

# ANCDS Bulletin Board

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## **Evidence-Based Practice Recommendations: Caregiver-Administered Active Cognitive Stimulation for Individuals with Alzheimer's Disease**

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The Academy of Neurologic Communication Disorders and Sciences (ANCDS), the American Speech-Language-Hearing Association (ASHA), its Special Interest Division 2 (SID-2, Neurophysiology and Neurogenic Speech and Language Disorders), and the Veterans Administration (VA) collaborated to establish evidence-based practice recommendations for speech-language pathologists working with individuals with Alzheimer's disease (AD) and their caregivers. A writing committee was formed and generated a comprehensive technical report with evidence tables based on systematic review and classification of literature related to assessment and use of direct and indirect interventions with individuals with AD. Subsequent to writing this technical report, clinical papers



have been published providing a detailed summary of the scientific evidence pertaining to specific intervention approaches. This clinical article provides a summary of the scientific evidence related to one type of indirect intervention, caregiver-administered active cognitive stimulation for home-dwelling individuals with AD. Three studies were reviewed and judged to provide Class II evidence to support the training of caregivers to administer interventions to individuals with AD. Participant characteristics, the nature of the intervention and training, outcomes, methodological concerns, trends across studies, and recommendations for clinical practice and future research are discussed.

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The Dementia Practice Guidelines Writing Committee was formed as a collaboration between the Academy of Neurologic Communication Disorders and Sciences (ANCDS), the American Speech-Language-Hearing Association (ASHA), and the Veterans Administration (VA) to establish evidence-based practice recommendations for speech-language pathologists working with individuals with Alzheimer's disease (AD). Existing literature was critically reviewed and the strength of the research evidence was judged by the writing committee (Bayles, et al., 2005).

The purpose of this article, which is one of a series of reports, is to summarize research findings pertaining to indirect interventions for individuals with AD (interventions aimed at caregivers who then work directly with patients). Specifically, this article includes a review of research on the effects of training family caregivers to administer active cognitive stimulation to individuals with AD in the home environment. Training family caregivers is important because of funding limitations that often restrict speech-language pathology services for individuals with AD, despite the fact that some patients are able to benefit from intervention programs (Chapman, Weiner, Rackley, Hynan, & Zientz, 2004). If caregivers can be trained to administer cognitive stimulation, functional gains can be realized in a cost-effective way. In the articles reviewed, active cognitive stimulation is defined as actively engaging an individual with AD in a specific task (e.g., playing a game of Hangman). Active cognitive stimulation involves task participation of both caregivers and individuals with AD and can be contrasted with spending time together in more passive pursuits (e.g., sitting quietly, watching television, etc.).

Weiner (2003) defines *dementia* as an impairment or reduction of "multiple cognitive abilities, including memory, sufficient to interfere with self-maintenance, work, or social relationships" (p. 13). Alzheimer's disease is the most common form of

dementia, with prevalence rates of approximately 1% in individuals age 65–69 and approximately 10% in individuals age 80–84 (Bachman et al., 1992). Diagnosis of Alzheimer's disease requires four basic features, according to the DSM-IV-TR:

1. presence of dementia;
2. gradual onset with continuing decline in cognitive function;
3. exclusion of other causes of dementia by physical examination, history, and laboratory testing; and
4. occurrence not exclusively during the course of a delirium (American Psychiatric Association, 2000).

Lipton and Weiner (2003) define *Alzheimer's disease* by "the presence of amnesia (memory disorder) plus one or more of the following: agnosia (perceptual disorder), aphasia (language disorder), apraxia (disorder of voluntary movements), and abstraction/executive functioning" (p. 138).

## PROCEDURES

### Systematic Review of the Literature

A comprehensive search of the literature was conducted in several electronic databases, including Medline (1966–August 2002), PsychInfo (1967–August 2002), and Language and Linguistic Behavioral Abstracts (1960–August 2002). The following search terms were used: Alzheimer's/Alzheimer disease, dementia of the Alzheimer's type, dementia, caregivers, caregiver training, cognitive-linguistic, cognitive interventions, cognitive stimulation, cognitive therapy, cognitive training, behavioral intervention, indirect, non-pharmacological interventions, therapy, treatment, and intervention. Hand searches were also conducted of relevant studies cited in articles. Related to these



search terms, 144 articles on caregiver intervention were identified for review. After excluding studies that addressed caregiver support, psychological or psychiatric issues, activities of daily living, interventions in which aspects of cognitive-communication abilities were not a primary focus peripheral component, and those that did not include AD participants, three articles were selected for this review. In all three studies, investigators trained caregivers to administer active cognitive stimulation to family members with AD. The three studies were conducted by Quayhagen and colleagues (Quayhagen & Quayhagen, 1989, 2001; Quayhagen, Quayhagen, Corbeil, Roth, & Rodgers, 1995). An updated literature search was subsequently conducted in early 2007 and resulted in no additional relevant studies.

### **Classifying the Evidence**

Each study was evaluated based on several parameters, including purpose, subject characteristics, internal and external validity, dose-response characteristics (frequency, intensity, duration) of intervention, and outcome measures used to document intervention effects. To ensure reliability of coding, two members of the writing committee rated each article independently. Key questions adapted from Sohlberg et al. (2003) were used to outline the evidence evaluated. The questions were the following:

1. What is the purpose and content of caregiver-administered active cognitive stimulation?
2. Who are the participants who received this intervention?
3. What are the outcomes of the intervention?
4. What are the key methodological concerns?
5. What are the clinically applicable trends across these studies?

(See [www.ancds.org](http://www.ancds.org) for the technical report and evidence table related to caregiver-administered cognitive stimulation programs.)

### **Summary of Evidence for Training Caregivers to Administer Active Cognitive Stimulation**

#### ***What is the Purpose and Content of Caregiver-Administered Active Cognitive Stimulation?***

According to researchers in the three studies reviewed (Quayhagen & Quayhagen, 1989, 2001;

Quayhagen et al., 1995) the purpose of active cognitive stimulation programs is to maintain over time levels of cognitive and behavioral functioning in individuals with AD. In each study, family caregivers were trained to administer active cognitive stimulation, which consisted of specific activities addressing memory (e.g., reminiscing, discussing current events, or recalling a daily schedule), problem solving (e.g., playing cards, planning a trip, categorizing objects), and conversational abilities (e.g., justifying an opinion, giving facts, or having a conversation). Caregivers were provided with a workbook that contained “prescribed activities” in order of increasing complexity. The activities were designed to elicit active responses from the individuals with AD. The study investigators and/or researcher assistants conducted the training. Although the purpose and general content of the programs were similar across studies, some variations existed in treatment format, including frequency, intensity, and duration.

Quayhagen and Quayhagen (1989) evaluated outcomes between two groups of individuals with AD: one receiving caregiver-administered active cognitive stimulation and a control group that received no stimulation. Intervention was conducted 1 hour per day, 6 days per week. Duration of the treatment was unspecified.

Quayhagen et al. (1995) investigated outcomes of groups of individuals with AD who received active cognitive stimulation, passive stimulation (i.e., watching Wheel of Fortune without actively participating), and no stimulation. Caregivers in the Quayhagen et al. (1995) study provided active cognitive stimulation 1 hour per day, 6 days per week for a total of 72 hours over 12 weeks.

Quayhagen and Quayhagen (2001) expanded the previous research to compare single active practice (addressing one of the three domains [memory, problem solving, conversational abilities] separately for 1 week at a time) to integrated active practice (addressing each of three areas every day). Caregivers in the single active practice provided intervention 1 hour per day, 5 days per week for a total of 60 hours over 12 weeks. Caregivers in the integrated active practice provided intervention 1 hour per day, 5 days per week for a total of 40 hours over 8 weeks.

In two of the studies (Quayhagen et al., 1995; Quayhagen & Quayhagen, 2001) investigators specified the amount of training provided to the caregivers as weekly in-home, 1-hour instructional sessions. Caregivers and individuals with AD were



trained together by a member of the research team during these times, with the trainer observing and modeling interactions. Quayhagen et al. (1995) required caregivers to demonstrate how to implement active cognitive stimulation techniques as part of the training. In Quayhagen and Quayhagen (1989) and Quayhagen et al. (1995), caregivers were asked to keep a weekly log of the intervention activities, time spent, and any feedback from the individual with AD.

### ***Who Are the Participants Who Received This Intervention?***

Quayhagen and Quayhagen (1989) included 16 caregiver/patient dyads (10 in the active cognitive stimulation group, 6 in the no-stimulation group). The Quayhagen et al. (1995) study included 78 caregiver/patient dyads (25 in the active stimulation group, 28 in the passive stimulation group, 25 in the no-stimulation group). Quayhagen and Quayhagen (2001) analyzed data from 56 caregiver/patient dyads from the Quayhagen et al. (1995) study and compared those data to new data from 30 caregiver/patient dyads.

All of the studies included information pertaining to age of the participants, which averaged 68 years for the caregivers and 71 years for the patients. Information about gender was also included in all studies (72% of the caregivers were women; 34% of the patients were women). Two studies (Quayhagen et al., 1995; Quayhagen and Quayhagen, 2001) included information on ethnicity of the participants (86% were Caucasian, 13% were Hispanic or African-American). None of the studies included information regarding participants' hearing and vision, and no mention was made of the presence of depression. All dyads were community dwelling.

For the patients, diagnostic criteria for AD were not specified in any study, although the researchers reported that each individual had a diagnosis of AD. The investigators described functional status of the patients and staged dementia severity using the Global Deterioration Scale (Reisberg, Ferris, De Leon, & Crook, 1982), and all patients scored 90 or better on the Mattis Dementia Rating Scale (Coblentz et al., 1973), which is indicative of a mild to moderate degree of impairment. Information about medications patients were taking was not available, nor was information about the number of years since the diagnosis of AD was made.

### ***What Are the Outcomes of the Intervention?***

The investigators used several patient outcome measures to evaluate the effects of active cognitive stimulation (focused on memory, problem solving, and conversational skills) administered by family caregivers. Researchers employed a combination of the following outcome measures: memory, conceptualization, and initiation subtests from the Dementia Rating Scale (DRS; Coblentz et al., 1973), Logical Memory subtest and associated learning items from the Wechsler Memory Scale Form II (Stone, Girdner, & Albrecht, 1946), Logical Memory I, Figural Memory, Visual Reproduction I, Visual Memory Span, and Digit Span subtests from The Wechsler Memory Scale-Revised (Wechsler, 1987), FAS (Benton, 1968), animal fluency (Goodglass & Kaplan, 1983), Geriatric Coping Schedule (Quayhagen & Chiriboga, 1976), and the Memory and Behavior Problems Checklist (Zarit, Reever, & Bach-Peterson, 1980).

Results from the Quayhagen and Quayhagen (1989) study, in which researchers evaluated the differences between active cognitive stimulation and no stimulation, showed that the patients receiving active cognitive stimulation ( $n = 10$ ) maintained global cognitive function at posttest and at an 8-month follow-up after intervention ceased, including memory, problem solving, and conversational abilities, as measured by the Dementia Rating Scale (Coblentz et al., 1973), whereas the patients who received no stimulation ( $n = 8$ ) showed decline at posttest and at the 8-month follow-up. The group that received active cognitive stimulation also maintained behavioral function, as measured by the Memory and Behavior Problems Checklist (Zarit et al., 1980), whereas the group that received no stimulation demonstrated increased frequency of behavioral symptoms.

Results from the Quayhagen and colleagues (1995) study indicated that patients who received active cognitive stimulation ( $n = 25$ ) improved significantly in cognitive (memory, problem solving, and fluency) and behavioral status at posttest but regressed toward baseline performance at the 9-month follow-up (6 months after treatment ended). The passive stimulation group (those who observed an activity or task without actively participating;  $n = 28$ ) showed no change over time in general memory function (as measured by the memory factor of the DRS (Coblentz et al., 1973) and memory subtests from the Wechsler Memory Scale-Revised (Wechsler, 1987). However, they showed a decline from baseline performance on measures of fluency



(as measured by the initiation factor of the DRS, Coblenz et al., 1973) and FAS (Benton, 1968) and general cognitive ability (as measured by the DRS; Coblenz et al., 1973). The no-stimulation group ( $n = 25$ ) declined in all of these areas.

Quayhagen and Quayhagen (2001) expanded their paradigm and compared the effects of single active practice over 12 weeks (in which one domain [e.g., memory problem solving, conversational abilities] was the focus each week) to integrated active practice over 8 weeks (in which all domains were practiced each week). After single active practice, participants achieved significantly higher scores on measures of immediate memory and verbal fluency but not on measures of delayed memory or problem solving. After the integrated active practice, participants increased their scores on measures of problem solving and verbal fluency.

Caregiver well-being also was assessed in one of the studies (Quayhagen & Quayhagen, 1989). Investigators used the following outcome measures: The Burden Interview (Zarit et al., 1980), Hopkins Symptom Checklist (Derogatis, Lipman, Rickels, Uhlenhuth, & Covi, 1974), and the Health Assessment Scale (Rosencranz & Pihlblad, 1970). Results from the Quayhagen and Quayhagen (1989) study showed that caregivers who were trained in and provided active cognitive stimulation showed no deterioration over time in mental health status (measured by the presence of affective symptoms such as depression and obsession-compulsion) or level of burden. These caregivers also reported more effective coping methods, an increased awareness of intact patient abilities, and new ideas about patient management. Caregivers in the no-stimulation group showed increased affective symptoms, particularly noted in depression, and perceived burden.

### ***What Are the Key Methodological Concerns?***

The review committee rated all studies with regard to internal validity (the ability to make causal inferences), external validity (generalizability of the findings), dose response characteristics (information about strength of treatment and response of the participants), and construct validity (relevance and strength of the outcome measures). Methodological concerns from the studies reviewed were primarily related to external validity and dose response characteristics.

**External Validity.** External validity refers to the generalizability of research findings and in-

cludes replicability, treatment fidelity, manipulation checks, and causal generalizability. Only the Quayhagen et al. (1995) study was judged to be replicable. The investigators specifically stated that they incorporated an instruction workbook with step-by-step procedures for the active cognitive stimulation program. In the other two studies, information about procedures was not detailed enough to be considered replicable. Although Quayhagen and Quayhagen (1989) stated that the “caregivers were provided with a taxonomy of activities of increasing complexity from which to choose” (p. 152) for each program component, it was unclear to the review committee how caregivers selected specific activities for practice. Manipulation checks (assurance that treatment was carried out as described) in the form of weekly instruction by a member of the research team in the home were reported in all studies, although the Quayhagen and Quayhagen (1989) study did not specify the duration of these visits. Two of the three studies (Quayhagen et al., 1995; Quayhagen & Quayhagen, 2001) were rated as having sufficient methodological quality as to have confidence in the generalizability of the findings to other individuals with mild to moderate AD. The Quayhagen and Quayhagen (1989) study had limited generalizability because the no-stimulation group was comprised of families who refused to comply with the structure of the study. This selection bias may have skewed the results to be applicable only to a select group who were willing to commit to an intensive treatment schedule. Causal generalizability was rated moderate (rated 1 on a 3-point scale: 0 = presence of one or more clear confounding variables; 1 = presence of possible confounding variable; 2 = absence of apparent confounding variables) for all the studies reviewed because of the possible confound of increased attention to caregivers and individuals with AD rather than the intervention itself that may have caused differences between the stimulation and no stimulation groups.

**Dose-Response Characteristics of the Treatment.** Information on treatment duration was not provided by Quayhagen and Quayhagen (1989). Dose response characteristics (i.e., frequency, intensity, duration) or format of the initial training of caregivers were also not provided in any study.

### ***What Are the Clinically Applicable Trends Across These Studies?***

The results from the four studies reviewed for this article revealed the following clinically applicable trends:



1. Family caregivers can be trained to administer in-home intervention programs to their loved ones who have AD (Quayhagen & Quayhagen, 1989, 2001; Quayhagen et al., 1995) using practical activities, such as planning a trip and reminiscing. The presence of manipulation checks may enhance caregivers' ability to administer tasks, as they are provided with instruction and demonstration.
2. Caregivers in the active cognitive stimulation group showed improvement in their overall well-being on objective measures and reported a subjective benefit from the intervention (Quayhagen & Quayhagen, 1989) (i.e., ability to recognize their loved ones' strengths despite continuous losses; more effective coping methods).
3. Active cognitive stimulation (actively engaging an individual in an activity or task) administered by family caregivers was shown to be more beneficial than passive stimulation (passive participation in an activity or task, such as watching television), but any stimulation was better than none (Quayhagen et al., 1995). The active cognitive stimulation group showed improvement at the end of treatment, but they regressed toward baseline performance 6 months after termination of treatment. The passive stimulation group, on the other hand, showed relative stability at the end of treatment, whereas the no-stimulation group showed continued decline (Quayhagen et al., 1995).
4. Some individuals with AD, a progressive neurological disease, can maintain abilities in specific areas that are trained (e.g., memory, problem solving, conversational abilities) for the duration of an active cognitive stimulation program (Quayhagen & Quayhagen, 1989, 2001; Quayhagen et al., 1995).

### What Have We Learned From This Review?

The three studies reviewed provide Class II evidence to support the training of family caregivers to administer active cognitive stimulation to individuals with AD. All three of the studies were rated and classified as Phase II outcome studies, with investigators refining their research hypotheses and methodology (Robey & Schultz, 1998).

Although the results were generally positive, with benefits for both individuals with mild to moderate AD and their family caregivers, methodological limitations warrant cautious interpretation of the findings. The small sample size in the Quayhagen and Quayhagen (1989) study limits

its internal validity. Further, time spent working with caregivers and individuals with AD may have contributed to beneficial outcomes that are attributed to the training programs specifically. Another concern is the selection bias of the control group in the Quayhagen and Quayhagen (1989) study who were not interested in following study protocol. Extra attention to and motivation of certain dyads to participate may have contributed to the benefits beyond the intervention itself. Based on the overall findings, recommendations for clinical practice are outlined below.

1. *Appropriate candidates for caregiver training to administer active cognitive stimulation to individuals with AD:*
  - Family caregivers of community-dwelling individuals with early to moderate AD
  - Family caregivers and individuals who are motivated to participate in an intervention program
2. *Implementation of caregiver training to administer active cognitive stimulation to individuals with early to moderate AD:*
  - Family caregivers can be trained to engage individuals with early and moderate AD in active cognitive tasks, such as memory, problem solving, and conversation
  - Caregivers should be provided with a manual containing explicit instructions for specific activities
  - Manipulation checks may encourage and enhance caregiver administration of active cognitive stimulation, although the time required of a professional may limit its feasibility
3. *Expected outcomes of caregiver-administered active cognitive stimulation to individuals with early to moderate AD:*
  - Short-term benefit (less than 9 months) in specific cognitive functions trained (e.g., memory, problem solving, conversation abilities) for individuals with early and moderate AD
  - Possible improvement in well-being of family caregivers during the duration of the intervention

### FUTURE RESEARCH DIRECTIONS

Further research in this area is required to more clearly understand the effectiveness of training family caregivers to administer active cognitive stimulation to individuals with early to moderate AD. First, comparing the outcome of active



cognitive stimulation using naturalistic versus drill-type activities is necessary. Generalization to activities outside the specific task exercised is the gold standard of treatment and may occur with more naturally occurring activities. Second, it is critical to evaluate how long beneficial effects are maintained with periodic follow-up sessions. If benefits are not maintained once active cognitive stimulation is terminated, as shown in these studies, perhaps follow-up or "booster" sessions could help with maintenance of abilities. Third, it is important to determine the optimal treatment dose required to achieve treatment benefits. All of the studies were designed around 60-minute sessions on a daily basis, daily ranging from 5 to 6 days over 8 to 12 weeks for a total of 40 to 72 hours of treatment. Perhaps a combination approach of intensive short-term or less intensive long-term treatment may result in the same outcomes. Furthermore, evaluation of the potential of families coping with a progressive neurological disease to sustain the physical and emotional energy required to achieve these benefits is worthy of further research. Fourth, determining what motivates caregivers to incorporate active cognitive stimulation into every day life is essential, as more consistent stimulation may enhance generalization of abilities for the individual with AD. Fifth, it is important to compare a caregiver-led intervention program with a clinician-driven (i.e., speech-language pathologist or nurse) program to ascertain whether degree of benefit in the patients varies as a function of the person administering the treatment. Finally, addressing attention as a variable in the outcome can help determine whether increased attention to caregivers and individuals with AD allowed for increased cognitive and behavioral function or whether the cognitive challenge of the active cognitive stimulation reduced the rate of decline.

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