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Alzheimer's Disease Cooperative Study (ADCS) Prevention Instrument Project Assessing Resource Use and Volunteer and Paid Work among Healthy Elders, a Longitudinal Study

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Dr. Whitehouse: assisted design and reviewing and commenting on manuscript

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To the Editor

Therapeutic development for dementia is rapidly shifting to prevention as there is growing recognition that interventions at the time of symptoms may be “too late”.^[1] A major challenge in designing prevention trials is the measurement of subtle changes at pre-symptomatic stages of the disease. Currently available instruments are designed for individuals with dementia and may not be sufficiently sensitive to measure changes in asymptomatic individuals. To fill this gap, the Alzheimer’s Disease Cooperative Study (ADCS) conducted a 4-year simulated prevention trial, the Prevention Instrument (PI) Study, to develop instruments that are able to capture changes that occur as elders transition from normal aging to earliest stages of cognitive and functional impairment.^[2] Among these instruments is the Resource Use Inventory (RUI), designed to assess health-related resource use (e.g., hospitalizations, doctor visits, informal care). A unique aspect of the RUI is the addition of items that assess subjects’ participation in productive activities. Specifically, the RUI asks about subjects’ participation in volunteer and paid work, and for those who participated, hours of participation. An earlier study demonstrated the RUI was sensitivity to demographic and clinical characteristics in a non-demented elderly population. Feasibility, reliability, and efficiency of administering the RUI at home have also been reported.^[3]

Active and socially integrated lifestyles have been shown to be associated with better cognitive status.^[4-6] However, whether subtle differences in cognition affect elders’ participation in productive activities, such as volunteerism and participation in the workforce, is yet to be documented. As retirement age is delayed and demand on elders’ volunteerism and continued participation in the workforce grows, preventing cognitive impairment and maintaining paid or volunteer work efforts may become an increasingly important component of the economics of cognitive impairment.

In this study we use data from the PI study to examine subjects’ participation in volunteer and paid work over four years. Subjects were recruited from 39 ADCS sites in the US. At study entry, subjects were at least 75 years of age, living in the community, non-demented, in good physical and mental health, with no exclusionary medical conditions and not taking any excluded medications. Both cognitively normal subjects (Clinical Dementia Rating, CDR=0) and subjects with mild cognitive impairment (MCI, CDR=0.5) were included. Subjects were followed for four years, with annual in-person follow up assessment. 61.2% of the subjects completed the four-year study. The longitudinal cohort included 642 subjects and their study partners, providing a total of 2,592 observations. Mean age at baseline was 80, 42% were male, 56% were married, with an average of 15 years of education. Because of the requirement that each site achieve at least 20% minority enrollment, 23% of the subjects were non-white. Average CDR-SOB score was 0.3 (sd=0.5), with 62% at CDR-SOB of 0. Mean mMMS score was 95 (sd=3.6), and mean ADCS-ADL

was 49 (sd=4.1). Subjects showed minimal symptoms of depression with mean GDS score of 1.5 (sd=2.0).

Random effects logistic regression analyses were used to examine the relationships between rates of participation in volunteering and paid work and subjects baseline cognition (CDR=0.5 vs. CDR=0). Control variables included subjects' clinical characteristics (baseline ADAS-ADL, current mMMS, and number of comorbidities), demographic characteristics (subject and study partner age, gender, race/ethnicity, marital status, and education), and subject/study partner relationship and living arrangement.^[7] Results show that during the study period, participation in volunteer and paid work decreased progressively, from 52% to 45% and 14% to 10%, respectively (Figure). Over time, difference in the rate of volunteering by baseline cognition was sustained, with higher participation rate at every assessment in subjects with CDR=0 compared to those with CDR=0.5. These results suggest that in addition to examining health-related resource use, there may be important changes in subjects' volunteering and paid work in the transition from normal cognition to impairment. As retirement age increases and demand on elders' volunteer and paid work time grows, this work effort may become an increasingly important component of the economics of cognitive impairment. These results also suggest that elders' volunteer work as potential real world outcomes in future prevention trials, supplementing measures of cognition, function or global decline that are currently included. Results in this study underscore the need to consider multiple domains and endpoints in evaluating interventions aimed at preventing cognitive and functional decline in the elderly. Data from this study can aid in the design of future trials.

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Figure.
Rates of Volunteer and Paid Work by Baseline CDR