Early-Stage Memory Loss Support Groups: Outcomes from a Randomized Controlled Clinical Trial

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Objectives. This article describes results of a randomized controlled trial comparing a time-limited early-stage memory loss (ESML) support group program conducted by a local Alzheimer’s Association chapter to a wait-list (WL) control condition.

Methods. One hundred and forty-two dyads were randomized in blocks to ESML (n = 96) or WL (n = 46). Mean age of participants was 74.9 years, and mean Mini-Mental State Examination was 23.4. The primary outcome was participant’s quality of life; secondary outcomes included mood, family communication, and perceived stress.

Results. On the intent-to-treat (ITT) pre–post analysis, significant differences were seen in participant quality of life (p < .001), depression (p < .01), and family communication (p < .05). Within the care partner groups, there was no significant difference between ESML and WL in the ITT analysis. A post hoc exploratory examination of changes that were associated with improved quality of life in ESML participants revealed significant reductions of depressive symptoms and behavior problems (p < .05), improved family communication (p < .05), self-efficacy (p < .01), Medical Outcomes Study short form (SF-36) role—emotional (p < .05), SF-36 social functioning (p < .05), and SF-36 mental health components (p < .01) in improvers.

Discussion. These results support the efficacy of ESML support groups for individuals with dementia.

Key Words: Alzheimer’s disease—Caregivers—Dementia—Depression—Quality of life.

EARLY-STAGE diagnosis of Alzheimer’s disease (AD) and other types of dementia has become both feasible and accepted as good clinical practice as diagnostic procedures have become more sophisticated and treatment options more widely available. Early-stage diagnosis has many benefits: Treatment can be started sooner, legal and financial planning can be addressed while the individual is able to participate in decision making, and support services can be mobilized earlier (Gauthier, 2002). However, receiving a dementia diagnosis is also a life-altering event for diagnosed individuals and their families and creates a need for education and psychosocial services appropriate for their unique needs (Whitehouse, Frisoni, & Post, 2004). Although there are neurophysiological and cognitive substrates underlying some of the psychological symptoms of early dementia, many symptoms of psychological distress are direct reactions to lifestyle changes and losses, such as frustration about being unable to think clearly, depression associated with giving up driving and other valued activities, and worry about future problems, such as having to move into residential care or becoming a burden to family. These anticipatory or reactive psychological responses may be more prevalent or amplified in persons who receive an early diagnosis (Phinney, 2002).

Programs and resources are needed to help newly diagnosed individuals and their families learn about AD so that they can cope with the impact of the diagnosis (Harris, 2002; Sabat, 1998). Alzheimer’s Association chapters and other community organizations have begun providing education and support programs, where participants meet with other newly diagnosed individuals in their community to share their experiences and concerns, learn more about their disease, reduce feelings of isolation, and provide assistance in coping with lifestyle changes and long-term care planning (Roberts & Silverio, 2005; Zarit, Femia, Watson, Rice-Oeschger, & Kakos, 2004). The formats of these groups vary widely in terms of the number and frequency of sessions, level of cognitive impairment of participants, inclusion of caregivers, and content of sessions. Some are open ended and unstructured, whereas others are educational, structured, and time limited. All groups, however, share a common goal of improving quality of life for individuals with dementia and their families.

A growing body of research indicates that these early-stage support groups can be beneficial. Snyder, Bower, Arneson, Shepard, and Quayhagen (1994) reported that an eight-session early-stage support group allowed 15 participants to express negative feelings about their symptoms and diagnosis as well as positive feelings of belonging, purpose, and gratification regarding their support group participation. Goldsilver and Gruneir (2001) reported that participants in an eight-session Canadian project, Circle of Care, not only...
reported positive outcomes including camaraderie, affirmation, and improved confidence but also expressed feelings of helplessness and frustration. Twenty-three participants in a 10-session early-stage dementia “Memory Club” program reported being with other supportive people, being able to express their feelings about dementia, and feeling less isolated as the greatest benefits of the group. Their care partners reported that they believed the groups helped their relatives become more aware and accepting of their memory problems and that the groups positively facilitated discussions about future planning, decision making regarding driving and retirement, and discussing the illness with other people (Zarit et al., 2004). Logsdon, McCurry, and Teri (2006) reported that 39 participants and care partners who attended a 9-week Alzheimer’s Association early-stage support group reported experiencing increased emotional support and decreased isolation as a result of attending the group. Care partners of these participants rated information about community resources and future medical, legal, and financial planning as important group benefits. Finally, Snyder, Jenkins, and Joosten (2007) administered a survey questionnaire to 70 support group participants with AD from eight well-established groups across the United States. Benefits reported by these individuals included education, positive socialization, and improved ability to accept the diagnosis and cope with symptoms.

As is common in any newly developing area of research, these studies are limited by small samples, lack of control groups, and lack of standardized outcome measures. Each concluded that randomized controlled trials with objective outcomes assessments are needed to evaluate the efficacy of early-diagnosis support groups for both individuals with dementia and their caregivers. This investigation reports results of a randomized controlled clinical trial designed to objectively assess participant and care partner outcomes following a nine-session structured early-stage support group program developed and run by the Alzheimer’s Association Western and Central Washington State Chapter. Groups were held in community settings and facilitated by trained volunteers, using a service provision model that can be adopted by other Alzheimer’s Association chapters and similar service providers. A manual for the early-stage memory loss (ESML) program is available from the Alzheimer’s Association Western and Central Washington State Chapter (http://www.alzwa.org).

Methods

Procedure

Participants and care partner dyads were recruited via referrals from the Alzheimer’s Association Western and Central Washington State chapter (AAW). Because an important goal of this investigation was to evaluate outcomes of ESML support groups provided within a naturalistic community-based setting that can be replicated by other social service providers, inclusion criteria were designed to be as inclusive as possible of individuals served by the AAW early-stage programs. Persons were eligible to participate if they a) had a diagnosis of dementia confirmed by the individual’s primary care physician, b) had a Mini-Mental State Examination (MMSE) score of 18 or higher, c) were aware of their memory loss and able to communicate verbally, d) were able to participate independently in a group setting (without their family members present), e) had no significant history of severe mental illness that would impede their ability to take part in support group activities, and f) both the person with dementia and a family care partner (husband, wife, or other adult family member) agreed to participate in the evaluation. ESML groups were conducted and staffed by the AAW, and individuals were not required to participate in the research study in order to be in an ESML group, but those who met the study eligibility criteria were offered the opportunity to learn about the study and participate. Ninety-eight percent of individuals who were eligible and referred for the study by the AAW agreed to participate in the research. Supplementary Figure 1 illustrates the flow of participants through the trial.

ESML groups have been part of the AAW’s regular programming since 1995 and are conducted in the spring and fall in various locations throughout Western Washington. Twenty-five ESML groups held in 15 different locations were included in this investigation. Because the logistical arrangements for groups requires a considerable amount of advance planning, treatment condition was randomized in advance by assigning each location to start with either ESML or wait-list (WL) control at the outset of the current study and then to alternate between conditions. Participants were assigned in blocks to whichever condition was scheduled next in the location nearest to their residence when they called to inquire about possible programs. Participants were assigned to ESML or WL in a 2:1 ratio. This allocation was chosen to facilitate recruitment and to increase experience with the experimental ESML program.

Treatment Conditions

ESML intervention.—The ESML condition is a structured support group program that follows a written manual originally developed by L.S., MSW, LCSW, and colleagues (Snyder et al., 1994) that has been revised and updated regularly by AAW staff to ensure continued accuracy and regional applicability. ESML sessions averaged 90 min in duration and met weekly for 9 weeks. Each session included both individuals with early-stage dementia and a family care partner, who met together for part of the session and separately for part of the session. All groups were provided free of charge to participants. Groups were held in convenient community locations (adult day centers, senior centers,
Participants who were assigned to the WL—

Each ESML group had three to four volunteer facilitators, who were recruited by the AAW. At least two facilitators in each group were master’s degree level professionals experienced in working with individuals with dementia, who had already conducted one or more early-stage support groups prior to participating in this investigation. To ensure treatment fidelity, facilitators participated in a daylong training workshop each year to familiarize them with research procedures and refresh their knowledge of the intervention. At these workshops, taught by coinvestigators L.S., P.H., and R.G.L., all facilitators received a standardized procedure manual with step-by-step instructions for each session and copies of all handouts. Updated handouts were mailed to facilitators as they became available.

**WL control.**—Participants who were assigned to the WL condition received written educational materials routinely provided by AAW. These materials provided information about dementia and AD, described services provided by the Alzheimer’s Association, and provided a contact phone number. Participants in this condition were invited to call the AAW office if any questions or concerns arose during the study period, and AAW staff members provided additional educational material and information about local referral sources as needed. Participants in this condition were encouraged to use any primary, acute/emergency, or supportive care services that were normally available to them in their communities. After their follow-up assessment, WL participants were given an opportunity to participate in the next available ESML seminar within their community.

**Outcomes**

Assessments of outcomes of both the person with dementia and the family care partner were completed at baseline and posttreatment. Primary outcomes focused on quality of life of the person with early-stage dementia and the family care partner. Secondary outcomes focused on factors that have been demonstrated in prior research to be associated with early-stage support group participation, including mood, family communication, and self-efficacy (Logsdon et al., 2006; Snyder et al., 2007; Zarit et al., 2004). Measures were completed by participants about themselves and by care partners about both the participants and themselves. Demographic information was obtained during a joint interview with both the participant and the care partner. Participants completed all the measures in an interview format, with the interviewer reading the questions and response choices (following the instructions of each measure), whereas the participant used a “response card” to remind him or her of the response choices. Care partners completed measures as article and pencil questionnaires, with assistance from the interviewer as needed to clarify instructions or response options.

**Primary outcomes.**—**Overall quality of life.** The Quality of Life-Alzheimer’s disease (QOL-AD; Logsdon, Gibbons, McCurry, & Teri, 1999, 2002) is a 13-item measure designed to provide a global measure of perceived well-being. It has been widely used to evaluate quality of life outcomes in individuals of all ages. Adequate internal reliability, test–retest reliability, and validity.

**Health-related quality of life.** The Medical Outcome Study short form (SF-36; Stewart, Hays, & Ware, 1988) is a 36-item measure that has been widely used to assess health-related quality of life outcomes in individuals of all ages. Adequate internal reliability, test–retest reliability, and validity.

**Secondary outcomes.**—**Mood.** The Geriatric Depression Scale (GDS; Sheikh & Yesavage, 1986) provides an assessment of participant and care partner mood. The internal consistency reliability of the GDS is excellent for both patients and caregivers and was not adversely affected by cognitive status in a prior investigation by the first author (Logsdon et al., 2002).

**Communication and interpersonal relationships (COM).** The communication, affective expression, and involvement subscale of the Family Assessment Measure (Skinner, Steinhauser, & Santa-Barbara, 1983) provides an assessment of the level of interpersonal conflict in the participant–care partner relationship. It has been shown in studies with AD patients and caregivers to have good internal reliability and to be related to caregiver burden and depression (Williamson & Schulz, 1990).

**Stress.** The Perceived Stress Scale (PSS; Cohen, Kamarck, & Mermelstein, 1983) is a 14-item self-report questionnaire designed to provide a global measure of perceived stress. It has been widely used to evaluate stress in caregivers of patients with dementia. The measure has good internal consistency and test–retest reliability, and it correlates with life events and health care service utilization.
Exploratory outcomes.—Self-efficacy. Self-efficacy represents an individual’s belief that he or she can effectively cope with challenges and has been associated with performance in a variety of areas, including cognitive, functional, and health status. The Self-Efficacy Scale used in the McArthur Studies of healthy aging consists of nine items and assesses interpersonal efficacy and instrumental efficacy. It has good test–retest reliability, and normative data are available from more than 1,000 informants (Seeman, McAvay, Merrill, Albert, & Rodin, 1996).

Assessment of memory-related behavior problems. The Revised Memory and Behavior Problem Checklist (RMBPC; Teri et al., 1992) provides an overall caregiver-reported evaluation of behavior problems in dementia. The RMBPC consists of 24 items rated by caregivers to measure both the frequency of each problem and the caregiver’s reaction to each problem, and psychometric qualities of the scale are excellent (Teri et al., 1992).

Statistical Methods

Data analyses were conducted using Stata (StataCorp, 2007). Baseline equivalence on outcome measures and demographic characteristics between groups was examined with t tests and chi-square tests for interval-level and categorical variables, respectively. Posttest analyses were based on intent to treat (ITT), with baseline values carried forward for all dyads missing the posttest. Change scores were calculated for all clinical and quality of life domains by subtracting baseline from posttest scores. Treatment effects were tested on change scores using multivariate general linear models. Separate models were developed for participants and family caregivers, adjusting for age, sex, and change in participant cognitive functioning. Because the effect on both ESML participants and WL controls at a site could be correlated, groups were clustered on location and robust standard errors estimated. To correct for multiple comparisons in the primary and secondary outcomes, the Bonferroni correction was applied, dividing the alpha level (of .05) by 3 for the primary outcomes (QOL-AD + two summary scores of the SF-36) and by 3 for the secondary outcomes (GDS + COM + PSS). Thus, the critical value for both primary and secondary outcomes analysis is set at .02. Data were explored in detail to ensure that effects observed were not due to specific influential cases in the data.

In an exploratory post hoc analysis to identify participant and care partner characteristics that were associated with improvement on the primary outcome (QOL-AD scores), participants and care partners were classified as “improvers” or “nonimprovers,” and a series of chi square and analyses of variances were conducted to examine how the two groups differed on baseline characteristics and changes in other outcomes. For this analysis, individuals whose QOL-AD scores improved from baseline to posttreatment were classified as “improvers,” and those whose scores remained the same or got worse were classified as “nonimprovers.” Because this analysis was exploratory, no correction for multiple comparisons was applied, and results of this analysis should be interpreted with caution.

Results

One hundred and forty-two dyads were randomized in a 2:1 ratio to ESML (n = 96) or WL (n = 46). At baseline, mean age of participants was 74.9 years, mean MMSE score was 23.4, and Clinical Dementia Rating Scale scores reported by care partners ranged from 0 to 1 (86% scored 0.5), consistent with early-stage dementia. Eighty percent of care partners were spouses, 14% were adult children, and the rest were other relatives or friends. Care partners reported few depressive symptoms at baseline, with mean GDS scores = 2.2 (SD = 2.2). There were no significant differences on any assessment measures at baseline between treatment conditions, and treatment conditions were equivalent on all patient and caregiver characteristics (sex, race/ethnicity, education, MMSE score, and relationship to patient) except age, for which ESML participants and caregivers were older, t(140) = 4.44, p < .001 and t(119) = 3.34, p < .01, respectively (Table 1).

Of 142 dyads who began the study, 136 (96%) completed posttreatment assessment, and there was no differential dropout between intervention groups (Fisher exact test, p = 1.0). Table 2 shows mean scores for outcome measures at baseline and posttreatment. On the primary outcomes ITT pre–post analysis, controlling for age, sex, and change in participant MMSE scores, ESML participants reported significantly improved QOL-AD scores, whereas participants in WL reported decreased QOL-AD (β = 1.74; p < .001), R² = .05, effect size d = .36. No significant differences were found on the SF-36 summary scores or subscales.

On secondary measures ESML participants’ scores on the GDS improved, whereas scores for WL participants were worse (β = −1.34, p < .01), R² = .05, effect size d = .36. No care partner outcomes were significantly different for ESML versus WL conditions in the ITT analysis.

In a post hoc exploratory analysis to explore factors that might influence ESML group outcomes, participants were classified according to whether their scores were the same or worse (nonimprovers) or improved (improvers) on the primary outcome measure (the QOL-AD) between baseline and posttest. Using this criterion, 48% of ESML participants were classified as improvers, and 30% of WL participants improved, χ²(1, N = 142) = 3.98, p < .05.

An analysis of variance revealed no significant baseline demographic, cognitive, or functional differences between improvers and nonimprovers in either ESML or WL participants. For the WL group, improvement was not associated with baseline scores on any outcome measure. In contrast,
within the ESML condition, improvers had significantly higher baseline levels of depression on the GDS (p < .05), higher perceived stress (p < .01), and more distress on several SF-36 subscales, including mental health (p < .05), vitality (p < .05), general health perceptions (p < .01), and bodily pain (p < .05). Thus, ESML participation appears to have been most beneficial for participants who were experiencing higher levels of distress at baseline.

An examination of pre–post change scores associated with improved QOL revealed that ESML group participants whose quality of life improved also reported significantly greater improvement in mood (SF-36 mental health components summary, p < .01 and GDS, p < .05), family communication (p < .05), and self-efficacy (p < .01) compared with nonimprovers.

For care partners, there was no significant difference in percent improved between ESML and WL (39% of those in ESML improved on the QOL-AD compared with 30% of those in the WL condition). Within the ESML condition, improvers were significantly more likely to be spouses of the participant rather than adult children or other partners, with 49% of spouses reporting improved QOL-AD scores as opposed to 24% of other relatives/partners reporting improvement (χ² [1, N = 96] = 3.64, p < .05).

## Conclusions

Results of this investigation demonstrate that, for individuals with early-stage memory loss, participating in a nine-session ESML support group resulted in significantly better quality of life and decreased depressive symptoms compared with a WL control condition. Although the amount of change seen in these outcomes is modest, these findings are consistent with qualitative reports of the benefits of early-stage support groups and provide empirical support for the efficacy of these groups on areas of clinical importance to individuals with dementia. Furthermore, these results indicate that individuals who were experiencing more distress at baseline experienced greater improvement in quality of life following participation in
ESML groups and that improved QOL was associated with improved mental health, family communication, and self-efficacy.

Although these results are promising, additional work is needed to clarify the benefits of ESML groups compared with other possible early-stage services. The ESML program in this investigation was not designed for individuals with clinical psychopathology or with high levels of psychological and interpersonal distress; such individuals will likely require more focused and individualized treatment. Although a statistically significant difference between ESML and WL participants was seen in depression change scores on the GDS, with a decrease in scores for ESML participants while WL participants’ scores increased, mean GDS scores remained at the cutoff for possible depression. Thus, these groups should not be considered an alternative for depression treatment in individuals with significant clinical depression.

Care partners who attended the ESML groups along with the person with early-stage dementia did not report significant changes in their own quality of life. The ESML groups evaluated in this investigation were designed primarily to meet the needs of the person with early-stage dementia and focused on concerns of the diagnosed individual. Care partners are included to support the participants, and many care partners in the early stages do not consider themselves to be “caregivers.” In the current study, spouse partners participating in the ESML groups were more likely to report improvement in their own quality of life than nonspouses. Since most non-spouses were adult children, this difference may be due to the added burden that attending a weekly support group places on adult children who are frequently still working and have other family responsibilities. Additional research is needed to evaluate other types of early-stage interventions for both persons with dementia and family care partners.

This investigation differed from many randomized clinical trials, in that the ESML intervention originated within a community-based setting rather than in an academic research environment. The success of the project illustrates the feasibility of conducting rigorous research in community-based settings, provided both the research team and the community partner recognize the requirements of the other partner. Conducting the ESML groups within the community in a way that can be replicated by other community organizations facilitates the translation of this intervention into the larger service provider community.

Participants in this investigation had contacted the Alzheimer’s Association about available services and were well educated and predominantly White. Individuals and families with different ethnic or cultural backgrounds are likely to have needs and expectations that differ from those of participants in this investigation. Individuals who live in rural areas may not have access to support group programs, such as the ESML groups, and it is challenging to provide groups in rural areas because of the need to assemble a critical mass of early-stage dyads to form a group. Individuals with early-onset dementia (age 35–65 years) face a different set of problems than those with later onset and may not feel they fit into the typical early-stage group. Clearly, more research is needed on types of services and service provision models for these diverse communities. But, in the interim, early-stage support groups may offer hope to many participants and care partners. We have begun to define and objectively measure these benefits and will undoubtedly learn much more about how these groups can best serve these individuals and families in the future.

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SUPPLEMENTARY DATA
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