criticized them, let them down, or got on their nerves (1=Never, 4 = Often).  
4  
5 Higher scores indicate greater family strain (Walen & Lachman, 2000;  $\alpha = 0.71$ ).  
6

7  
8 Caregiving outcomes were measured using established scales assessing multiple  
9  
10 dimensions of caregiver stress. **Caregiver burden** was assessed using the 12-item version of the  
11  
12 Zarit Burden Interview to capture both personal and role strain associated with caregiving (e.g.,  
13  
14 Do you feel stressed between caring for your relative and trying to meet other responsibilities  
15  
16 (work/family)?). Responses were on a 4-point Likert-type scale and summed, with higher  
17  
18 average scores indicating greater burden (Bédard et al., 2001;  $\alpha = 0.82$ ). **Caregiving-related**  
19  
20 **guilt**, a measure of feelings of guilt (e.g., I keep thinking I should be doing more for the person  
21  
22 living with dementia), was comprised 7-items adapted from the Caregiver Guilt Questionnaire  
23  
24 (Losada et al., 2010;  $\alpha = 0.88$ ). Items were rated on a 4-point Likert-type scale and summed,  
25  
26 with higher scores indicating stronger feelings of guilt. **Role captivity**, the perception of being  
27  
28 trapped or captive in the caregiving role, (e.g., How often have you wished you were free to lead  
29  
30 a life of your own), was measured using 3-items adapted from Pearlin's Stress Process Model  
31  
32 (Pearlin et al., 1990;  $\alpha = 0.56$ ). Responses were on a 4-point Likert-type scale and summed,  
33  
34 where higher average scores indicating greater role captivity.  
35  
36  
37  
38  
39

#### 40 **Analysis**

41  
42 We used qualitative data to understand relationship dynamics that influence nieces' and  
43  
44 nephews' caregiving experiences (RQ1). The qualitative analysis was guided by the underlying  
45  
46 principles of a life history approach (Coles & Knowles, 2001), a qualitative method that relies on  
47  
48 individuals' social construction of personal experiences and the connections between past and  
49  
50 current situations (Hagemaster, et al, 1992). We uncovered continuities, changes, and  
51  
52 complexities in the nieces'/nephews' lives to create a nuanced, holistic, and contextualized  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 understanding of their lived experience as dementia caregivers. The open-ended interview  
4  
5 questions evoked memories or stories about influences on their past relationship with their  
6  
7 aunts/uncles, and how they came to be their caregivers. Further, they provided the backdrop or  
8  
9 context for understanding how they navigate their current caregiving role and responsibilities.  
10  
11

12         The first author read the caregivers' interviews in their entirety multiple times, noting life  
13  
14 stages, supporting and challenging family situations, and key aspects of their relationship with  
15  
16 their aunts/uncles. Although the life history approach does not require devising and strictly  
17  
18 adhering to rigid coding and categorization (Coles & Knowles, 2001), we used an Excel  
19  
20 spreadsheet to systematically focus our attention and document (1) relationships with  
21  
22 aunts/uncles (2) broader family dynamics, (3) who helps provide care, and (4) caregiving  
23  
24 experiences and challenges, paying careful attention to the details and complexities of their lives.  
25  
26 Based on our holistic understanding of the caregivers' life, we identified emergent themes and  
27  
28 patterns in the data, which allowed us to develop a collective depiction of the lives of  
29  
30 niece/nephew dementia caregivers (Coles & Knowles, 2001). The second author verified the  
31  
32 family descriptions and emergent themes; disagreements were resolved through discussion and  
33  
34 themes refined as needed. As it became clear that there were distinct ways in which the  
35  
36 nieces/nephews' engaged others in the care of the aunts/uncles, further coding was done within  
37  
38 the care systems theme. Using the same process as described above, the coding/analysis within  
39  
40 this theme was led by the second author and verified by the first author.  
41  
42  
43  
44  
45  
46

47         To address our second research question (relationship between caregiving stressors, non-  
48  
49 caregiving stressors, and caregiver outcomes) the qualitative and quantitative data were analyzed  
50  
51 separately, and then findings were combined to interpret and discuss the results (Creswell et al.,  
52  
53 2003). Given the small sample, quantitative data were analyzed using Spearman's rank-order  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 correlations ( $r_s$ ) for ordinal variables and point biserial correlations involving binary variables  
4  
5 ( $r_{pbs}$ ) to examine the relationship between caregiving experiences and outcomes (Table 2).  
6  
7

## 8 Findings

9  
10 We organized the study findings around four overarching themes to tell the caregiving  
11 story of these extended family caregivers: (1) Relationship Foundations; (2) Pathways to  
12 Caregiving; (3) Care Systems; and (4) Trials and Tribulations. These themes reveal the complex  
13 interplay between past relationships, caregiving responsibilities, support systems, and caregiving  
14 challenges faced. We synthesized the data, highlighting common patterns and any outliers within  
15 each theme and utilized poignant and exemplifying quotes from the interviews to illustrate the  
16 findings (Eldh et al., 2020). Pseudonyms were used to protect participant identity.  
17  
18  
19  
20  
21  
22  
23  
24  
25

### 26 Relationship Foundations

27  
28 *Childhood Beginnings.* Contact with aunts/uncles typically began early in the  
29 participants' childhood. Growing up, 17 of the nieces/nephews lived in the same town as their  
30 aunts/uncles. Spending birthdays and holidays with extended kin was the norm for most of these  
31 families. Daily to weekly interactions were common among those who lived nearby. For 7  
32 participants who lived at a distance or in different states from their aunts/uncles, visits typically  
33 occurred annually. Only Noah (age 64) did not meet his aunt until he was 12 years of age. He  
34 visited her one additional time at age 15, followed by a 40-year gap in contact.  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44

45 Emotionally close relationships with their aunts/uncles were established during childhood  
46 for 17 of the 25 participants, even among those who lived at a distance. They described their  
47 relative in positive terms (“fun”; “favorite”) and viewed them as someone with whom they  
48 confided or turned to for advice. In two families, the aunt took on more of a “mother” role.  
49 Nadine (age 54), who was raised in an abusive household, described her aunt as “more of a  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 mother than my mother” and the person she could talk to “about what I was going through at  
4 home.” Nate (age 60), whose mother had alcoholism, explained that he was raised by his aunt  
5 early on. When he was nine years old, his mother became sober, and he moved in with her. Even  
6 then, he stayed at his aunt’s house most weekends.  
7  
8  
9  
10

11  
12 Participants did not have any serious or long-lasting conflicts with their aunts/uncles.  
13 When a conflict occurred, it centered around typical childhood behaviors (e.g., breaking rules;  
14 blaming behavior) or their relative’s ways of being (e.g., mean streak; manic behavior).  
15  
16  
17  
18

19 *Emerging Adulthood – Changing Lives.* With life transitions, nieces/nephews and their  
20 aunts/uncles often went separate ways. College and work, marriage and divorce, and raising  
21 children were common reasons for less frequent contact and limited time to maintain or grow  
22 their relationship. However, geographic separation and other changes did not interfere with  
23 especially close relationships. Nadiya (age 56) explained that she and her uncle were close in  
24 age; she “saw him all the time growing up and [they] went everywhere together.” They remained  
25 close “even when she went off to college.” After college, although she worked in PA and he  
26 lived in NJ, “He was the first one I told when I was getting married, and when I was pregnant, he  
27 was the first to know.” Similarly, Nan (age 63) who remained close to her aunt throughout  
28 adulthood explained how their relationship changed from “a kid relationship to an aunt to an  
29 adult relationship.”  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43

44 We would always talk, and catch up; she'd ask about school. Or, as I got married, she was  
45 just somebody you could always ask for feedback. As I got divorced, she was somebody  
46 who had also been divorced, so she was somebody that I could talk to about that.  
47  
48  
49  
50  
51 These early relationship dynamics often set the stage for the various pathways through which  
52 nieces and nephews became caregivers.  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3           *Establishing Bonds in Adulthood.* For six nieces and two nephews, their relationship  
4 with their aunts/uncles did not solidify or become close until they were adults. Geographic  
5 distance contributed to a lack of closeness in six of these relationships, whereas personalities  
6 came into play for two nieces who lived close to their relative. In all families, it was life  
7 circumstances that brought them together in adulthood. Noah (age 64) explained that his mother  
8 and her sister (aunt) were not close and had gone “their separate ways all through life.” His aunt  
9 returned to her hometown in midlife. That was when the sisters “became reacquainted and  
10 became much closer.” It was not until seven years later when he moved back to his hometown to  
11 care for his mother that he began to get to know his aunt. Although they had some disagreements  
12 about his mother’s care, they became “quite close as friends.”  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25

26           In two families, their relative’s mental state (e.g., mental illness, alcoholism) contributed  
27 to the lack of closeness early on. Nancy (age 61) said she “did not bond with my uncle growing  
28 up.” He was an entertainer and traveled a lot.  
29  
30  
31  
32

33           It was after he was back home, later on in years. . . . My uncle was an alcoholic in the  
34 later years of his life. . . . Him and I grew close together because I had to take him out of  
35 his home, sober him up, then put him back with his wife. . . . We had to do a lot of  
36 business together, so that's when we became more close, and talking, and doing things  
37 with each other.  
38  
39  
40  
41  
42  
43  
44

### 45 **Caregiving Pathways and Responsibilities**

46  
47           *Becoming a caregiver.* Sixteen nieces and three nephews never expected to be their  
48 relative’s caregiver. Typically, they either gradually “fell into it” or abruptly assumed the role  
49 because of “family circumstances” that left no one else willing or able to assume care for the  
50 aunts/uncles. Nicholas (age 60) said being a caregiver for the aunt “was not part of the plan,”  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 and that he assumed the role because his wife and her sisters all worked outside the home  
4  
5 whereas he worked remotely and had more flexibility. At first, he provided minimal help with  
6  
7 banking and transportation, but over time his responsibilities increased to include daily IADL  
8  
9 assistance (e.g., cooking, cleaning).  
10  
11

12 When more help was needed and/or because of “altercations” in care relationships, seven  
13  
14 nieces took on the primary caregiving role. Naomi (age 52) shared that her mother [aunt’s sister],  
15  
16 whose “health was bad,” first cared for the aunt.  
17  
18

19 She [aunt] lived at my mom’s and then it proved too much for my mom. They'd get in  
20  
21 fights and [aunt] would throw canned food at my mom's head. She [mother] wasn't  
22  
23 physically able to do anything, but she had a sharp tongue, so they'd get into some  
24  
25 altercations.  
26  
27

28 Prior to her transition to full-time caregiver, Naomi was paid through a state-funded program to  
29  
30 provide a few hours of care for her aunt and her aunt frequently stayed with her. Naomi’s mother  
31  
32 eventually told her, “Go ahead and take her.”  
33  
34

35 Only four nieces and two nephews expected to be their relative’s caregiver. Family care  
36  
37 was often seen as the norm or obligation in these families. Nadine (age 54) explained,  
38  
39

40 My older son lived in her [aunt] household coming up because I was working too early to  
41  
42 leave them home. And because of the care that she gave him, I just felt obligated . . .like  
43  
44 I'm supposed to do what I'm doing.  
45  
46

47 Nash (age 43) said that his aunt (father’s sister) moved in with his father about three years ago to  
48  
49 help her brother while he was recovering from an accident. During this time, they all agreed that  
50  
51 living with family “was a good place for her to be.” Having his aunt live nearby allowed Nash  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 “to step in and fill the [care] role as needed without telling her that” as he “could see that her  
4  
5 memory or dementia was just progressing.”  
6

7  
8 *Care responsibilities.* Initially, it was not uncommon for the nieces/nephews to provide  
9  
10 minimal help with IADLs and social/emotional support before taking on more frequent or  
11  
12 intense responsibilities. Nala (age 43) said at first, she did simple things for her aunt, “like call at  
13  
14 meal time and tell her how to heat something up. . . .then it got to where I was hanging around  
15  
16 more, trying to see how she's doing.” Currently, the niece was also doing “all of her cooking  
17  
18 [and] most of the cleaning.” Nara (age 53) equated the early help she provided her aunt as “being  
19  
20 like a friend,” sometimes helping [aunt] with grocery shopping, cooking, and driving her to  
21  
22 doctor's appointment. When interviewed, she also was providing PADLs assistance.  
23  
24

25  
26 Sometimes [aunt's] balance is not so good getting dressed, so I help her; sometimes  
27  
28 helping her get out of chairs when she's not able to, and sometimes she has occasional  
29  
30 incontinence so help clean up the messes, help her get in/out of the shower.  
31  
32

### 33 **Care Systems**

34  
35 Although the nieces/nephews identified as primary caregivers, only Nash (age 43) was a  
36  
37 sole caregiver for his aunt. The other caregivers most frequently received help from their own  
38  
39 family members as well as those of the person living with dementia. Because assistance with  
40  
41 caregiving ultimately centers on the needs of the person living with dementia, we identified  
42  
43 family helpers within the care system by how they were genealogically related to the person  
44  
45 living with dementia. Specifically, if the helper's closest genealogical tie was to the person living  
46  
47 with dementia, we labeled them as the family of the person living with dementia (e.g., the  
48  
49 person's sister is their family helper even though she may be the mother of the primary  
50  
51 caregiver). Conversely, if the helper's immediate genealogical tie was to the primary caregiver  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 (e.g., spouse, children) we label them as family of the primary caregiver. The primary  
4  
5 caregiver's helpers often provided help with IADL and PADLs, while assistance from relatives  
6  
7 of the person living with dementia was usually limited to companionship or light tasks. Natalie  
8  
9 (age 58), who helps her aunt with chores and checks on her about eight times a day, relies on her  
10  
11 daughter to "watch out" for the aunt when she needs to be out of town. Nicholas (age 60) called  
12  
13 himself the "captain of the team." He provides regular daily assistance for the aunt whereas his  
14  
15 wife and her sisters help with bathing. In rare instances, the caregivers spoke about "taking  
16  
17 shifts." Natasha (age 55) provided care for her aunt in the mornings, her mother [aunt's sister]  
18  
19 took the afternoon shift, and the aunt's other sister comes on Friday night and spends most of  
20  
21 each Saturday caring for her sister.  
22  
23  
24  
25

26  
27 It was more common for members of the aunts'/uncles' immediate family to provide help  
28  
29 with distinct IADL tasks. Nan (age 63) explained that "[My aunt's] daughter takes on full  
30  
31 financial responsibility for her mother" and "helps with transportation." More often, the  
32  
33 immediate family of the person living with dementia provided sporadic help, but typically only  
34  
35 when the caregivers asked, and their help was not always forthcoming. Nixie (age 32) said that if  
36  
37 she really needed help, "My grandpa's [aunt's father] right next door. I mean, if push comes to  
38  
39 shove, he'll help."  
40  
41

42  
43 More than half of the niece/nephew caregivers (n=18) also relied on paid service  
44  
45 providers. Typically, caregivers who used in-home or community-based care (e.g., Meals-on-  
46  
47 Wheels; Program of All-Inclusive Care for the Elderly [PACE]) were employed or had physical  
48  
49 conditions that limited their abilities to provide hands-on care. The common sentiment among  
50  
51 these caregivers was that if they did not have formal help to supplement the help they and their  
52  
53 family provided, "it would be much, much harder" to care for their aunts/uncles.  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 Analyzing the flow of assistance across families, four distinct patterns emerged reflecting  
4 how nieces/nephews organized support for caregiving (Figure 1). *Coordinated Family Support*  
5 involved both the niece's/nephew's own family and members of the aunt's/uncle's family  
6 actively helping with PADLs and IADLs, indicating strong collaboration and the recognition of  
7 the niece/nephew as a primary caregiver. For example, Netta (age 64), whose aunt lives alone,  
8 provides hands-on-care and assistance at least three days a week. Her aunt's daughter "comes in  
9 after work . . . and every [Netta's] mom lives close by and goes in to check on her every  
10 evening." In addition, Netta's cousin "has a friend that she will pay to go in on a morning that  
11 [Netta] can't go." *Caregiver Centric Support* was characterized by the niece's/nephew's own  
12 family primarily helping with PADLs and IADLs, while the aunt's/uncle's family typically  
13 provided companionship and peripheral support, mainly with IADLs. For instance, Nicole's (age  
14 58) mother [aunt's sister] will frequently spend the day with her aunt. "[Mother] has dementia  
15 too, but together they can spend hours just playing cards. So, I know on those days she has  
16 company. I'll still check in, but I know that they're good, they're confined together . . . playing  
17 cards or watching TV all day." In these families, the nieces/nephews also had paid helpers to  
18 supplement their caregiving efforts, suggesting acceptance of their caregiver role, but also  
19 reflecting potential gaps or limitations in family engagement. *Task-Focused Distributed Support*  
20 occurred when nieces/nephews received targeted help with specific IADLs from both their own  
21 and their aunt's/uncle's family. Aunts/uncles in this pattern typically required minimal assistance  
22 with PADLs. In these families, the niece/nephew caregivers appeared to function as a  
23 coordinator of care tasks and were supported by the family in fulfilling specific care needs. As  
24 Nan (age 63) explained, "In all honesty, [Aunt's] daughter is part caregiver, because we both live  
25 in the house. But when it comes to day-to-day functioning and managing activities, I am the one  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 who takes responsibility for that.” *Exclusive Paid Support* was observed when nieces/nephews  
4  
5 relied only on paid helpers to assist with PADLs and IADLs, indicating situations where  
6  
7 informal support was either unavailable or insufficient. Such was the case for Nina (age 54)  
8  
9 whose aunt lives with her. She provides all of the care for her aunt and has an “aide come in  
10  
11 during the day ecause I work.”  
12  
13

14  
15 Integrating these qualitative patterns with quantitative findings provide additional depth  
16  
17 to our understanding of the caregiving arrangements. Quantitative analyses revealed that  
18  
19 nieces/nephews who relied on family support for a greater number of caregiving activities for  
20  
21 their relative reported higher family strain ( $r_s = 0.60, p < 0.01$ ) and experienced greater caregiver  
22  
23 burden ( $r_s = 0.53, p < 0.01$ ). Notably, niece caregivers reported more difficulties with other  
24  
25 family members than nephew caregivers ( $r_{pbs} = 0.45, p < 0.03$ ). Together, these findings suggest  
26  
27 that while family support is essential, it may also contribute to increased burden and strain due to  
28  
29 coordination challenges and uneven distribution of caregiving tasks.  
30  
31

### 32 33 **Trials and Tribulations**

34  
35 On average, the nieces/nephews reported that their aunts/uncles experienced nearly 10  
36  
37 memory and behavior problems, most frequently forgetting the day, repeatedly asking the same  
38  
39 question, difficulty remembering recent events, losing or misplacing items, feeling sad or  
40  
41 anxious, and challenges in controlling bowel and bladder function. Correlation analyses further  
42  
43 supported qualitative findings: nieces/nephews whose aunts/uncles had a greater number of  
44  
45 problems experienced greater caregiver burden ( $r_s = 0.43, p = 0.04$ ) and more family strain ( $r_s =$   
46  
47  $0.46, p = 0.03$ ), underscoring the direct relationship between severity of care needs and caregiver  
48  
49 stress.  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 Caring for aunts/uncles requiring assistance with both IADLs and PADLs, as well as for  
4 those in the latter stages of cognitive decline, was demanding and took a toll on the  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

Caring for aunts/uncles requiring assistance with both IADLs and PADLs, as well as for those in the latter stages of cognitive decline, was demanding and took a toll on the nieces'/nephews' patience. Nadiya's (age 56) comment that "it's like [having] a forever baby" was echoed by others. She explained.

Can't just pick up and leave without somebody being there with him. . . You never get done doing anything, and you have to always remember that 'this is going to happen, I have to do this, I can't get this, and you can't leave this out here, pick this up'.

Nieces/nephews also reported that the ways their aunts/uncles responded to their help contributed to the challenges they associated with caregiving. At times, some of the aunts/uncles not only resisted help or refused to follow instructions, but responded in ways the nieces/nephews construed as "mean" and "unappreciative." For example, Natasha (age 55) said that her aunt was "very stubborn" and often responded to attempts to help her by saying things like, "She [aunt] don't need no help. Nobody needs to do anything for her. She can do it herself." Such responses further compounded the stress of caregiving.

Most nieces/nephews did not anticipate how "all-consuming caregiving is." Neil (age 49) stated "The hardest part is just having the time; being able to divide the time from what you have to do in your own personal life versus the time [uncle] requires." Similarly, Nancy (age 61) commented, "Some days you just don't feel like it, but you have to push yourself to do the thing, to go around there and speak to him [uncle]. It can be very stressful sometimes. Sometimes you're just tired." These reflections illustrate how caregiving demands impinge on caregivers' personal lives, leaving them physically and emotionally exhausted.

## Discussion

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

Demographic trends suggest the need to expand the study of dementia family caregiving beyond spouse and adult child caregivers. Furthermore, there is insufficient recognition of the growing complexity to American family life and variations in family structures that present both opportunities and challenges for the care of persons living with dementia (Roberto & Blieszner, 2015). The findings of this study begin to address this dearth of knowledge and provide new insights into the care arrangements for aunts/uncles living with dementia. Specifically, they underscore the evolving nature of their relationships with their nieces/nephews and the unique experiences of nieces/nephews in caregiving roles.

In early childhood, nieces'/nephews' interactions with aunts/uncles were linked to their parents' involvement with their siblings (Milardo 2010) and the establishment of shared family relationships and associated activities over time (Elder 1998). Emotionally close relationships with their aunts/uncles developed for most of the nieces/nephews during childhood and adolescence, only to be interrupted by life events and individual transitions. In adulthood, interdependent, and often reciprocal relationships, were (re)established. Our findings align with Milardo's (2010) observations of the importance of early family interactions in shaping extended kin relationships. We extend his work by highlighting how these relationships evolve into primary caregiver roles, demonstrating how early life bonds influence caregiving decisions later in life.

The transition to the caregiver role marked a significant change in the nieces'/nephews' relationship identity and role involvement (Elder, 1998). This transition appeared seamless, particularly for nieces/nephews actively engaged in their aunt's/uncle's life prior to the onset of dementia. Even so, unlike for spouse and adult children who accept caregiving as an expected and often obligatory role, most nieces/nephews did not anticipate becoming their relative's

1  
2  
3 caregiver (Schulz & Eden, 2016). Rather, some viewed their situation as an opportunity to give  
4  
5 back their aunts/uncles for the help and support they received from them at earlier stages of life  
6  
7 (Bui et al., 2022).  
8  
9

10 Our findings also point to the importance of understanding family context for dementia  
11 care. While early research on family relationships speculated that singlehood and childlessness  
12 increased reliance on extended family for care (Wegner & Burhold, 2001), our findings suggest  
13 that current life circumstances, rather than traditional family structures, play a larger role.  
14  
15

16 Notably, while only three of the aunts/uncles in our study were married when the nieces/nephews  
17 assumed their care, nearly one-half had at least one living child, and over two-thirds had a living  
18 sibling, yet nieces/nephews assumed primary caregiving responsibilities. The nieces/nephews did  
19 not express animosity about being a caregiver, but rather evoked family care norms (Gans &  
20 Silverstein, 2006) and personal beliefs that extended beyond their immediate family members. In  
21 a few situations, the parents of the nieces/nephews relinquished the primary caregiver role for  
22 their siblings (i.e., the aunts/uncles) because of personal health and relational challenges in  
23 managing their care needs. Perhaps addressing the needs of their parents, rather than a sense of  
24 responsibility or feeling obligated for their extended family members, propelled them into  
25 providing care for their aunts/uncles. These findings exemplify the concept of linked lives,  
26 showing how caregiving roles are shaped not just by direct relationships with care recipients, but  
27 by interconnected familial obligations and the relational dynamic across the extended family  
28 network (Elder, 1998). In addition, most nieces/nephews had a positive relationship with their  
29 aunts/uncles. As in older parent-adult child relationships, this affectual assessment of their  
30 relationship appeared to underly their willingness to assume their primary caregiver role  
31 (Leopold et al., 2014).  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 As is common in caregiving journeys, the nieces/nephews noted patterns of stability and  
4 change in care needs and relationships with their aunts/uncles (Aneshensel et al., 1995). When  
5 their involvement progressed from providing minimal assistance and oversight to providing  
6 hands-on help with PADLs and IADLs, nieces/nephews often found the shift in their  
7 responsibilities disconcerting, and reinforced the importance of seeking additional assistance to  
8 meet their aunts'/uncles' care needs and influenced how they perceived and managed their  
9 dementia-related behaviors (Roberto et al., 2024).

10  
11  
12  
13  
14  
15  
16  
17  
18  
19 Whereas more than half of spouses and nearly three-quarters of adult children typically  
20 provide hands-on care for their relatives entirely on their own (Ornstein et al., 2019; Lin et al.,  
21 2020; Ornstein et al., 2019), nieces/nephews in our study predominantly served as care  
22 coordinators, facilitating and managing the care of their aunts/uncles through distributed care  
23 systems. Typically, the aunts'/uncles' immediate family members helped with IADLs, rarely  
24 extending their support beyond these tasks. Caregivers tried to ensure that their relatives' care  
25 needs were being met by engaging individual family members when needed, but there was little  
26 or limited coordination among the family helpers. The fragmented nature of caregiving systems  
27 and structures underscore the need for more coordinated and proactive approaches to supporting  
28 extended family caregivers to ensure that the needs of older adults living with dementia are  
29 adequately addressed (Koehly et al., 2015). As is commonly reported in the service use literature  
30 (Ornstein et al., 2022), few nieces/nephews relied on assistance from paid services to meet the  
31 care needs of their aunts/uncles. When services were used, they tended to supplement IADL  
32 help they and other family members provided.

33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60  
As well documented in the family caregiving literature, stressors associated with  
providing care to aunts/uncles stemmed from both primary and secondary sources (Pearlin et al.

1990). The cognitive changes associated with dementia were significant sources of stress which were often exacerbated by the aunt/uncle's hesitation to accept help. These challenging interactions heightened feelings of helplessness and frustration among caregivers as they attempted to balance providing care and support while respecting their relatives' autonomy and boundaries. The uneven distribution of care responsibilities among family members also played a critical role in shaping the caregiving experience, placing a disproportionate responsibility on the niece/nephew caregivers to manage the bulk of caregiving duties on their own or coordinate between multiple care helpers, leading to significant caregiver burden. Conversely, having at least one other family member help with the care of the person living with dementia may have protected niece/nephews from feelings of role captivity.

### **Limitations and Future Research**

This study provides the first focused examination of niece/nephew dementia primary caregivers, but it is not without limitations. While we examined caregiving relationships from the perspective of nieces/nephews, the study of the experiences of extended family caregivers would benefit from the use of methodological approaches yielding data from multiple points of view. Nieces/nephews provided mostly a retrospective account of their family relationships, changes in caregiving responsibilities, and care systems used. Longitudinal studies of extended family caregiving are needed to explore care and relationship dynamics as a relative's dementia progresses and family circumstances change. In addition, larger samples of niece/nephew primary caregivers are necessary to explore nuances in caregiving experiences, care patterns, and outcomes (e.g., burden, guilt) by gender, race, the composition of care dyads, and the intersections of such variables. Studying contemporary family structures and circumstances

1  
2  
3 surrounding the care of persons living with dementia will offer new insights about kin  
4  
5 composition and support beyond the traditional nuclear family model of care.  
6

### 7 8 **Practice Implications** 9

10 Study findings suggest that nieces/nephews are not bound by traditional family structures  
11 and roles and are acknowledged by their family as the primary caregiver for their aunts/uncles. In  
12 this role, nieces/nephews were responsible for providing direct care as well as managing  
13  
14 complex care arrangements. Specifically, as primary caregivers, they often coordinate with  
15  
16 multiple immediate and extended family members to help them with the care of their aunt/uncle.  
17  
18 However, some niece/nephew caregivers encountered difficulties in engaging other family  
19  
20 members to share caregiving tasks. Given these challenges, nieces/nephews may benefit from  
21  
22 interventions that focus on helping them effectively obtain support and distribute caregiving  
23  
24 responsibilities among available family members and other informal and paid help.  
25  
26  
27  
28  
29

30  
31 Professionals need to recognize nieces and nephews as primary caregivers and help them  
32  
33 navigate any confusions or conflicts related to their role. Providing families and healthcare  
34  
35 providers with resources that clarify and affirm the contributions of extended family caregivers  
36  
37 may also help reduce uncertainty and improve support for niece/nephew caregivers. Importantly,  
38  
39 these interventions must be tailored with the understanding that multiple family members may  
40  
41 need to be engaged to achieve optimal outcomes for both the family and their relative living with  
42  
43 dementia (Freedman et al., 2024). Evidence-based programs should incorporate family-focused  
44  
45 approaches to improve coordination, communication, and equitable distribution of caregiving  
46  
47 responsibilities, when possible. Emerging mobile apps show promise in facilitating care  
48  
49 coordination among family members, but this area of research is still in its early stages  
50  
51  
52 (Grossman et al., 2018).  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 Similarly, ensuring that niece/nephew caregivers are informed about and have access to  
4 home-and-community based services for their older relatives is critical, as service use can  
5 enhance and extend their ability to provide dementia care (Schulz & Eden, 2016). Local and state  
6 agencies, healthcare providers, and advocacy organizations must proactively disseminate  
7 information about available resources, including respite care, support groups, and financial  
8 assistance programs. Moreover, local, state, and national strategies must respect families'  
9 diverse circumstances, beliefs, and preferences in supporting older relatives living with  
10 dementia.  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23

24 Funding: This work was supported by the National Institute on Aging at the National Institutes of  
25 Health (R01AG069818).  
26

27 Conflict of Interest: Authors have no conflicts of interest to report.  
28

29 Data Availability: The study data are not available because data collection for the project is in  
30 progress and the investigators have not completed planned or expected analyses for future  
31 publications. The study was not preregistered.  
32  
33

34 Acknowledgements: The authors would like to thank Brandy Renee McCann for her role as  
35 Project Coordinator. We would also like to thank the graduate and undergraduate student team  
36 members for their assistance with recruitment and interviews. We also acknowledge Virginia  
37 Tech's Center for Gerontology and Institute for Society, Culture and Environment for their  
38 technical and infrastructure support.  
39  
40

41 Author Contributions: K. A. Roberto and J Savla planned the study and conceptualized the  
42 paper. K.A, Roberto led the preparation of and analysis of the qualitative data, and led the  
43 writing of the paper. J. conducted the quantitative analysis, verified the quantitative coding, and  
44 contributed to writing the paper. Both authors discussed the results and interpretation and  
45 commented on the manuscript.  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

## References

- 2024 Alzheimer's disease facts and figures. (2024). *Alzheimer's & dementia: The Journal of the Alzheimer's Association*, 20(5), 3708–3821. <https://doi.org/10.1002/alz.13809>
- Aneshensel, C. S., Pearlin, L. I., Mullan, J. T., Zarit, S. H., & Whitlatch, C. J. (1995). *Profiles in caregiving: The unexpected career*. Academic Press.
- Bastawrous, M., Gignac, M. A., Kapral, M. K., & Cameron, J. I. (2015). Factors that contribute to adult children caregivers' well-being: A scoping review. *Health & Social Care in the Community*, 23(5), 449-466. <https://doi.org/10.1111/hsc.12144>
- Bédard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. A., & O'Donnell, M. (2001). The Zarit Burden Interview: A new short version and screening version. *The Gerontologist*, 41(5), 652–657. <https://doi.org/10.1093/geront/41.5.652>
- Bui, C. N., Kim, K., & Fingerman, K. L. (2022). Support now to care later: Intergenerational support exchanges and older parents' care receipt and expectations. *The Journals of Gerontology: Psychological Sciences and Social Sciences*, 77(7), 1315–1324. <https://doi.org/10.1093/geronb/gbac059>
- Cole, A. L., & Knowles, J. G. (2001). *Lives in context: The art of life history research*. Rowman Altamira.
- Creswell J. W., Plano Clark V., & Guttman M. (2003). Advanced mixed method research designs. In Tashakkori A., & Teddlie C. (Eds.), *Handbook of mixed methods research in social and behavioral research* (pp. 209–240). Sage.
- Davis-Sowers, R. (2012). “It just kind of like falls in your hands” Factors that influence Black aunts’ decisions to parent their nieces and nephews. *Journal of Black Studies*, 43(3), 231-250. <https://doi.org/10.1177/0021934711415243>

- 1  
2  
3 Elder, G. (1998). The life course and human development. In R. M. Lerner (Ed.), *Handbook of*  
4 *child psychology: Vol: 1. Theoretical models of human development* (5th ed., pp. 939-  
5 991). John Wiley & Sons.  
6  
7  
8  
9  
10 Eldh, A. C., Årestedt, L., & Berterö, C. (2020). Quotations in qualitative studies: Reflections on  
11 constituents, custom, and purpose. *International Journal of Qualitative Methods*, 19,  
12 <https://doi.org/10.1177/1609406920969268>  
13  
14  
15  
16  
17 Freedman, A.V., Cornman, J.C., & Wolff, J.L. (2024). Caregiving trajectories and unmet care  
18 needs in later life, *The Gerontologist*, gnae136, <https://doi.org/10.1093/geront/gnae136>  
19  
20  
21 Gans D and Silverstein M (2006) Norms of filial responsibility for aging parents across time and  
22 generations. *Journal of Marriage and Family*, 68(4), 961–976.  
23  
24 <https://doi.org/10.1111/j.1741-3737.2006.00307.x>  
25  
26  
27  
28 Greenwood, N., & Smith, R. (2019). Motivations for being informal carers of people living with  
29 dementia: A systemic review of qualitative literature. *BMC Geriatrics*, 19, 169.  
30  
31 <http://doi.org/10.1186/s12877-019-1185-0>  
32  
33  
34  
35 Grossman, M. R., Zak, D. K., & Zelinski, E. M. (2018). Mobile apps for caregivers of older  
36 adults: Quantitative content analysis. *JMIR MHealth and UHealth*, 6(7), e162.  
37  
38 <https://doi.org/10.2196/mhealth.9345>  
39  
40  
41  
42 Hagemaster, J N. (1992) Life history: A qualitative method of research.” *Journal of Advanced*  
43 *Nursing*, 17(9): 1122-1128. <https://doi.org/10.1111/j.1365-2648.1992.tb02047.x>  
44  
45  
46  
47 Hughes, C. P., Berg, L., Danziger, W. L., Coben, L. A., & Martin, R. L. (1982). A new clinical  
48 scale for the staging of dementia. *The British Journal of Psychiatry* 140(6), 566-572.  
49  
50 <https://doi.org/10.1192/bjp.140.6.566>  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

- 1  
2  
3 King, D. B., O'Rourke, N., & DeLongis, A. (2014). Social media recruitment and online data  
4  
5 collection: A beginner's guide and best practices for accessing low-prevalence and hard-  
6  
7 to-reach populations. *Canadian Psychology*, 55(4), 240-249.  
8  
9 <https://doi.org/10.1037/a0038087>  
10  
11  
12 Katz, S., & Akpom, C.A. (1976). Index of ADL. *Medical Care*, 14(5), 116-118.  
13  
14 <https://doi.org/10.1097/00005650-197605001-00018>  
15  
16  
17 Kiraly, M., Humphreys, C., & Kertesz, M. (2021). Unrecognized: Kinship care by young aunts,  
18  
19 siblings and other young people. *Child & Family Social Work*, 26(3), 338-347.  
20  
21 <https://doi.org/10.1111/cfs.12814>  
22  
23  
24 Koehly, L. M., Ashida, S., Schafer, E. J., & Ludden, A. (2014). Caregiving networks--Using a  
25  
26 network approach to identify missed opportunities. *The Journals of Gerontology:*  
27  
28 *Psychological Sciences and Social Sciences*, 70(1), 143–154.  
29  
30 <https://doi.org/10.1093/geronb/gbu111>  
31  
32  
33 Lawton, M. P., & Brody, E. M. (1970). Assessment of older people: Self-maintaining and  
34  
35 instrumental activities of daily living. *The Gerontologist*, 19(3), 179-186.  
36  
37 [https://doi.org/10.1093/geront/9.3\\_Part\\_1.179](https://doi.org/10.1093/geront/9.3_Part_1.179)  
38  
39  
40 Leopold T, Raab, M., & Engelhardt, H. (2014) The transition to parent care: Costs,  
41  
42 commitments, and caregiver selection among children. *Journal of Marriage and Family*,  
43  
44 76(2), 300–318. <https://doi.org/10.1111/jomf.12099>  
45  
46  
47 Lin, I-F., & Wolf, D. A. (2020). Division of parent care among adult children. *The Journals of*  
48  
49 *Gerontology: Psychological Sciences and Social Sciences*, 75(10), 2230–2239,  
50  
51 <https://doi.org/10.1093/geronb/gbz162>  
52  
53  
54  
55  
56  
57  
58  
59  
60

- 1  
2  
3 Losada, A., Márquez-González, M., Peñacoba, C., & Romero-Moreno, R. (2010). Development  
4 and validation of the Caregiver Guilt Questionnaire. *International Psychogeriatrics*,  
5 22(4), 650–660. <http://doi.org/10.1017/S1041610210000074>  
6  
7  
8  
9  
10 Ma, M., Dorstyn, D., Ward, L., & Prentice, S. (2018). Alzheimer's' disease and caregiving: a  
11 meta-analytic review comparing the mental health of primary carers to controls. *Aging &*  
12 *Mental Health*, 22(11), 1395–1405. <https://doi.org/10.1080/13607863.2017.1370689>  
13  
14  
15  
16  
17 Mather, M., & Scommegna, P. (2020, May). The demography of dementia and dementia  
18 caregiving. *Today's Research on Aging*, no. 40. Population Reference Bureau.  
19  
20  
21 <https://www.prb.org/resources/the-demography-of-dementia-and-dementia-caregiving/>  
22  
23  
24 Milardo, R. M. (2010). *The forgotten kin: Aunts and uncles*. Cambridge University Press.  
25  
26  
27 National Alliance for Caregiving. (2017). Dementia Caregiving in the U.S. Bethesda.  
28  
29 [https://www.caregiving.org/wp-content/uploads/2020/05/Dementia-Caregiving-in-the-](https://www.caregiving.org/wp-content/uploads/2020/05/Dementia-Caregiving-in-the-US_February-2017.pdf)  
30 [US\\_February-2017.pdf](https://www.caregiving.org/wp-content/uploads/2020/05/Dementia-Caregiving-in-the-US_February-2017.pdf)  
31  
32  
33 National Poll on Health Aging. (2017). Dementia caregivers: Juggling, delaying, and looking  
34 forward. University of Michigan. [https://www.healthyagingpoll.org/sites/default/](https://www.healthyagingpoll.org/sites/default/files/2017-10/NPHA_Caregivers-Report-PROOF_101817_v2.pdf)  
35 [files/2017-10/ NPHA\\_Caregivers-Report-PROOF\\_101817\\_v2.pdf](https://www.healthyagingpoll.org/sites/default/files/2017-10/NPHA_Caregivers-Report-PROOF_101817_v2.pdf)  
36  
37  
38  
39  
40 Ornstein, K. A., Ankuda, C. K., Leff, B., Rajagopalan, S., Siu, A. L., Harrison, K. L., Oh, A.,  
41 Reckrey, J. M., & Ritchie, C. S. (2022). Medicare-funded home-based clinical care for  
42 community-dwelling persons with dementia: An essential healthcare delivery  
43 mechanism. *Journal of the American Geriatrics Society*, 70(4), 1127–1135.  
44  
45  
46  
47  
48  
49 <https://doi.org/10.1111/jgs.17621>  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

- 1  
2  
3 Ornstein, K. A., Wolff, J. L., Bollens-Lund, E., Rahman, O. K., & Kelley, A. S. (2019). Spousal  
4  
5 caregivers are caregiving alone in the last years of life. *Health Affairs*, 38(6), 964–972.  
6  
7 <https://doi.org/10.1377/hlthaff.2019.00087>  
8  
9  
10 Parker, L. J., & Fabius, C. (2022). Who's helping whom? Examination of care arrangements for  
11  
12 racially and ethnically diverse people living with dementia in the community. *Journal of*  
13  
14 *Applied Gerontology*, 41(12), 2589-2593. <https://doi.org/10.1177/07334648221120247>  
15  
16  
17 Pashos, A., & McBurney, D. H. (2008). Kin relationships and the caregiving biases of  
18  
19 grandparents, aunts, and uncles. *Human Nature*, 19(3), 311-330.  
20  
21 <https://doi.org/10.1007/s12110-008-9046-0>  
22  
23  
24 Pearlín, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress  
25  
26 process: An overview of concepts and their measures. *The Gerontologist*, 30(5), 583–  
27  
28 594. <https://doi.org/10.1093/geront/30.5.583>  
29  
30  
31 Pillemer, K., & Suiitor, J. J. (2014). Who provides care? A prospective study of caregiving  
32  
33 among adult siblings. *The Gerontologist*, 54(4), 589–598.  
34  
35 <https://doi.org/10.1093/geront/gnt066>  
36  
37  
38 Quinn, C., & Toms, G. (2019). Influence of positive aspects of dementia caregiving  
39  
40 on caregivers' well-being: A systematic review. *The Gerontologist*, 59(5), e584-e596.  
41  
42 <https://doi.org/10.1093/geront/gny168>  
43  
44  
45 Roberto, K. A., & Blieszner, R. (2015). Diverse family structures and the care of older persons.  
46  
47 *Canadian Journal on Aging*, 34(3), 305-320.  
48  
49 <https://doi.org/10.1017/S0714980815000288>  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

- 1  
2  
3 Roberto, K. A., McCann, B. R., & Blieszner, R. (2013). Trajectories of care: Spouses coping  
4 with changes related to MCI. *Dementia: The International Journal of Social Research*  
5 *and Practice*, 12(1), 45-62. <https://doi.org/10.1177/1471301211421233>  
6  
7  
8  
9  
10 Roberto, K.A., McCann, B.R., Savla, J., & Blieszner, R. (2024). Family caregivers' management  
11 of behavioral expressions of dementia. *The Gerontologist*, 64(6), gnae020.  
12 <https://doi.org/10.1093/geront/gnae020>  
13  
14  
15  
16  
17 Roberto, K.A., & Savla, J. (2022). Extended family caregivers for persons living with dementia  
18 *Journal of Family Nursing*, 28(4), 396-407. <https://doi.org/10.1177/10748407221115455>  
19  
20  
21  
22 Roberto, K.A., Savla, J., McCann B.R., Blieszner, R., & Knight, A. (2022). Dementia family  
23 caregiving in rural Appalachia: A sociocultural model of care decisions and service use.  
24 *The Journals of Gerontology, Series B: Psychological Sciences & Social Sciences*, 77(6),  
25 1094-1104. <https://doi.org/10.1093/geronb/gbab236>  
26  
27  
28  
29  
30  
31 Shaghghi, A., Bhopal, R. S., & Sheikh, A. (2011). Approaches to recruiting 'hard-to-reach'  
32 populations into research: A review of the literature. *Health Promotion Perspectives*,  
33 1(2), 86-94. <https://doi.org/10.5681/hpp.2011.009>  
34  
35  
36  
37  
38 Schulz R., & Eden J. (Eds) (2016). *Families caring for an aging America*. National Academies  
39 Press. <https://doi.org/10.17226/23606>  
40  
41  
42  
43 Shiff, H. M., Allison, T. A., Halim, M., Covinsky, K. E., Smith, A. K., Barnes, D. E., Gubner, J.  
44 M., & Zamora, K. (2025). "I Aim to Fulfill My Promise": Dementia caregiving from the  
45 perspective of spouses and partners. *Journal of Applied Gerontology*,  
46 <https://doi.org/10.1177/07334648241310707>  
47  
48  
49  
50  
51 Tashakkori, A., Teddlie, C., & Teddlie, C. B. (2002). *SAGE handbook of mixed methods in*  
52 *social & behavioral research*. Sage.  
53  
54  
55  
56  
57  
58  
59  
60

- 1  
2  
3 Teri, L., Truax, P., Logsdon, R., Uomoto, J., Zarit, S., & Vitaliano, P. P. (1992). Assessment of  
4 behavioral problems in dementia: The Revised Memory and Behavior Problems  
5 Checklist. *Psychology and Aging*, 7(4), 622-631. [https://doi.org/10.1037/0882-](https://doi.org/10.1037/0882-7974.7.4.622)  
6 [7974.7.4.622](https://doi.org/10.1037/0882-7974.7.4.622)  
7  
8  
9  
10  
11  
12 Travers, J. L., Rosa, W. E., Shenoy, S., Bergh, M., & Fabius, C. D. (2023). Characterizing  
13 caregiving supportive services use by caregiving relationship status. *Journal of the*  
14 *American Geriatrics Society*, 71(5), 1566–1572. <https://doi.org/10.1111/jgs.18213>  
15  
16  
17  
18  
19 van den Kieboom, R., Snaphaan, L., Mark, R., & Bongers, I. (2020). The trajectory of caregiver  
20 burden and risk factors in dementia progression: A systematic review. *Journal of*  
21 *Alzheimer's Disease*, 77(3), 1107-1115. <https://doi.org/10.3233/JAD-200647>  
22  
23  
24  
25  
26 Whalen, H. R., & Lachman, M. E. (2000). Social support and strain from partner, family and  
27 friends: Costs and benefits for men and women in adulthood. *Journal of Social and*  
28 *Personal Relationships*, 17(1), 5-30. <https://doi.org/10.1177/0265407500171001>  
29  
30  
31  
32  
33 Wegner, G. C., & Burholt, V. (2001). Differences over time in older people's relationships with  
34 children, grandchildren, nieces and nephews in rural North Wales. *Ageing and Society*,  
35 21(5), 567–590. <https://doi.10.1017/S0144686X01008406>  
36  
37  
38  
39  
40 Wolff, J. L., Spillman, B. C., Freedman, V. A., & Kasper, J. D. (2016). A national profile of  
41 family and unpaid caregivers who assist older adults with health care activities. *JAMA*  
42 *Internal Medicine*, 176(3), 372-379. <http://doi.org/10.1001/jamainternmed.2015.7664>  
43  
44  
45  
46  
47 Zarzycki, M., Morrison, V., Bei, E., & Seddon, D. (2023). Cultural and societal motivations for  
48 being informal caregivers: A qualitative systematic review and meta-synthesis. *Health*  
49 *Psychology Review*, 17(2), 247-276. <https://doi.org/10.1080/17437199.2022.2032259>  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

Downloaded from <https://academic.oup.com/gerontologist/advance-article/doi/10.1093/geronl/gnaf154/8162695> by GSA Society Access user on 10 July 2025

## Tables

Table 1.

Sample Demographics (N=25)

Demographics	N (%)	M (SD)
<i>Primary Caregiver</i>		
Age ( $R = 38-67$ )		54.44 (8.68)
Women	20 (80)	
Race		
White	16 (64)	
African American	8 (32)	
American Indian/Alaska Native	1 (4)	
Care Dyad Relationship		
Niece—Aunt	17 (68)	
Niece—Uncle	3 (12)	
Nephew—Aunt	4 (16)	
Nephew—Uncle	1 (4)	
Caregiving Context		
Years since assuming responsibility for Aunt/Uncle ( $R = .12-20$ )		3.62 (3.94)
Assistance Provided by Primary Caregiver		
With at least 1 PADL activity	18 (72)	
With at least 1 IADL activity	25 (100)	
Assistance Provided by Other Informal Helpers		
With at least 1 PADL activity	10 (40)	
With at least 1 IADL activity	15 (60)	
Assistance Provided by Paid Helpers		
With at least 1 PADL activity	4 (16)	
With at least 1 IADL activity	9 (36)	
Family Strain ( $R = 1-3.5$ )		2.49 (0.70)
Caregiver Burden ( $R = 0-2$ )		0.96 (0.54)
Caregiver Guilt ( $R = 0-2.3$ )		0.77 (0.67)
Caregiver Role Captivity ( $R = 0-2.3$ )		1.01 (0.78)
<i>Person living with Dementia</i>		
Age ( $R = 56-97$ )		78.96 (10.64)
Co-resides with Primary Caregiver	8 (32)	
Women	19 (76)	
Currently Married	3 (12)	
Have at least 1 living adult child	10 (40)	
Have at least 1 living sibling	20 (80)	
Weekly contact in person or by phone		
Adult Children	9 (90)	

1			
2			
3	Siblings	14 (70)	
4	Memory and Behavioral Expressions of Dementia ( $R = 3-18$ )		9.72 (4.25)
5	Number of PADLs Needing help ( $R = 0-6$ )		2.68 (2.04)
6	Number of IADLs Needing help ( $R = 0-7$ )		6.48 (1.22)
7			
8	<hr/>		
9	Note: PADL = Personal Activities of Daily Living; IADL = Instrumental Activities of Daily		
10	Living		
11			
12			
13			
14			
15			
16			
17			
18			
19			
20			
21			
22			
23			
24			
25			
26			
27			
28			
29			
30			
31			
32			
33			
34			
35			
36			
37			
38			
39			
40			
41			
42			
43			
44			
45			
46			
47			
48			
49			
50			
51			
52			
53			
54			
55			
56			
57			
58			
59			
60			

Note: PADL = Personal Activities of Daily Living; IADL = Instrumental Activities of Daily Living

Table 2. Correlations between Caregiving Stressors and Outcomes

Characteristics	Role Captivity	Burden	Guilty	Family Strain
Woman <sup>a</sup>	0.10	0.16	0.27	0.45*
Memory and Behavioral Expressions of Dementia <sup>b</sup>	0.28	0.43*	0.34	0.46*
Assistance Provided by Primary Caregiver for PADLs <sup>b</sup>	0.32	0.33	0.15	0.34
Assistance Provided by Other Informal Helpers for PADLs <sup>b</sup>	0.34	0.53**	0.25	0.60**
Assistance Provided by Paid Helpers for PADLs <sup>b</sup>	0.17	0.40	0.00	0.29

<sup>a</sup>point biserial correlation coefficient ( $r_{pbs}$ ); <sup>b</sup>spearman rank correlation coefficient ( $r_{sp}$ ); PADLs = personal activities of daily living. \* $p < 0.05$ ; \*\* $p < 0.01$

## Figures

Figure 1.

*Care Systems: Patterns and Illustrative Examples*

**Alt text:** Four graphics illustrating multidimensional patterns of caregiving support for persons living with dementia. Inner squares represent assistance with Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). Outer squares identify the type of helpers: Niece/Nephew Caregiver, Caregiver's Own Family, Person Living with Dementia's Family, and Paid Help. Shaded squares indicate which helper groups provide each type of assistance within each caregiving pattern.

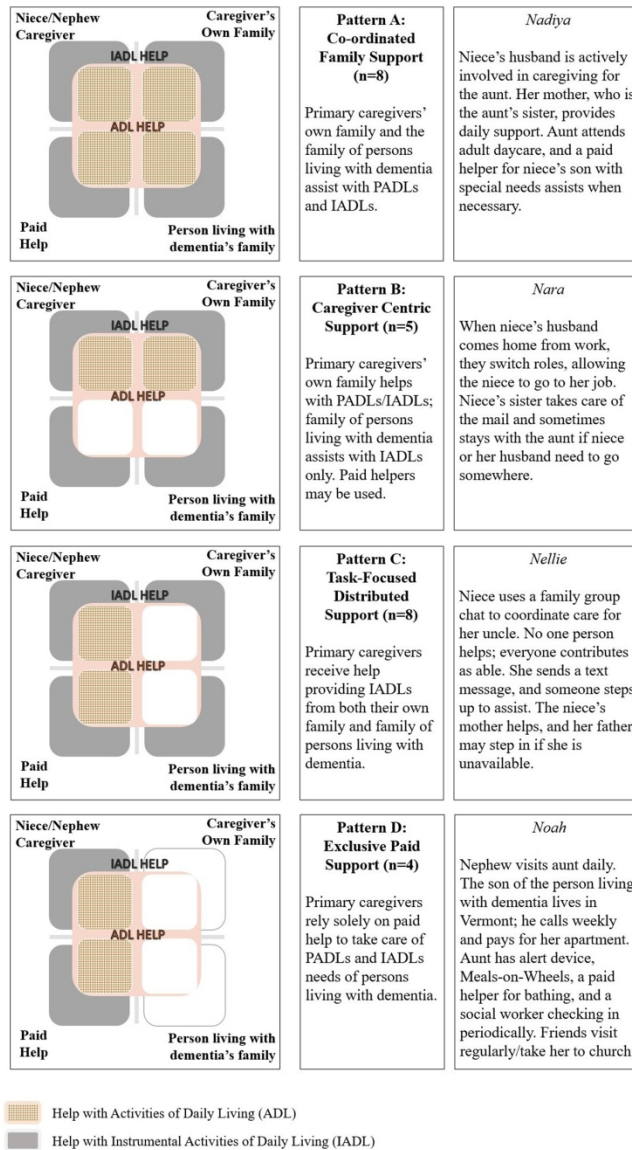


Figure 1: Care Systems: Patterns and Illustrative Examples

Alt text: Four graphics illustrating multidimensional patterns of caregiving support for persons living with dementia. Inner squares represent assistance with Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). Outer squares identify the type of helpers: Niece/Nephew Caregiver, Caregiver's Own Family, Person Living with Dementia's Family, and Paid Help. Shaded squares indicate which helper groups provide each type of assistance within each caregiving pattern.

899x1164mm (72 x 72 DPI)