

Family Caregivers

Examining caregiver characteristics, caregiving support, and other caregiving dynamics that differ between short term and long term caregivers

PURPOSE

This profile examines the differences in demographics and the dynamics at play between “short term” caregivers who reported that they have only been caregiving for two or fewer years (n=388) and “long term” caregivers who reported that they have been caregiving for more than two years (n=1,180). 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 family (or informal) caregivers.



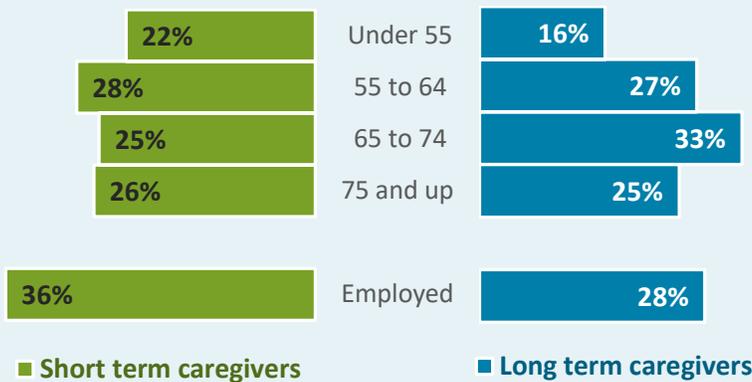
“Short term” caregivers are those who have been caregiving for 2 years or fewer



“Long term” caregivers are those who have been caregiving for more than 2 years

CAREGIVER DEMOGRAPHICS

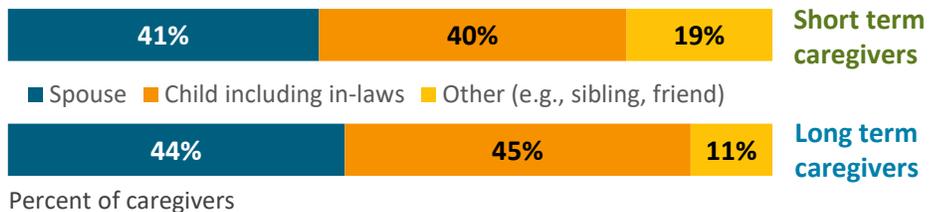
Short term and long term caregivers by age group and employment status (%)



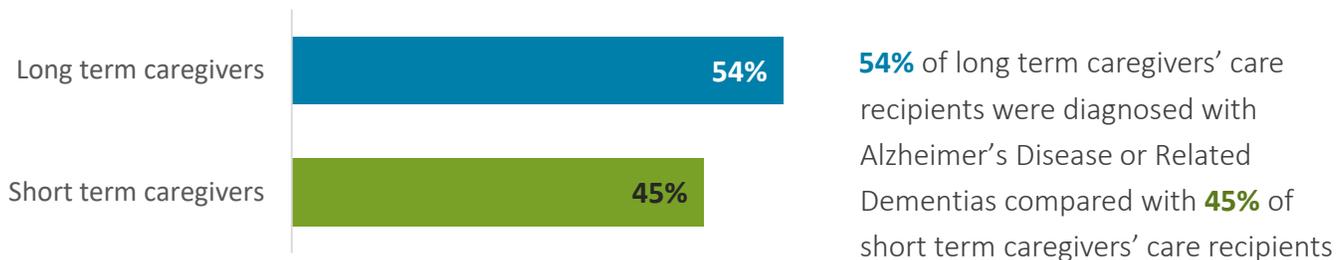
- The mean number of years caregiving among short term caregivers was 1.5 years; the mean for long term caregivers was 9 years
- The mean age among all caregivers was 65.8
- A higher percentage of short term caregivers were younger than age 55 (22%) compared with long term caregivers (16%)
- Short term caregivers were less likely to be between the ages of 65-74 than long term caregivers: 25% vs. 33%
- More short term caregivers were employed (36%) compared with long term caregivers (28%)

RELATIONSHIP TO CARE RECIPIENT

Caregivers are mainly the care recipient’s **spouse** or **child**, especially among long term caregivers.



CARE RECIPIENT DIAGNOSED WITH DEMENTIA OR ALZHEIMER'S



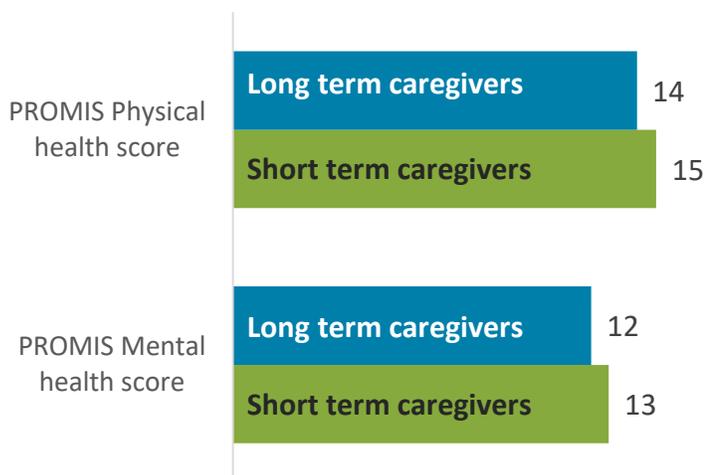
CAREGIVING INTENSITY

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. **Twenty-one percent of short term caregivers** provided assistance with four or five ($\geq 80\%$) of the five ADLs daily compared with **29% of the long term caregivers**.

Caregiving Intensity as a Percentage of Five ADLs Provided Daily



CAREGIVER SELF-REPORTED HEALTH



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

Each health score is a sum of four items. Higher scores indicate better self-reported health. A score of 20 is the highest possible.

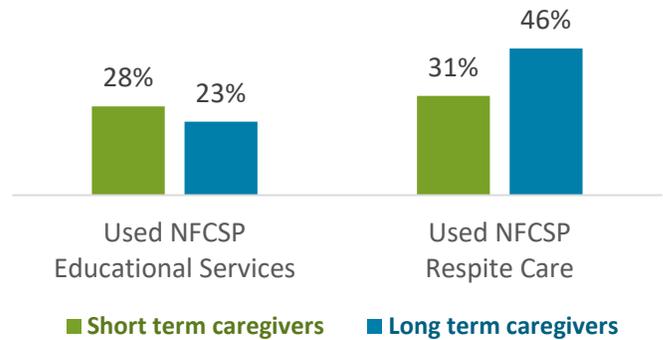
On average, short term caregivers had higher health scores than long term caregivers.

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

USE OF NFCSP SERVICES

Among a subgroup of 1,242 caregivers who were listed as clients of an Area Agency on Aging (AAA):

- **23%** of long term caregivers used NFCSP educational services in the past 6 months compared with **28%** of short term caregivers
- **31%** of short term caregivers used NFCSP respite care in the past 6 months compared to **46%** of long term caregivers



Key Differences Between Short and Long Term Caregivers

- Long term caregivers were generally older than short term caregivers. Fifty-eight percent of long term caregivers were age 65 or older compared to 51% of short term caregivers.¹
- Short term caregivers were more likely to have part-time or full-time employment.²
- The care recipients of long term caregivers were more likely to be diagnosed with Alzheimer's Disease or Related Dementias in comparison to short term caregivers.²
- Short term caregivers were less likely to report daily caregiving intensity of 80% or higher in comparison to long term caregivers.³
- On average, self-reported physical health and mental health scores were higher (i.e., better) for short term caregivers than long term caregivers.³
- Among the subset of caregivers who were AAA clients, long term caregivers were more likely to use NFCSP respite care in the past 6 months.³

DATA SOURCES

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 1,568 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.

¹ Significantly different at $p\text{-value} < 0.05$ ² $p\text{-value} < 0.01$ ³ $p\text{-value} < 0.001$

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 short term and long term caregivers. Percentages were rounded to the nearest whole number.