

Formal and informal care use over the course of dementia among adults with limitations in daily activities

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Abstract

Background: The dynamics between formal and informal care among persons with an activity limitation may substantially differ over the course of their cognitive decline.

Method: Based on a nationally representative study of older adults, the sample included 3,685 adults (11,856 year-persons) who had at least one activity of daily living (ADL) limitation at the time of interview and transitioned to dementia between the years of 1998 – 2016. We estimated probabilities of using formal care and informal care in the years prior to and over the course of dementia, after controlling for sociodemographic factors, survey mode, and proxy interview status.

Result: Among study participants with an ADL limitation, the probability of receiving care from an informal helper increased before the onset of dementia: 36% (95% CI 32-40) in 4 years prior to the onset (T=-4); 46% (95% CI 43-50) at T=-2; and 48% (95% CI 46-51) at T=0 (onset); the likelihood of receiving care changed very little over the subsequent years of dementia. In contrast, changes in the probability of receiving formal care are pronounced primarily at the onset of dementia. For example, the probability of overnight nursing home stay was significantly greater at the onset of dementia compared to the years prior to the onset: 12% (95% CI 10-15) at T=-2 vs. 31% (95% CI 28-34) at T=0; this increased over the subsequent years of dementia (e.g., 39% at T=6; 95% CI 34-43). The probability of receiving nursing home care at the onset of dementia was significantly greater for women vs. men (e.g., Adjusted risk ratio (ARR)=1.21; p=0.010); non-Hispanic white vs. Hispanic (e.g., ARR=1.62; p=0.004); those with low wealth vs. high wealth (e.g., ARR=1.60; p<0.001); those without a spouse vs. with a spouse prior to the onset (e.g., ARR=1.39; p<0.001); and those with all adult children living far vs. at least one coresident adult child prior to the onset (e.g., ARR=1.51; p<0.001).

Conclusion: Public policies and interventions aimed at planning and providing for the needs of people with dementia should consider disparities in care use over the course of dementia and the potential role of economic resources and family care availability.