

# Caring for Individuals with Alzheimer’s Disease or Related Dementias (ADRD)

A comparison of caregivers who have a care recipient (CR) with Alzheimer’s Disease or Related Dementias (ADRD) with caregivers who have a CR without ADRD

## PURPOSE

This profile examines the differences in caregiver demographics and the dynamics at play between those who are caring for an adult at home with ADRD (n=810) and those who are caring for an adult 60 years of age or older at home for another reason (n=756). The data used in this profile were collected by interview in December 2016 for the Administration for Community Living’s outcome evaluation of the Older Americans Act Title III-E National Family Caregiver Support Program (NFCSP).

These comparisons can help organizations in the National Aging Network, an informal network of home- and community-based care providers, understand the needs and the characteristics of ADRD caregivers.



**ADRD caregivers** are those who are caring for an adult at home with Alzheimer’s Disease or Related Dementias (ADRD)

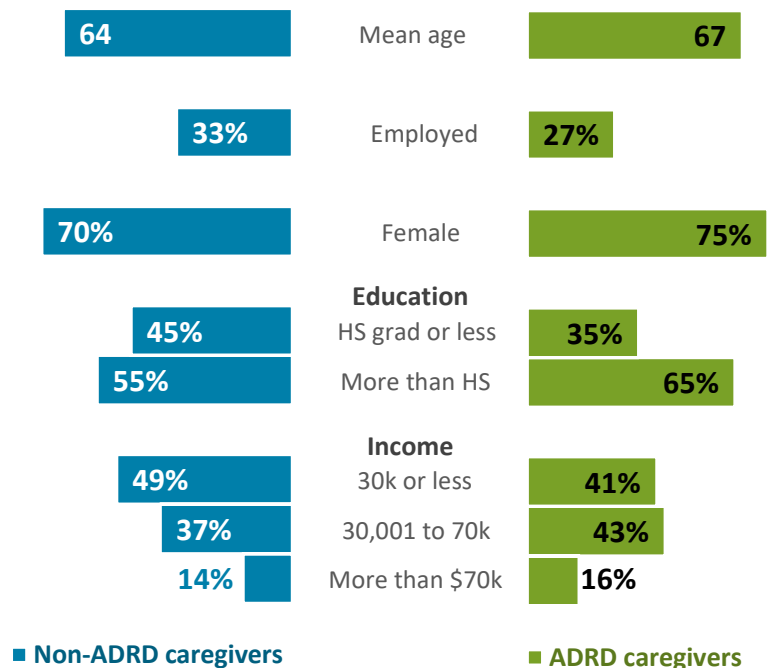


**Non-ADRD caregivers** are those who are caring for an adult 60 years of age or older at home for another reason

## CAREGIVER DEMOGRAPHICS

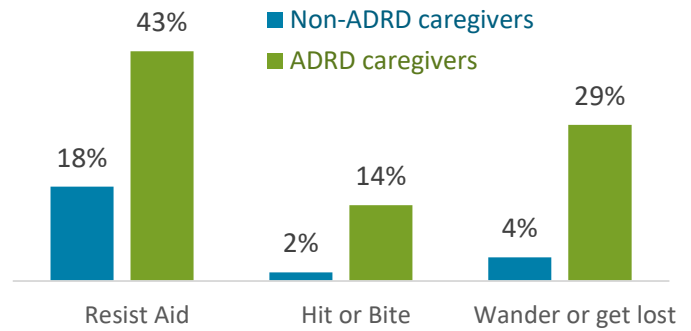
- The mean age of Non-ADRD caregivers was 64, while the mean age of ADRD caregivers was 67. Among all caregivers, the mean age was 65.9.
- More Non-ADRD caregivers were employed (33%) compared with ADRD caregivers (27%).
- About three-quarters of both Non-ADRD and ADRD caregivers identified as female.
- More than half of Non-ADRD caregivers and almost two-thirds of ADRD caregivers had attained education beyond a high school degree.
- About half (49%) of Non-ADRD caregivers had annual incomes of \$30k or less compared with 41% of ADRD caregivers.

**Non-ADRD and ADRD caregivers by mean age, employment status, gender, educational attainment, and income**



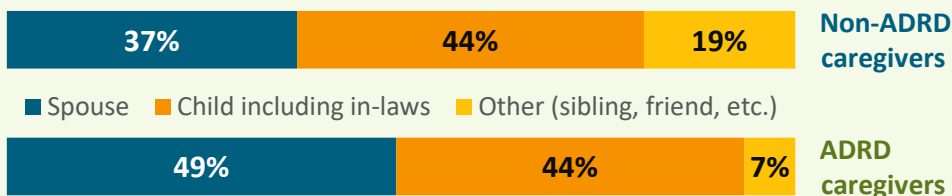
## CARE RECIPIENT CHARACTERISTICS

**ADRD caregivers face unique challenges with care recipients.** More ADRD caregivers experienced a care recipient resisting aid (**43%**), hitting or biting (**14%**), and wandering or getting lost (**29%**) compared with Non-ADRD caregivers (**18%**, **2%**, and **4%**, respectively).



## CAREGIVING SITUATION

### Relationship to care recipient



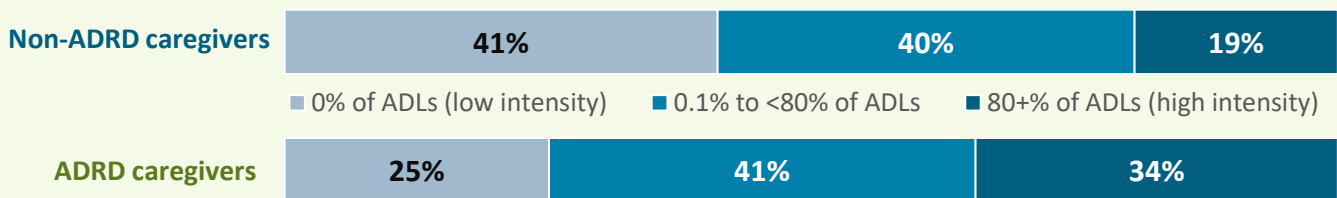
Percent of caregivers

More ADRD caregivers are the care recipient's **spouse (49%)** compared with Non-ADRD caregivers (37%).

### Caregiving intensity

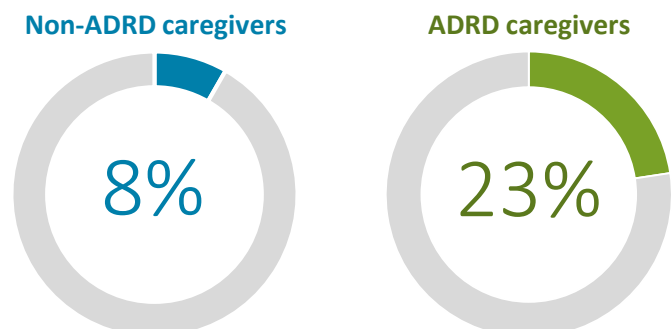
Caregiving intensity was measured as the percentage of five activities of daily living (ADLs) with which the caregiver provided assistance daily (eating, dressing, toileting, and mobility), or daily/several times a week (bathing), with greater percentages indicating greater intensity. **Thirty-four percent of ADRD caregivers** provided assistance with four or five ( $\geq 80\%$ ) of the five ADLs daily compared with **19% of Non-ADRD caregivers**.

### Caregiving Intensity as a Percentage of Five ADLs Provided Daily



Percent of caregivers

**23% of ADRD caregivers** reported that caregiving is emotionally very difficult, compared with **8% of Non-ADRD caregivers**.



## Most difficult tasks



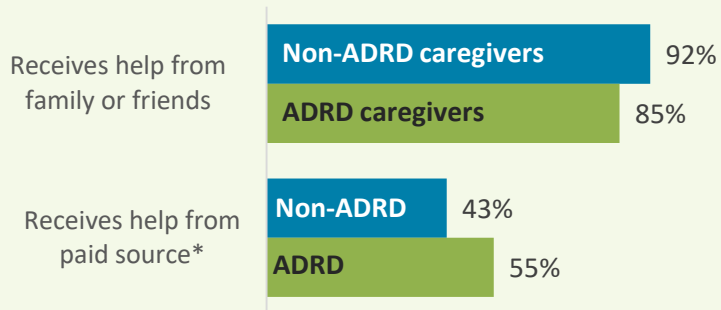
Among **Non-ADRD caregivers**, mobility tasks such as walking, getting out of bed, or standing were most commonly reported as the most difficult caregiving task (**14%**).



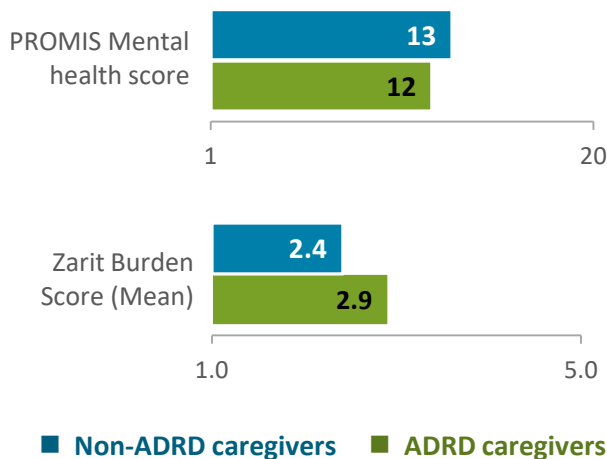
Among **ADRD caregivers**, bathing or showering (**18%**) and eating, getting dressed, and using the toilet (**14%**) were most commonly reported as the most difficult caregiving tasks.

## CAREGIVING SUPPORT

- Fewer ADRD caregivers received help from family or friends (**85%**) compared with Non-ADRD caregivers (**92%**).
- More ADRD caregivers received help from a paid source\* (**55%**) compared with Non-ADRD caregivers (**43%**).



## CAREGIVER SELF-REPORTED HEALTH



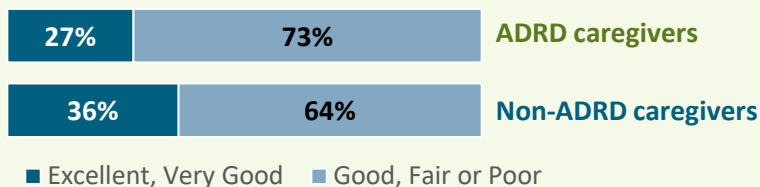
Caregiver health was measured using survey items from the Adult Patient Reported Outcomes Measurement Information System (PROMIS®) Global Short Form.\*\*

The Mental health score is a sum of four items. Higher scores indicate better self-reported mental health. A score of 20 is the highest possible. On average, Non-ADRD caregivers had higher mental health scores than ADRD caregivers.

Using the Zarit Burden Inventory, with a score of 5 representing the “most burden,” ADRD caregivers reported more burden than Non-ADRD caregivers.

## Caregiver quality of life

More Non-ADRD caregivers (36%) reported having **Excellent or Very Good** quality of life compared with ADRD caregivers (27%).



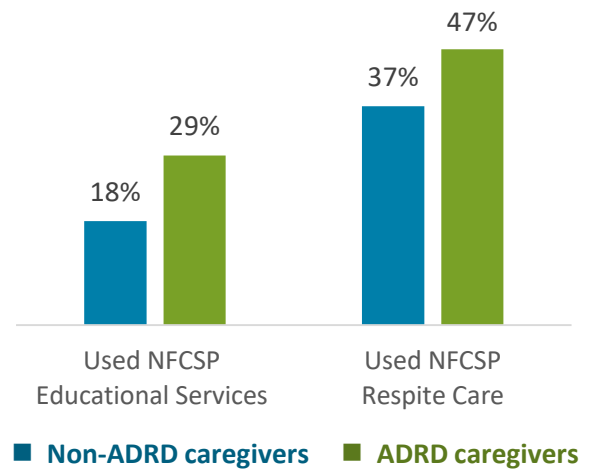
\* A paid source can be an agency, private provider, or housekeeper.

\*\* Information available at <http://www.healthmeasures.net/explore-measurement-systems/promis>

## USE OF NFCSP SERVICES

**ADRD caregivers used NFCSP services more than Non-ADRD caregivers.** Among a subgroup of 1,241 caregivers who were listed as clients of an Area Agency on Aging across the country:

- **29%** of ADRD caregivers used NFCSP educational services in the past 6 months compared with **18%** of Non-ADRD caregivers
- **47%** of ADRD caregivers used NFCSP respite care in the past 6 months compared to **37%** of Non-ADRD caregivers



## Key Differences Between ADRD and Non-ADRD Caregivers

- ADRD caregivers were generally older than Non-ADRD caregivers, with mean ages of 67 and 64, respectively.<sup>2</sup>
- ADRD caregivers, on average, were more highly educated than Non-ADRD caregivers.<sup>1</sup>
- ADRD caregivers were more likely to experience a care recipient resisting aid, hitting or biting, and wandering or getting lost compared with Non-ADRD caregivers.<sup>2</sup>
- ADRD caregivers were more likely to report daily caregiving intensity of 80% or higher in comparison to Non-ADRD caregivers.<sup>2</sup>
- ADRD caregivers were more likely to report that caregiving is emotionally very difficult compared with Non-ADRD caregivers.<sup>2</sup>
- Although ADRD caregivers reported more paid caregiving support than Non-ADRD caregivers, they reported receiving less caregiving support from family and friends.<sup>2</sup>

## DATA SOURCE

The NFCSP outcome evaluation performed by Westat measured NFCSP service use and the difference in outcomes between caregivers who received support from NFCSP and those who did not. This profile utilized the data collected at baseline from 1,566 caregivers residing in 43 states in the U.S. Information about NFCSP, evaluation sample design, and the evaluation findings are publicly available at [https://acl.gov/sites/default/files/programs/2018-12/Caregiver\\_Outcome\\_Evaluation\\_Final\\_Report.pdf](https://acl.gov/sites/default/files/programs/2018-12/Caregiver_Outcome_Evaluation_Final_Report.pdf).

<sup>1</sup> Significantly different at  $p$ -value < 0.01    <sup>2</sup>  $p$ -value < 0.001

Group means and frequencies were calculated for each characteristic.  $T$ -test, Chi-square, and Mantel-Haenszel chi-square statistics were used to test significant differences between ADRD and Non-ADRD caregivers. Percentages were rounded to the nearest whole number.