Family Caregiving and Out-of-Pocket Costs: 2016 Report

The purpose of this study was to explore the out-of-pocket costs of caregiving and the financial strain on the family caregiver. In addition to out-of-pocket costs, this study also looks at other financial and personal strains family caregivers may experience. For example, many family caregivers may need to cut back on spending in other areas (e.g., personal spending, basic living expenses, retirement savings, etc.) due to the costs of caregiving.

Key Findings

- Family caregivers, on average, are spending roughly $7,000 ($6,954) per year on out-of-pocket costs related to caregiving. A financial strain measure (average annual family caregiver expense divided by the caregivers’ annual incomes) shows family caregivers are spending, on average, nearly 20% of their income on caregiving expenses.

- Household expenses garner the largest share of family caregivers’ expenses with 41% of total spending. This includes rent/mortgage payments, home modifications, as well as other household expenses. Medical expenses account for the second largest share (25%). This includes in-facility care, insurance costs, and other medical expenses.

- Long-distance caregivers (defined as those living more than one hour away from their care recipient) incurred the highest out-of-pocket costs ($11,923) compared to caregivers living with or close by their care recipients.

- Those caring for an adult with dementia reported nearly twice the out-of-pocket costs than those caring for someone who does not have dementia ($10,697 vs. $5,758).

- The individuals most “highly financially-strained” tend to be lower income, non-White/non-Asian family caregivers, and caring for someone who needs assistance with at least one Activity of Daily Living (ADL). There are, however, subgroups in every income group that are “highly financially-strained”.

- More than half of family caregivers (56%) experience at least one work-related strain. This may take the form of working different hours, fewer/more hours, and taking time off (whether paid or unpaid).

Methodology

This study was conducted using a mixed method approach that included both a survey and diary component in order to calculate an annual figure of out-of-pocket spending for each family caregiver. This study utilized GfK’s national, probability-based online Knowledge Panel®. The study was conducted from July 18, 2016 to August 28, 2016 among 1,864 family caregivers.

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