

Everyday Technologies Across the Continuum of Dementia Care*

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Abstract— The nomenclature for Alzheimer disease has recently been revised to include preclinical and mild cognitive impairment stages, along with dementia. These new stages provide an opportunity for primary, secondary, and tertiary prevention strategies. Everyday technologies have a key role to play in all of these strategies as well as caregiver education and support. Primary prevention strategies include development of cognitive reserve through computerized brain fitness programs. Secondary prevention involves the development of routines, including mobile device based strategies to compensate for memory deficits. Telemedicine approaches can facilitate tertiary invention, and communication and internet resources aid in caregiver support and education.

I. INTRODUCTION

New nomenclature for Alzheimer and other dementias

Recent scientific advances involving the ability to identify amyloid accumulation, regional metabolic change, and regional atrophy in the brain, as well as amyloid depletion and tau accumulation in the cerebrospinal fluid, provide the basis for great utilization of biomarkers in early, even preclinical detection of Alzheimer's disease. Recently, task forces empaneled by the National Institute on Aging and the Alzheimer's Association released new consensus criteria for Alzheimer's disease diagnoses. The current proposal for Alzheimer's disease related diagnoses include three phases 1. Preclinical Alzheimer's disease [1], 2. Mild Cognitive Impairment (MCI) due to Alzheimer's disease [2], 3. Alzheimer's disease Dementia [3]. These various phases provide new opportunities for the application of a variety of technologies not only to assist with detection/diagnosis, but also to optimize functioning in patients that may have Alzheimer's disease. We have undertaken a variety of projects, employing various technologies targeted to each of these phases. These projects are described in turn below.

II. INTERVENTION STUDIES AT EACH ALZHEIMER'S DISEASE PHASE

A. Preclinical Alzheimer's: Building Cognitive Reserve

Between 2009-2011, we completed a first large-scale randomized controlled clinical trial of a broadly available computerized cognitive training program based on neuroplasticity principles and targeted to older adults [4,5]. Significant improvement favoring the experimental group on a performance measure directly related to the trained tasks

was expected and consistent with the generally large effect sizes seen on directly trained tasks in other programs [6,7]. Unique to this study, performance improvements generalized to untrained standardized measures of memory and attention, implying that robust gains occurred across systems serving auditory-based cognition. Moreover, self-reported improvements by participants suggest the changes may be behaviorally significant. This study was one of the first to show generalization of trained performance gains to untrained, standardized measures of memory and attention. While it is always possible in cognitive training studies that observed performance gains in the experimental group represent improved test-taking skills resulting from test-taking practice, this is an unlikely explanation in this study because an active control was included. Our results demonstrate that a cognitive training program designed to improve the speed/accuracy of central auditory system function while strongly engaging neuromodulatory systems can drive benefits that generalize to untrained measures of memory and attention. Moreover it showed that the improvement is significantly larger than that seen with a program of general cognitive stimulation. Most recent research is evaluating the effects of similar approaches on the trajectory of cognitive decline in normal aging. New research is likely to focus on the impact of similar approaches to bolster cognitive reserve in people with markers of preclinical disease.

B. Mild Cognitive Impairment Phase: Maintaining Maximal Independence

The emerging trend is to consider multi-component interventions for persons with MCI. In 2008, we at Mayo Clinic launched a multicomponent MCI intervention program called Healthy Action to Benefit Independence and Thinking (HABIT). In its current form, this program is a 10-day, 50-hour program. It includes five components: 1) Memory compensation training with a calendar/journaling tool [8,9]; 2) "Brain Fitness" using a commercially available computerized cognitive training tool [4,10] 3) Physical fitness [11]; 4) Caregiver and patient support groups; and, 5) Educational programming.

We assess the success of the memory compensation training phase via a 0-6 rating of learning. A score of six implies mastery. Figure 1 shows longitudinal outcomes on an informant-based scale assessing memory-based activities of daily living. These results show that people with MCI who can master the memory compensation tool have improved function at end of intervention and stable function at one-year. In contrast those that don't reach mastery show no initial benefit and the expected pattern of longitudinal decline. While this program has not yet been subjected to randomized clinical trials, preliminary program evaluation

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data also suggests positive impact on self-efficacy outcomes for patients and caregivers. This type of approach lends itself to technology. Modern mobile devices can provide a platform for the cognitive fitness training program, can serve as a tool for calendaring and journaling and can serve as a vehicle for education and support. Preliminary prototypes of these systems are appearing on the commercial market (cf. memorymate.com).

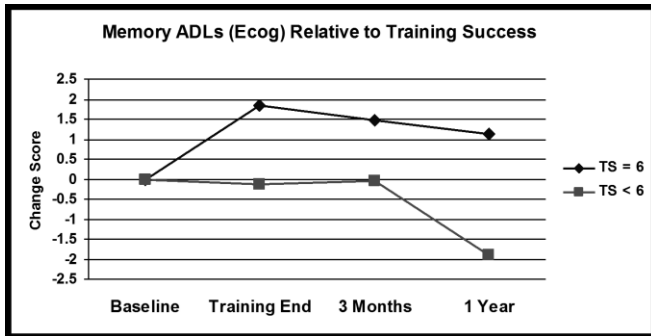


Figure 1. Functional outcomes for people with MCI by mastery status for a memory compensation tool

C. Dementia Phase: Avoiding Premature Placement

Population-based studies completed in our Alzheimer’s Disease Research Center (ADRC), reveal over 90% of persons with dementia will receive continuous nursing home placement prior to time of death compared to just 50% of cognitively intact matched normal [12]. The presence of live-in caregivers, especially spouses, mitigates rapid placement of people with dementia live-in assistance but providers are absent for a significant proportion (31-44%) of patient with dementia [12,13]. In these patients, even with mild functional impairments, safety concerns such as inability to manage medications, are important in decisions to institutionalize [14]. Technology can assist in supervision of safety issues. Dating all the way back to the late 1990s, we used two-way interactive video technology to bring “virtual” medication monitors into the homes of 14 people with mild dementia [15]. This project was a within subject design involving three counterbalanced phases, a video monitoring phase, a plain ordinary telephone (POTS) monitoring phase and a standard unmonitored care phase. Fourteen 14 people living alone with mild dementia were enrolled. Eight of these 14 received all three phases of the project. The remaining six participants received only POTS and/or unmonitored care as match controls to video participants that could not serve as their own control in all three phases. We conducted more than 4000 telemedicine contacts. We assessed technical success, medication self-administration accuracy, neuropsychiatric symptoms, and mood burden as key indicators of efficacy. We found adequate technical outcome in 82% of calls. End medication compliance was 81% in our video monitored group compared to 66% in our controls ($p < .05$) and 76.5% on the phone arm (Figure 2).

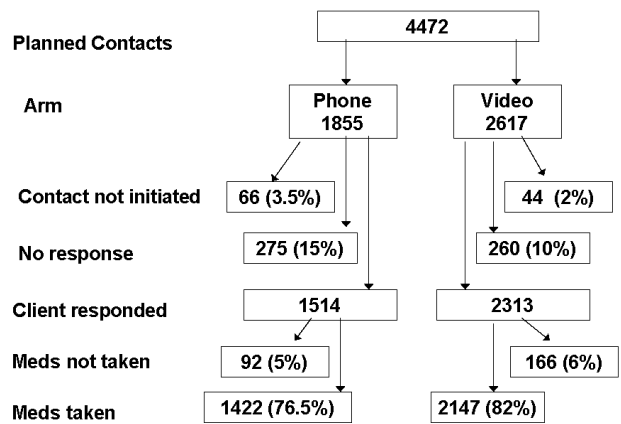


Figure 2. Outcome of planned contacts for phone vs. video monitoring.

Comparison of compliance from initial to end ratings revealed that video monitored participants compliance remained stable (change of 0.7 percentage points) while unmonitored patients compliance fell 12 percentage points, consistent with expectations for dementia. This difference was significant at the $p < .01$ level (Figure 3). We also conducted qualitative interviews with the caregivers regarding their experience of this project. The virtual caregivers not only ensured medication safety they also increased social interaction, adding to quality of life [15].

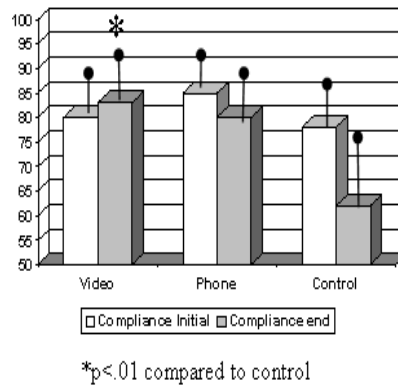


Figure 3. Change in medication compliance score from beginning to end of monitoring phase.

In the time since this project, communications systems to support Skype, FaceTime, and other products have yielded significantly reduced cost and increased bandwidth to enable this kind of service. However it is not clear if any providers have established a significant market foothold in providing this kind of virtual monitoring targeted to the safety concerns of families caring for dementia.

Addressing behavior problems in situ

Skype technology has also permitted us to extend the reach of our Dementia Behavioral Assessment and Response Team (DBART) at Mayo Clinic in Rochester. This team provides outreach into care facilities to assess dementia-related disruptive behavior in the environment where it is

occurring. Evidence of the efficacy for this type of outreach is provided in Figure 4 [16]. This outreach enables the team to emphasize environmental adaptation as an alternative or augmentation to medications. Certain types of medication used for behavior management have recently been shown to increase mortality risk [17].

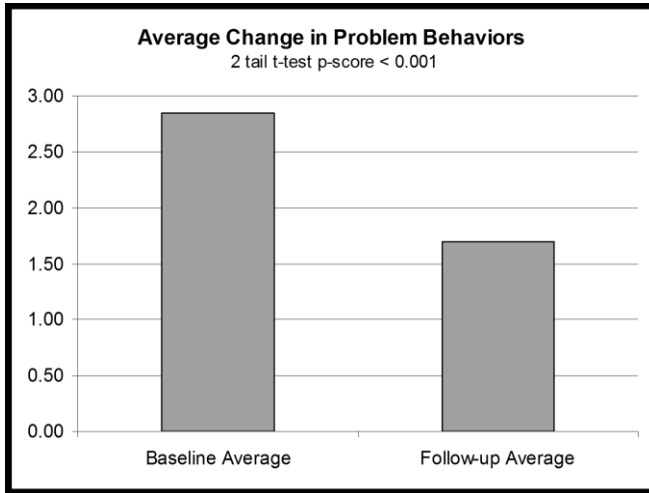


Figure 4. Average frequency of problem behaviors before and following intervention of outreach team. N=50. 0=a few times a month, 1=1-2 times/week, 2= 3-4 times per week, 3=daily.

D. The need for caregiver education and support across the continuum.

There are numerous resources available to families of persons diagnosed with AD. The Alzheimer’s Association provides extensive education and support to persons wanting to know about AD. Other resources include the Alzheimer’s Disease Education and Referral Center (ADEAR), the Family Caregiver Alliance, and the National Institute on Aging’s network of Alzheimer’s Disease Research Centers. In addition, there are books, brochures, articles, websites, education classes, and support groups in many communities to assist families dealing with a diagnosis of AD.

But when the diagnosis is MCI or pre-clinical Alzheimer’s disease where do families turn? What should they think, feel, how should they respond? Is this a devastating diagnosis, or a relief to the family? Is it useful or reasonable to deluge them with information on AD? Does receiving education on the stages of AD and caregiving strategies precipitate early symptoms of burden for the family or help them prepare and develop mastery? Certainly early detection may enable caregiver systems to anticipate needs sooner, gather information before “hands-on” care needs are overwhelming and include the affected person in decision making [18]. However, for this to be true preclinical and MCI online resources must be accessible and credible.

As implied by the fourth and fifth component of HABIT mentioned earlier, support groups for people with MCI and their family members, as well as educational efforts, are now being tailored to address a diagnosis of MCI. Information about the latest research findings and clinical trials involving MCI are accessible online as is information that assists the

family in openly and effectively planning for the future. Educational approaches that emphasize prevention and active coping deliver a powerful and positive message to people diagnosed with MCI and their families, possibly minimizing early feelings of burden.

Our health education portal provides dementia and MCI specific education content at www.mayoclinic.com/health/alzheimers-disease. We have also established an expert blog targeted to caregivers there. This site receives over 50,000 pages view a month. This utilization reveals that caregivers are seeking forums for exchange not just sites for one-way online education. Finally, our HABIT program discussed above is also using social media technology to provide a post-program ‘electronic support group’ utilizing the Facebook secret group function. The examples reveal the potential of electronic platforms to meet the needs of families and caregivers across the continuum of dementia phases.

III. CONCLUSION

We now understand that the pathophysiology of the Alzheimer disease is developing over a decades, and includes a mild cognitive impairment prodrome. Both the preclinical and MCI phases provide prevention opportunities to delay or mitigate the impending deficits of the dementia phase of Alzheimer’s disease. Interventions at the preclinical phase may permit avoidance of deficits. Intervention at the MCI phase can result in compensation for mild focal deficits. Intervening at the dementia stage is primarily going to result in mitigation of effects of significant impairment. Technology will contribute substantially to these prevention strategies if developers understand peoples’ function, needs, and goals for intervention at each stage.

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