



Published in final edited form as:

Alzheimers care today. 2007 ; 8(4): 309–318.

Evidence-Based Interventions to Improve Quality of Life for Individuals with Dementia

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Abstract

Individuals with cognitive impairment, their family members, and their care providers have all identified “quality of life” as a central goal in the treatment of dementia. In this article, we identify factors that influence quality of life for individuals with cognitive impairment, review evidence-based psychosocial interventions that improve quality of life for community-residing individuals with dementia, and describe innovative ongoing randomized clinical trials designed to improve or maintain quality of life for individuals with mild to moderate memory problems.

Keywords

Alzheimer's disease; dementia; evidence-based interventions; psychosocial interventions; quality of life

From the first suspicion that something is wrong, through the progression of cognitive, behavioral, and social changes that occur following a diagnosis, Alzheimer's disease (AD) and related dementias affect individuals' quality of life (QOL) in profound ways. Individuals in the early to middle stages of AD and related dementias are often able and willing to talk about their experiences with memory loss and other aspects of the disease, and are reliable reporters of their own QOL when they are provided a framework to help organize their thoughts.^{1–4} Furthermore, many individuals with dementia rate their overall QOL as good or excellent, despite losses that some would consider devastating.^{5–7} As a result, QOL has been identified as an important indicator of the overall impact of interventions for individuals with dementia, and improving QOL has been identified (along with improving cognitive and functional abilities, delaying decline, and reducing effective and behavioral disturbances) as a primary goal of dementia treatment.⁸

In this article, we identify factors that have been empirically demonstrated to be associated with QOL for community-residing individuals with cognitive impairment. We summarize evidence from a series of clinical trials of psychosocial interventions that have targeted these

factors and evaluate their impact on QOL. Finally, we describe innovative, ongoing investigations aimed at improving or maintaining QOL in individuals with cognitive impairment.

What Influences QOL in Dementia?

Recent studies by independent investigators using a variety of measures have provided clinicians and researchers with a number of empirically derived factors that are associated with QOL in dementia from the perspectives of both the person with dementia and family caregivers.⁴⁻⁹⁻¹⁵ As these studies have accumulated, the factors that influence QOL have been remarkably consistent. For persons with dementia reporting about their own QOL, these factors include mood, engagement in pleasant activities, and the ability to perform activities of daily living (ADLs). For family caregivers reporting about QOL of their care recipient, factors include mood, engagement in pleasant activities, physical functioning, and cognitive functioning. The overlap is obvious: positive mood and engagement in pleasant activities are essential features of good QOL for individuals with dementia; additional components include preserved ADL functioning, physical mobility and health, and maintenance of cognitive ability.

After the identification of essential features of good QOL in dementia, the key question is: how can we use this information to improve QOL for individuals with dementia? In the following section, we will examine psychosocial interventions that target QOL-associated outcomes, that have been tested in randomized controlled trials in community (nonresidential) settings, and that appear promising in improving QOL in individuals with dementia. This is not meant to be an exhaustive review of psychosocial interventions for dementia, but to provide a representative sample of promising approaches. The focus of this article is on the person with dementia; readers who are particularly interested in psychosocial interventions to provide support to caregivers are referred to a review of evidence-based caregiver interventions by Gallagher-Thompson.¹⁶ For a more extensive review and evaluation of evidence-based interventions for individuals with dementia, readers are referred to a recent publication by the Old Age Task Force of the World Federation of Biological Psychiatry.¹⁷ Our review focuses on 4 empirically derived components of good QOL for individuals with dementia as follows: (1) depression and pleasant events, (2) ADLs, (3) physical functioning and mobility, and (4) cognitive functioning.

Interventions to Decrease Depressive Symptoms and Increase Pleasant Events

Behavior therapy interventions

The close relationship between mood and pleasant events for individuals of all ages has been demonstrated for many years.¹⁸⁻²⁰ Older adults with chronic illness, particularly those with dementia, are especially vulnerable to loss of pleasant events and subsequent mood disturbances, as increasing cognitive impairment causes a loss of ability to engage in rewarding and enjoyable activities, which in turn leads to increased depression and decreased QOL.²¹⁻²³ Care providers have long recognized the need for meaningful activity for individuals with AD, and have anecdotally reported that such activity provides a sense of efficacy, reduction in depression, and improved relationships with family members.²⁴⁻²⁷

In the first reported randomized clinical trial of a non-pharmacological intervention with depressed persons with dementia, Teri and colleagues²⁸⁻³⁰ randomly assigned 72 caregiver-care recipient dyads to behavioral treatment (BT) or a control group. The BT interventions focused on teaching caregivers specialized skills to identify and increase pleasant events for the person with dementia, to develop strategies to increase involvement in meaningful activities, and to prevent or reduce depressive behaviors in the care recipient. Change in

depression was the primary outcome. After 9 weekly treatment sessions, participants in BT showed significant improvement in depression symptoms in comparison with control subjects. Furthermore, 60% of the BT group participants showed clinically significant improvement in depression diagnosis (eg, change from a diagnosis of major depression to minor or no depression) that was maintained over a 6-month follow-up period, while only 20% of the participants in the control group experienced improvement.

Similar outcomes were obtained in a second randomized clinical trial with 95 community-residing individuals with dementia complicated by behavioral disturbances and their family caregivers.³¹ Participants received either behavior therapy³⁰ (now called STAR-C) or routine medical care (RMC). STAR-C consisted of 8 weekly home visits and 4 monthly telephone calls by consultants (master's degree level social workers or counselors) trained in behavior management and increasing pleasant events. Following treatment, the frequency, severity, and caregiver reactions to behavioral disturbances were significantly decreased, and care recipient's QOL was significantly better in the STAR-C group than in the RMC group.^{31,32}

Progressively lowered stress threshold interventions

Gerdner and colleagues^{33,34} developed an intervention to decrease behavioral disturbance and increased pleasant events for individuals with dementia based on the theory of Progressively Lowered Stress Threshold (PLST). PLST is based on the premise that as dementia progresses, the affected individual's ability to adapt to environmental and interpersonal stressors decreases. This approach teaches family caregivers problem-solving strategies to identify and provide activities that are appropriate for the individual's current level of functioning and to implement environmental modifications that support ADL function. In a randomized controlled trial of this approach, 237 caregiver/care recipient dyads from 8 research sites were randomly assigned to the PLST program ($n = 132$) or a usual care control group ($n = 105$). At the 12-month assessment, in comparison with the control group, the PLST group had significantly lower caregiver distress over behavior problems, and for nonspouses, the frequency of behavior problems was also significantly lower. Another version of this approach has also been applied in a randomized controlled investigation of 48 caregiver-care recipient dyads in Taiwan by Huang and colleagues,³⁵ and resulted in significantly reduced agitation in the treatment group in comparison with a control condition.

In combination, these studies demonstrate that behavioral and caregiver education interventions can improve QOL for individuals with dementia by increasing pleasant events, decreasing depression and behavioral disturbances, and lowering caregiver distress. Furthermore, they demonstrate that such interventions can be delivered by trained community-based clinicians, and are effective with individuals at all levels of cognitive function, from mild to severe dementia.

Interventions to Maintain ADL Functioning

Individuals with dementia have repeatedly identified the ability to perform ADLs as an important factor in maintaining QOL. Community-based interventions that focus on maintaining ADL functioning have typically provided family caregivers with education about the impact of dementia on functional skills and behavior as well as individualized recommendations for modifications to their specific physical environment and interpersonal interactions.

Gitlin and colleagues³⁶ conducted 2 randomized clinical trials of a home environmental skill-building program (ESP) provided by occupational therapists, designed to maximize function and decrease the occurrence of behavioral disturbances in individuals with dementia. In the first of these trials, 171 community-residing participant-family caregiver dyads were assigned

to the ESP or a usual care (UC) control group. At the posttreatment assessment, caregivers in the ESP group reported significantly less decline in care recipient instrumental ADLs than was reported by UC caregivers.³⁶ The second trial of the ESP intervention was included as part of the Resources for Enhancing Alzheimer's Caregiver Health (REACH) initiative.³⁷ In this investigation, 255 caregivers of community-residing persons with AD or related disorders were randomly assigned to receive ESP or UC. In comparison with UC control group, the ESP group produced significant caregiver skill enhancement, reduction in behavioral disturbances, reduced upset with behavioral disturbances, and improved caregiver affect at the 6-month assessment,³⁸ with further improvements in caregiver affect and trends for maintenance of other gains at 12 months.³⁹

A similar brief occupational therapy (OT) intervention was also evaluated in an investigation of 40 caregiver-care recipient dyads who were randomly assigned to OT or a no-treatment control group.⁴⁰ The OT participants received an individual consultation with an occupational therapist, and were provided with written recommendations regarding environmental modifications, caregiver approaches to care, and community-based assistance; outcomes included caregiver burden, frequency of pleasant activities, self-care, and positive affect in the person with dementia. At the follow-up assessment (mean time between assessments was 2 months, range was 1–6 months), OT participants had significantly higher levels of positive affect and independence in self-care, and caregivers had significantly lower levels of burden than the participants of the control group.

Finally, Graff and colleagues⁴¹ developed and tested a 5-week, 10-session OT intervention in which environmental modifications and caregiver training were used to improve activities of daily living, maximize independent functioning in individuals with dementia, and increase caregiver feelings of competence. In this investigation, 135 participants were stratified by cognitive level and randomly assigned to receive the OT intervention or waitlist (WL). Blinded interviewers conducted posttreatment assessments at 6 and 12 weeks. At both assessments, participants in the OT condition functioned significantly better than participants in WL on daily activities, and OT caregivers reported feeling significantly more competent to deal with dementia than those in WL.

In combination, these investigations provide convincing evidence supporting the use of OT interventions to maintain functioning in community-residing individuals with dementia, and they also demonstrate that such interventions can improve caregivers' affect, decrease burden, and increase feelings of competence and self-efficacy, all of which can result in improved QOL for the person with dementia.

Interventions to Maintain Physical Strength and Mobility

Caregivers have identified physical function as an important component of QOL for their care recipients with dementia. The importance of maintaining mobility and physical activity in dementia has been recognized in clinical and long-term care settings⁴² and randomized trials have demonstrated that individualized exercise programs are both feasible and beneficial for increasing strength and maintaining mobility for cognitively impaired nursing home residents.^{43–45} However, to date, randomized clinical trials of community-based interventions to promote physical activity in older adults have typically excluded individuals with cognitive impairment, either through explicit criteria or because such individuals are unable to successfully complete the programs and/or assessments.^{46–49}

To date, the only published randomized controlled clinical trial of exercise for community-dwelling individuals with dementia involved 153 individuals and their family caregivers.⁵⁰ Participants were assigned to an exercise and behavior management treatment condition in the Reducing Disability in Alzheimer's Disease (RDAD) program or to RMC. During the 12-week

treatment period, caregivers in active treatment were taught by home health providers to guide their care recipient in an individualized program of endurance activities (primarily walking), strength training, balance, and flexibility exercises.⁵¹

Exercise participation, health status, days of restricted activities, disability, falls, mood, and behavioral disturbances were evaluated at baseline, posttreatment, and 6-, 12-, 18-, and 24-month follow-up. Study findings indicated that 81% of caregivers were able to learn and consistently direct their care recipients to follow prescribed exercise activities. At posttest, the RDAD subjects exercised significantly more often, had fewer restricted activity days, better physical functioning, and fewer depressive symptoms than RMC subjects. Over 24 months of follow-up, changes in physical activity were maintained and mobility was improved. For individuals with dementia entering the study with higher levels of depression, significant improvements in depression were maintained at 24 months. Finally, at 24 months, the RDAD participants were less likely to have been institutionalized because of behavioral disturbance.⁵⁰

This randomized clinical trial provides preliminary evidence to support the application of individualized, caregiver-supervised exercise to improve or maintain physical functioning and mood in community-residing individuals with dementia. Other, nonrandomized trials of exercise interventions have also yielded promising results^{52,53} and they, along with a meta-analysis of exercise programs among persons with cognitive impairment,⁴² lend support to the impact of improved physical function on QOL among individuals with dementia.

Interventions to Maintain Cognitive Functioning

Cognitive Stimulation (CS) has been adapted from rehabilitation programs with individuals with head trauma, stroke, and other neurological disorders, and applied to older adults with dementia. Its goal is to improve memory, attention, and general cognitive function in individuals with mild to moderate dementia. Programs may include a variety of cognitive training strategies, including specific memory training, general problem solving, use of mnemonic devices, multisensory stimulation, word games and puzzles, social activities, and/or use of external memory aids such as notebooks or calendars.

Loewenstein and colleagues⁵⁴ compared the efficacy of 2 different cognitive stimulation programs. One was a focused cognitive rehabilitation program that used spaced-retrieval, cueing, procedural memory training, use of a memory notebook, and other tasks to provide focused cognitive training. The second program provided general mental stimulation using both conventional and computer-based games. Forty-four individuals with mild dementia were randomly assigned to treatment conditions. Both interventions significantly improved mood and memory, with the greatest and most lasting improvement in the focused cognitive rehabilitation group.

In another randomized clinical trial evaluating 2 cognitive stimulation programs in Spain, an interactive multimedia internet-based system (IMIS) and an integrated psychostimulation program were compared to a control condition⁵⁵ at baseline, 12 weeks, and 24 weeks. Participants were 46 mildly impaired, community-residing individuals diagnosed with Alzheimer's disease. Once again, both types of cognitive stimulation programs resulted in significant improvements in cognitive function in comparison to the control condition, with the IMIS producing enhanced results that were maintained or increased over the 24 weeks.

The largest randomized trial of cognitive stimulation and its impact on participant's QOL, to date, was conducted by Spector and colleagues⁵⁶ with 201 participants with moderate dementia in adult day centers in England. The CS consisted of biweekly, 45-minute cognitive stimulation sessions conducted by a trained therapist for 7 weeks, and included reality orientation, practice

in using money, word games, group discussion, and multisensory stimulation. The UC participants attended standard programs, and participated in usual activities (including nondirected time, playing bingo, listening to music, etc). After 7 weeks, the CS participants scored significantly higher on cognitive assessments, had less behavioral disturbance, had improved mood, and rated their QOL more positively than UC control group participants.^{7, 56} This improvement was maintained after 6 months for participants who continued to participate in weekly CS groups, but not for those who discontinued the CS groups.⁵⁷

Thus, several independent investigations of CS interventions have shown cognitive benefits for individuals with mild to moderate dementia, and preliminary evidence supports their positive impact on mood and QOL.

New Directions and Innovative Interventions for Improving QOL in Dementia

Early stage support groups

Advances in diagnostic procedures and treatment options have provided both the means and rationale for diagnosing individuals in the early stages of AD. While early diagnosis has many potential benefits, it may also have negative psychological and social consequences for the diagnosed individual, and early diagnosis creates an obligation for healthcare professionals to help individuals and their families cope with the impact of the diagnosis on QOL. Alzheimer's Association chapters and other organizations have begun providing early stage support groups (ESSGs) to address this need. The ESSGs typically focus on providing medical information about dementia, discussing strategies for coping with changes in mood and activities, and encouraging discussion among group participants and their family members about their personal experiences with memory loss and associated problems.^{58,59} Reports of outcomes of these groups are mixed. Although some indicate that groups improve QOL of participants, others have found that stress, depression, or family conflict may occur as a result of discussing current and future losses in the group.⁶⁰⁻⁶² Thus, there is a need to evaluate systematically the effects of ESSGs, so that information about their efficacy can be used to guide policy decisions about whether they should be offered, and, if offered, how to maximize positive outcomes.

In a preliminary study of time limited ESSG outcomes, Logsdon and colleagues⁶³ collaborated with the Alzheimer's Association to evaluate outcomes of ESSG participants in comparison to individuals who were placed on a WL prior to group participation. Over 2 months of active treatment, the ESSG participants reported less decline in QOL, and family caregivers who attended the ESSG group reported significantly improved QOL in comparison to those in WL. The ESSG participants also reported significantly decreased family conflict, whereas WL participants reported increased conflict.

On the basis of these promising early results, we are currently conducting a randomized controlled trial to evaluate community-based support group services for persons with early stage dementia and their family caregivers (R. G. Logsdon, principal investigator). One hundred fifty participant-caregiver dyads will be randomly assigned to attend either an 8-session ESSG or a half-day educational seminar. The local Alzheimer's Association chapter is conducting both the programs. A blinded interviewer is completing the assessments of outcomes of both the person with AD and the participating caregiver at baseline, posttreatment, and 6 months. Primary outcomes focus on QOL of the person with early stage dementia and the family caregiver. Secondary outcomes include mood, participation in pleasant activities, and family relationships. Finally, exploratory outcomes include memory-related distress and self-efficacy.

Exercise and physical activity

As discussed earlier, controlled randomized trials of exercise programs for community-residing individuals with cognitive impairment are lacking, although such programs appear promising to decrease disability and improve mood, physical functioning, and QOL of these individuals. We are currently conducting 2 randomized clinical trials of interventions that include exercise as a major component: one for individuals with AD and sleep disturbance who live at home with a family member (Nighttime Insomnia Treatment and Education for Alzheimer's Disease, NITE-AD), and other for individuals with mild cognitive impairment who reside in retirement homes (most of whom live alone).

NITE-AD

Sleep disturbances are common in persons with dementia,⁶⁴ and are often linked with nursing home placement.^{65–67} NITE-AD is a behavioral intervention⁶⁸ in which caregivers are helped to develop an individualized program to improve sleep for their care recipient, including daily walking and sessions sitting in front of a light box. Control caregivers receive general information and support. In a controlled clinical trial to evaluate the efficacy of NITE-AD to improve sleep, depression, and behavioral disturbances, 36 individuals with AD were evaluated at baseline, posttreatment, and 6-month follow-up. In comparison with control subjects, at posttest, NITE-AD participants spent an average of 36 minutes less time awake at night (a 32% reduction from baseline), and had 5.3 less nightly awakenings (also a 32% reduction from baseline). NITE-AD participants also exercised significantly more days per week, and had significantly lower levels of depression than control subjects. At 6 months, these results were maintained. Thus, NITE-AD was effective, not only for improving sleep in individuals with dementia but also for increasing physical activity and decreasing depression.

A follow-up randomized clinical trial of NITE-AD is now under way, with 136 participants with AD and caregivers (S.M. McCurry, principal investigator). Participants are randomly assigned to light exposure (L), walking (W), or a combination behavioral treatment (NITE-AD) to reduce nighttime behavioral disturbances, compared to RMC with Education. Treatment effects are being assessed at baseline, 1 month, 2 months, and 6 months, and residential care placement rates are being monitored for 1 year. Primary outcomes are total time awake at night and nighttime behavioral disturbances. Participant and caregiver affect, exercise time, and QOL are also being assessed as outcomes in this ongoing investigation.

Resources and activities for lifelong independence (RALLI)

In addition to caregiver-supervised exercise programs for individuals with dementia, there is a need for exercise programs for individuals with memory loss who live alone and/or do not have a caregiver available to assist them. RALLI is a weekly, 9-week exercise intervention that uses behavioral principles to help sedentary, memory impaired retirement home residents develop a regular physical activity program. Many of these residents are unable to participate in typical retirement home or senior center exercise groups because of their memory problems, and because there is no one available to provide individual assistance and reminders. The RALLI program is provided in small groups of 5 to 8 participants, with 2 instructors. Participants are led in a simple exercise routine that includes range of motion exercises for warming up, strength training using body weight, and moderate intensity aerobic activity (primarily walking). Exercises are repeated at each session, follow a logical progression, and are linked with cues to help participants remember them. External memory aids (such as a class notebook) are provided to make the program accessible and appropriate for older adults with memory loss, and written instructions for all exercises are laminated and given to participants. Each week, participants receive handouts and tracking forms to help them remember exercises and health information. In a preliminary feasibility study, 34 participants, aged 70 to 94 years, took part in RALLI groups held in 3 different retirement homes. Attendance and compliance

with the intervention were excellent, with participants attending 90% of scheduled classes. At posttest, average exercise time increased by 172 minutes per week. Physical function, general health, and emotional well-being ratings significantly improved and high-density lipoprotein cholesterol improved significantly following RALLI participation. Anonymous ratings of class materials and instructor effectiveness also indicated a very high level of satisfaction.

On the basis of these promising preliminary results, we are now conducting a randomized clinical trial of 170 participants with mild cognitive impairment, who will be randomly assigned to 1 of 2 RALLI groups: RALLI-Strength, which is the same program described above, and RALLI-Walking, which is a social walking group that meets weekly and encourages participants to initiate and maintain a walking program. Outcomes, including QOL, cognitive, functional, physical, and affective status, will be assessed at baseline, posttreatment, and at 6-month intervals for 36 months.

Can Psychosocial Interventions Improve QOL?

Caring for individuals with dementia is a challenging endeavor, and living with dementia is infinitely more challenging. Much has been written about the negative aspects of AD and related dementias, but we have also heard from those who have this disease that it is possible to maintain a sense of hope, resilience, and joy. In the words of Bea, a person with AD who is interviewed in Lisa Snyder's book *Speaking Our Minds*, "It's a difficult situation, but you have to accept it. Live with it, and try to be happy. That's all you can do. You have to take the good with the bad."⁶⁹(pp30–31)

In reviewing the evidence regarding the ability of psychosocial interventions to improve QOL for individuals with dementia, we found support for a variety of approaches that targeted 1 or more QOL-related outcomes. Interventions using behavior therapy, caregiver education, and environmental modifications can decrease depression and behavioral disturbances and increase pleasant events. Occupational therapy interventions can help preserve day-to-day functioning and promote participation in appropriate and meaningful activities. Physical activity or exercise programs can help maintain mobility, improve mood, and decrease behavioral disturbances. Cognitive stimulation can improve memory, problem solving, and mood, and decrease behavioral disturbances.

Although the interventions we reviewed used different approaches and targeted a variety of outcomes, they share some common features. Each provided training and support to family caregivers, each used a standard program that could be individualized to meet the specific and unique needs of participants, and each provided a means to identify and solve implementation problems. Clearly, future research on interventions will benefit from lessons learned in these investigations. As researchers refine these approaches and develop new ones, it is important to continue to evaluate their efficacy and safety, identify more powerful and efficient approaches, train caregivers to use them appropriately, increase their availability to those who will benefit from them, and continue to keep QOL as a central focus of care.

Acknowledgments

This study was supported by grants from the Alzheimer's Association (IIRG-0306319, PIO-1999-1800) and the National Institutes of Health (AG023091, AG014777, MH01644, MH072736, & MH01158). The authors thank their dedicated staff at the Northwest Research Group on Aging, and the research volunteers who have shared their lives and experiences with them.

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