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Feature Article

# Experiences of caregivers by care recipient's health condition: A study of caregivers for Alzheimer's disease and related dementias versus other chronic conditions

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ABSTRACT

This study described experiences of caregivers of persons with Alzheimer's disease and other dementias (ADRD) and caregivers of persons with other chronic conditions on self-reported health, type of assistance they provide, perceptions of how caregiving interferes with their lives, and perceived level of support. A secondary analysis was conducted of the 2013 Porter Novelli SummerStyles survey data. Of the 4033 respondents, 650 adults self-identified as caregivers with 11.6% caring for people with ADRD. Over half of all caregivers reported that caregiving interfered with their lives to some extent. The greater the perceived support caregivers reported, the less they thought that caregiving interfered with their lives ($p < .001$). No significant differences were found between ADRD and non-ADRD caregivers regarding general health, types of assistance they provided, and perceived level of support. These findings have the potential to inform future research and practice in the development of supportive services for caregivers.

## Introduction

Approximately 16.6% or 39.8 million adults 18 years of age and older in the United States (U.S.) self-identify as informal caregivers who provide care for adults with health conditions and disabilities.[1] Caregivers have reported that the person they care for needs assistance for a variety of reasons, including “old age” (14%), Alzheimer's disease and related dementias (ADRD) (8%), surgery/wounds (8%), cancer (7%), impaired mobility (7%), mental/emotional illness (5%), heart disease (5%), diabetes (5%), and stroke (4%).[1] A typical caregiver in the U.S. is a white woman in her late 40s.[2] The average duration of caregiving is four years, and caregivers spend an average of 24.4 hours per week performing caregiving tasks, with 59% of caregivers assisting with at least one activity of daily living (ADL).[1]

Caring for a friend or family member can have positive and negative impacts on the caregiver. Caregivers report that they feel appreciated[3–5]; however, caregiving can be time-consuming and emotionally and physically draining, resulting in negative effects on caregivers’ health.[6–9] These effects can be exacerbated by the disease progression of care recipients, including decline in physical capabilities, increasing cognitive impairment, and the presence and severity of negative behaviors.[7]

ADRD prevalence has increased dramatically in recent years. In 2018, an estimated 5.7 million adult Americans were diagnosed with ADRD.[10] Over 80% of the care provided to persons with ADRD comes from family members, friends, or other informal caregivers.[11] ADRD caregivers tend to be women and non-Hispanic whites.[6,12] ADRD caregivers spend approximately 21.9 hours per week assisting with a range of tasks including providing help with medical care and mobility that non-ADRD caregivers are less likely to provide.[1,6,10] ADRD caregivers reported high levels of emotional stress, depressive symptoms, and new or exacerbated health problems; 74% indicated that they were concerned about their personal health.[9,13,14]

Limited research has compared ADRD caregivers to caregivers of people with other diseases.[6,15,16] Little is known about how often caregivers receive the type and amount of support they need. The purpose of this study was to describe the experiences of ADRD and

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non-ADRD caregivers. Based on previous literature, we hypothesize that there are differences between ADRD caregivers and non-ADRD caregivers in caregivers' self-reported health, visits to health professionals, types of assistance they provide, perceived interference with other things in their lives, and perceived level of support.

## Methods

### *Survey data and sampling*

This study was a secondary data analysis of the Porter Novelli SummerStyles survey,[17] an online survey licensed to the Centers for Disease Control and Prevention (CDC). Survey panel members are randomly recruited using both random-digit dial and address-based sampling methods to reach respondents. The research panel (KnowledgePanel®) from which SummerStyles was drawn consisted of 50,000 online adult participants (aged 18 and above), weighted to match U.S. Current Population Survey (CPS) proportions.[17] Detailed information about weights is described elsewhere.[18] The summer wave (SummerStyles) used in this study was conducted from June 28 to July 26, 2013. Out of 50,000 panelists, 6105 panelists agreed to complete the survey. A total of 4033 adults completed the survey for a final response rate of 66%. This study focused on a sub-sample of 650 adults who self-identified as providing regular care or assistance to a friend or family member with a chronic health condition or disability.

### *Survey questions*

*Caregiving.* To be included in the analytic sample, respondents must have responded "yes" to the following question: "People may provide regular care or assistance to a friend or family member who has a health problem or disability. During the past month, did you provide any such care or assistance to a friend or family member?"

*Condition of care recipient.* Caregivers were classified into two categories based on their response to the question "What has the doctor said is the major health problem that the person you care for has?": (1) ADRD caregivers (i.e., respondents who chose "Alzheimer's disease or dementia"); and (2) non-ADRD caregivers (i.e. respondents who chose one of the following: cancer, chronic obstructive pulmonary disease, diabetes, heart disease or stroke, other unspecified health conditions).

*Self-reported health and visits to health professionals.* Caregivers' overall perception of their health was examined through a self-rated health question (response options ranged from 1 "excellent" to 5 "poor"; "excellent" was combined with "very good," resulting in a total of 4 options for the analysis) and types of health conditions[1] (i.e., anxiety, chronic pain, depression, high blood pressure, and insomnia/sleep disorder) experienced during the past year. Additionally, caregivers were asked whether they visited different types of health professionals, including physicians (primary care, specialists), and mental health providers for their own health care in the past 12 months (1 "one time or more", 0 "zero time").

*Assistance caregivers provided.* Type of assistance caregivers provided was measured by the question: "In what area do you provide the most help for the person that you care for?" Response options included managing daily activities, managing household tasks, managing medical conditions and medications, coordinating medical care, providing social support and related activities, helping with transportation outside of the home, and other types of assistance (participants could only select one option). Duration and amount of time per week for caregiving were measured by asking (1) "How many years have you been providing care?" and (2) "In an average week, how many hours do you provide regular care or assistance to your family member or friend?"

*Perceptions of caregiving interference and perceived support.* The extent to which caregiving interfered with other activities in caregivers' lives was examined by asking: "How often do you feel that caring for this person interferes with other things in your life?" A second item addressed the level of support caregivers received: "As a person who provides care, how often do you receive the type and amount of support you need to care for this person?" Response options for both questions ranged from 1 for "always" to 5 for "never" ("always" and "usually" were combined, resulting in total 4 options for the analysis).

### *Analysis*

Data analysis was conducted using SPSS version 19.0. Weighted descriptive statistics were used to compare ADRD and non-ADRD caregivers on demographic characteristics, type of assistance provided, caregivers' general health and visits to health professionals, perceived interference with their lives, and perceived level of support. Significance was tested using weighted chi-square tests set to $p < 0.05$.

## Results

### *Descriptive analysis*

Of the 650 respondents who self-identified as caregivers, 46 were excluded from the analyses as they did not report/know the major health problem of the care recipient. Of the 604 remaining caregivers, 11.6% ($n = 83$) cared for persons with ADRD and 81.0% ($n = 521$) were non-ADRD caregivers, including caregivers of persons with heart disease or stroke ($n = 82$, 14.8%), cancer ($n = 74$, 12.4%), diabetes ($n = 46$, 7.4%), chronic obstructive pulmonary disease ($n = 35$, 6.0%), and other diseases not identified ($n = 284$, 40.4%).

Table 1 details the comparison of ADRD and non-ADRD caregivers by demographic characteristics, duration of caregiving, and self-reported health. Among the 604 caregivers, 62.3% were women, and 34.7% were 60 years of age or older. The average duration of caregiving was 4.50 years (range = < 1–37; SD = 5.89). The average amount of time that caregivers provided help for care recipients each week was 20.2 hours (range = 1–168; SD = 33.94), with ADRD caregivers reporting 22.5 hours, and non-ADRD caregivers 19.8 hours. No significant differences were found between caregiver types on all demographic variables and duration of caregiving.

### *Self-reported health and visits to health professionals*

Among all caregivers in the sample, 41.9% reported their health as "very good/excellent," 36.2% as "good," 17.1% as "fair," and 4.8% as "poor" (Table 1). About 20.7% of caregivers reported no health problems. For those caregivers who reported health problems, 35.7% reported high blood pressure, 18.7% reported depression, 16.9% reported chronic pain, 15.2% reported anxiety, and 14.3% reported insomnia/sleep disorder.

Close to half (49.8%) of caregivers reported visiting a specialist for self-care, such as a cardiologist, oncologist, or dermatologist, at least once in the past year, and 80.7% visited their primary care doctor at least once (data not shown). Of the 15.0% ($n = 76$) who did not visit

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[1] Types of health conditions in the survey include: anxiety, arthritis, asthma, chronic pain, depression, diabetes, emphysema/COPD, enlargement of the prostate, epilepsy or seizure disorder, flu, high cholesterol, insomnia/sleep disorder, irritable bowel syndrome (IBS), male erectile dysfunction, migraine headaches, osteoporosis, overactive bladder or incontinence, seasonal allergies, high blood pressure, atrial fibrillation, congestive heart failure, other heart disease, lung cancer, skin cancer, other cancer, other mental health condition, other physical health condition.

**Table 1**
Caregiver characteristics.[a]

| Demographic information | All caregivers N (%) | ADRD caregivers N (%) | Non-ADRD caregivers N (%) |
|---|---|---|---|
| *Gender* | | | |
| Women | 394 (62.3) | 53 (57.3) | 341 (63.1) |
| Men | 210 (37.7) | 30 (42.7) | 180 (36.9) |
| *Race*[b] | | | |
| White | 505 (79.6) | 76 (87.2) | 429 (78.5) |
| Non-White | 99 (20.4) | 7 (12.8) | 92 (21.5) |
| *Education level* | | | |
| High school or below | 213 (45.4) | 26 (33.7) | 187 (47.1) |
| Some college | 208 (29.4) | 26 (29.1) | 182 (29.4) |
| Bachelor's degree or higher | 183 (25.2) | 31 (37.2) | 152 (23.5) |
| *Age group* | | | |
| <45 | 142 (28.8) | 16 (24.6) | 126 (29.4) |
| 45–59 | 227 (36.5) | 28 (37.5) | 199 (36.3) |
| 60+ | 235 (34.7) | 39 (37.9) | 196 (34.2) |
| *Employment status*[c] | | | |
| Employed | 296 (47.1) | 42 (51.0) | 254 (46.5) |
| Retired | 167 (23.7) | 26 (27.5) | 141 (23.1) |
| Unemployed | 141 (29.3) | 15 (21.6) | 126 (30.4) |
| *Average no. years providing care* | 4.50 (5.89) | 3.67 (3.82) | 4.36 (6.15) |
| *Self-reported health*[d] | | | |
| Excellent/very good | 262 (41.9) | 39 (51.1) | 223 (40.5) |
| Good | 234 (36.2) | 28 (29.0) | 206 (37.3) |
| Fair | 86 (17.1) | 15 (19.3) | 71 (16.8) |
| Poor | 19 (4.8) | 1 (0.6) | 18 (5.4) |
| Total | 604 | 83 | 521 |

[a] Data were weighted by gender, age, household income, race/ethnicity, household size, education, census region, metro status, and prior Internet access.

[b] Non-White includes African American, Asian, American Indian/Alaska Native, Hawaiian/Pacific Islander, and 2 + Races.

[c] Employed includes Paid employee and Self-employed; Unemployed includes Not working-disabled, Not working-looking for work, Temporary layoff from a job, and Not working-other.

[d] 3 missing cases in self-reported health.

any type of health professional for their own health care, 79.5% were non-ADRD caregivers.

### *Types of assistance caregivers provided*

Caregivers reported that they managed household tasks ($n = 144$, 23.5%), managed daily activities such as eating and dressing ($n = 99$, 19.4%), arranged transportation ($n = 93$, 14.5%), provided social support and related activities ($n = 94$, 13.8%), and managed medical conditions and medications for the care recipients ($n = 52$, 9.5%; Table 2). About 30% of ADRD caregivers reported managing daily activities (eating, dressing, bathing, etc.) as one of the most help provided for the care recipients compared with only 17.8% of non-ADRD caregivers.

**Table 2**
Types of assistance caregivers mostly provide.

| Types of assistance[a] | All caregivers *N* (%) | ADRD caregivers *N* (%) | Non-ADRD caregivers *N* (%) |
|---|---|---|---|
| Managing household tasks (cleaning, meals, etc.) | 144 (23.5) | 16 (17.6) | 128 (24.4) |
| Transportation | 93 (14.5) | 7 (7.5) | 86 (15.5) |
| Managing daily activities (eating, dressing, bathing, etc.) | 99 (19.4) | 20 (30.6) | 79 (17.8) |
| Providing social support | 94 (13.8) | 18 (18.6) | 76 (13.1) |
| Coordinating medical care (doctor visits) | 63 (9.2) | 6 (10.7) | 57 (9.0) |
| Managing medical conditions and medications | 52 (9.5) | 8 (8.4) | 44 (9.7) |
| Other | 54 (10.2) | 8 (6.6) | 46 (10.7) |
| Total | 599 | 83 | 516 |

[a] 5 missing cases in types of assistance.

### *Perceptions of caregiving interference and perceived support*

Over half of all caregivers in the sample reported that "caregiving interfered with other things" in their lives at least sometimes (21.9% reported "always/usually" and 30.7% reported "sometimes"). About 36% of ADRD caregivers reported that caregiving "always" or "usually" interfered with other things in their lives, compared with 19.8% of non-ADRD caregivers who reported the same level of interference.

In terms of perceived level of support, almost half of all caregivers (48.6%) said that they "always" or "usually" received the type and amount of support that they needed, 26.6% reported "sometimes," and 13.2% reported "rarely." 11.6% of caregivers reported they never received any type of support. As perceived support increased, caregivers were significantly less likely to think that caregiving interfered with other activities in their life ($\chi^2 = 69.02$, df = 9, $p < .001$).

## Discussion

This study provides information on caregivers' self-reported health, type of assistance they provide, perceptions of how caregiving interferes with their lives, and perceived level of support they receive using a national survey. Our results do not support the proposed hypothesis that there would be differences in experiences between ADRD caregivers and non-ADRD caregivers. Findings suggest that although care recipients have different diseases, caregivers have similar general health status, perform similar tasks, and identify similar levels of perceived support. Our findings highlight the important contribution of perceived support to mitigate the extent to which caregiving is seen as interfering with other activities and responsibilities. About 1 in 3 ADRD caregivers compared with 1 in 5 non-ADRD caregivers perceived caregiving always/usually interfere with their lives. The higher the level of perceived support, the less participants thought that caregiving interfered with their lives. Importantly, about one quarter of all caregivers reported that they "rarely" or "never" received the type and amount of support that they needed. This information is useful for nurse practitioners and other healthcare providers in the development of supportive services that may be able to serve different types of caregivers and address their unmet needs. Current programs and interventions aimed at supporting caregivers for persons with different chronic conditions have been effective in improving caregivers' overall perceived health and their abilities to cope with caregiving responsibilities and reducing caregiving strain.[19–22] Effective nursing interventions have used multidimensional resources to address caregivers' emotional and physical needs and encourage the use of a range of services and support to assist in providing care for the care recipient.[23–26] Programs to support caregivers also have the potential to improve outcomes of care recipients.[27] Future research is needed to understand what specific types of support caregivers think they lack and how support might be enhanced.

Our findings suggest that although care recipients have different diseases, caregivers have similar general health status, perform similar tasks, and identify similar levels of perceived support. The average weekly hours ADRD caregivers provided care in the current study (22.5 h) was similar to previous data (21.9 h).[10] More ADRD caregivers reported managing daily activities (eating, dressing, bathing, etc.) for the care recipients than non-ADRD caregivers.

This study has several limitations. There was a relatively small sample of ADRD caregivers, and some subcategories had fewer than 30 cases. However, caregivers of persons with ADRD account for 8% of all informal caregivers according to previous national survey data,[1] compared with 11% in the current study. The population of survey panel members comprised 50,000 online adult participants, weighted to match U.S. Current Population Survey proportions, and is considered representative of the U.S. population. The survey questions were limited and did not reveal all aspects of the caregiving condition (e.g., caregiving burden, type of support received). Also, additional response options may capture a wider array of caregivers' experiences. This study is cross-sectional, and any causal inferences made are limited. Despite these limitations, this study provides better understanding of caregivers of people with different types of chronic health conditions.

## Conclusions

This study provides insights on the caregiving experiences of ADRD and non-ADRD caregivers. The identified link between perceived support and the extent to which caregiving is perceived as interfering with one's life has important implications for future research and practice in the development of strategies to support caregivers and their unmet needs.

## Conflict of interest

The authors have no conflicts of interest to report.

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## Supplementary materials

Supplementary material associated with this article can be found in the online version at doi:10.1016/j.gerinurse.2018.09.012.

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