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The Memory Club: Providing Support to Persons with Early-Stage Dementia and Their Care Partners

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Abstract

There is a growing emphasis on delivering services for persons with early-stage dementia (ie, "persons with memory loss," or PWMLs) and their family members (care partners). The goal of this evaluation was to determine whether participation in the Memory Club, a 10- to 13-session joint support group, would result in decreased distress, enhanced preparation for care, and improved feelings of confidence managing the challenges of early-stage dementia. The single group, pre-/post-test evaluation included 63 PWMLs and 61 care partners who participated in three Memory Club sites in Minnesota. Paired *T*-test results found that care partners reported significant ($P < .05$) increases in preparation activities, feelings of preparation, and confidence in managing memory loss. The results suggest that the Memory Club can fill an important gap in early-stage dementia care by offering care partners the opportunity to plan, prepare, and increase coping skills in the face of early dementia progression.

Keywords

Alzheimer's disease, caregiving, early stage, cognitive impairment, caregiver intervention, support group

Introduction

An emerging recommendation in Alzheimer's disease (AD) research is early diagnosis and assessment, as it is assumed early detection of AD can result in various benefits for persons with AD and their family caregivers.[1-8] Consensus statements and clinical opinion suggest that early detection and diagnosis of AD provides more time to make advanced care decisions, offers the person with early-stage AD the opportunity to actively participate in health care decisions,[9] prevents catastrophic events such as driving accidents,[10] more effectively prevents dementias that are not caused by AD (eg, vascular dementia),[11] and increases the potential for existing treatments to exert stronger and longer benefits.[2,12] However, there exists little empirical evidence demonstrating the actual benefits of early diagnosis or detection (for a recent study examining the assumed benefits of early diagnosis of AD using Monte Carlo modeling, see Weimer & Sager, 2009).[13] A related concern linked to the drive for early diagnosis is whether there exist sufficient services and support (both pharmacologic and nonpharmacologic) to best meet the needs of persons with early-stage AD or their family members (called "care partners," as these individuals may or may not provide the intensive hands-on or instrumental care more typical of family "caregivers"). The purpose of the present study was to report evaluation results of a multisite implementation of "The Memory Club," a 10- to 13-session joint group support for persons with early-stage AD or other dementias (hereafter called "persons with memory loss," or PWMLs) and their care partners.

Supportive Strategies for Early-Stage Alzheimer's Disease or Other Dementias

Various descriptive studies have explored how to implement support groups for PWMLs and their possible benefits. These efforts often focused on planning, content, and the

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ramifications of including persons with early-stage dementia in support groups along with care partners.[14-17] The anecdotal and open-ended data implied that early-stage dementia support groups improved family function and care planning,[18] offered education,[19] created a sense of purposefulness along with fostering feelings of upheaval and helplessness for PWMLs,[15,20] increased confidence and coping for participants,[19,21] and enhanced communication between the PWML and care partner.[15]

Several research studies have evaluated joint support groups for persons with early-stage AD and their care partners. In particular, the work of Logdson and colleagues has generated the highest quality evidence regarding the efficacy of joint support groups. In a randomized controlled trial of a 9-session joint support program for 142 persons with early-stage memory loss and their care partners (96 dyads randomly assigned to the support program and 46 to wait-list control), results found that PWMLs reported significantly higher quality of life and family communication as well as reduced depression. However, care partners did not indicate significant differences.[22] In a smaller preliminary controlled study of the same joint support program, Logsdon and colleagues found that PWMLs in the support group protocol indicated decreased isolation and improved emotional support and care partners reported greater satisfaction with care planning guidance when compared to wait-list controls.[23]

A smaller-scale preliminary evaluation of a joint early-stage dementia support group called the "Memory Club" took place in the Los Angeles, California Alzheimer's Association region. A single-group pre-/posttest design of 23 persons with early-stage AD and care partners of the 10-session program found that participants rated the Memory Club very highly, particularly the skill of support group leaders. Open-ended comments suggested that persons with early-stage AD and care partners acknowledged the benefits of being with "people in the same situation." However, no statistical tests of change on key outcomes were reported.[24]

The Memory Club

Unlike traditional support groups that only include family members of relatives with middle- to late-stage dementia, the Memory Club aims to involve the care partner and PWML jointly to participate in discussions about the PWML's illness and care. This approach shares some similarity to traditional marital/family therapy approaches, which revolve around strengthening the couple's/parent-child relationship via learning about each other's difficulties in face-to-face interactions.[24] The Memory Club also recognizes the devastating impact of an AD or related dementia diagnosis on the care partner-PWML relationship and offers separate sessions to strengthen each individual so that they can, in the end, work more effectively as a dyad in facing dementia.[24] The Memory Club aims to increase information and knowledge about dementia, improve communication and relationship issues, improve confidence regarding future planning decisions, and enhance feelings of support via increased efforts to reach out to other family members and friends regarding the PWML's early-stage dementia.[24] These supportive aspects of Memory Club, via the joint and separate PWML and care partner sessions, are anticipated to have several benefits. These include reductions in the feelings of isolation in the care partner-PWML dyad, greater feelings of efficacy and independence on the part of the care partner and PWML, (respectively), enhanced communication within the care partner-PWML dyad as well as with others in participants' social network, increased well-being, and greater awareness of the available medical and community-based options available to PWMLs and their care partners.[24]

Each session of the Memory Club is moderated by 2 facilitators, includes from 10 to 13 weekly sessions lasting 90 to 120 minutes, and involves the following: (1) a joint interaction period that includes PWMLs and care partners; (2) separate group sessions for PWMLs and care partners; and (3) a "wrapping-up" session that involves both PWMLs and care partners jointly. Sessions are organized around specific topics related to early-stage dementia and also include expert speakers.

The primary goal of this study was to implement The Memory Club in 3 diverse settings in Minnesota. The single-group pre/post-test evaluation included care partner and PWML dyads across the 3 sites to address the following research questions:

1. Did care partners who participated in the Memory Club report statistically significant ($p < .05$) decreases in stress and depressive symptoms?
2. Did care partners who participated in the Memory Club report statistically significant increases in perceptions of effectiveness when performing care tasks and preparation?
3. Did PWMLs who participated in the Memory Club indicate statistically significant increases in perceptions of effectiveness when performing various activities and decreases in depressive symptoms?

Methods

Procedure

Memory Club support groups for PWMLs and their care partners were conducted at 3 locations in Minnesota: The Center for Senior Services at Park Nicollet Clinic in St. Louis Park (a suburb of Minneapolis); the Alzheimer's Association local office in Rochester (which held the sessions at the Alzheimer's Disease Research Center of the Mayo Clinic); and the Wilder Memory Loss Program in St. Paul. Each site has an active, joint support group for PWMLs and their care partners and has access to individuals who are interested in participating in Memory Club groups. Each site included 2 moderators who supervised the conduct of the Memory Club and the administration of assessments. Persons with early-stage dementia and their care partners were screened and then completed surveys

Table 1. Memory Club Session Outlines Across 3 Minnesota Sites

Week	Park Nicollet Center for Senior Services[a]	Rochester-Mayo Clinic[b]	Wilder Memory Loss Program[c]
1	Introductions and pre-Memory Club assessment; honoring our identity—past and present	Pre-Memory Club assessment; get acquainted	Pre-Memory Club assessment; welcome to the club; DVD: Alzheimer's disease: inside looking out
2	Understanding the disease process	Understanding the disease process	Understanding the emotions of early memory loss; (speakers: past participants of memory club)
3	Nutrition and exercise (speaker: local expert)	Participation in memory related research (video and brunch)	Understanding the medical aspects of memory loss (speaker: neuropsychologist)
4	Support Networks for Safety	Common Emotional and Psychological Reactions to the Diagnosis	Coping strategies from the Alzheimer's association (speaker: Alzheimer's association care specialist)
5	Partnering with your doctor (speaker: Alzheimer's association care specialist)	Honoring our identity—past and present	Daily living concerns and services to help: driving, safe return program, medications
6	Participation in memory related research (speaker: mayo clinic education specialist)	Safety concerns (safe return/ driving)	Communication with family and friends (speaker: local support group moderator)
7	Honoring independence	Communication with family and friends/family dynamics	Ducks in a row: financial and legal planning (speaker: elder-law attorney)
8	Living Well	Role transformation/honoring independence	Research update and more (speaker: Mayo clinic education specialist)
9	Plan for future/elder law Attorney-(speaker: elder-law Attorney)	Partnering with your doctor	Resiliency/planning for the future
10	Community resources	Coping strategies	Post-Memory Club assessment; new outlooks, graduation celebration
11	Post-memory club assessment/celebration	Practical planning for the future (legal/financial)	
12		Post-Memory Club assessment/ support group time	
13		Living fully celebration	

[a] Memory Club sessions held on Tuesdays from 1:00 to 2:30
[b] Memory Club sessions held on Wednesdays from 10:30 to 12:00
[c] Memory Club sessions held on Wednesdays from 1:00 to 3:00

in person immediately prior to the first Memory Club session. A final post-Memory Club survey was completed during the last session of each Memory Club program.

As part of the screening procedure, moderators administered the Mini-Mental Status Examination (MMSE) to PWMLs.[25] All moderators had extensive experience conducting the MMSE in their work with persons with AD and their caregiving families. The main objective of MMSE administration was to ensure that members were at an appropriate cognitive level to participate in Memory Club activities. If PWMLs scored 18 or over on the MMSE, they were invited to participate in the Memory Club and the subsequent evaluation. If there was evidence of greater impairment, moderators referred these individuals to care consultation and community-based services (via the Alzheimer's Association or the local Area Agency on Aging) that were more appropriate for their particular cognitive competence.

While participating in the Memory Club, dyads (the PWML and the care partner) completed a survey that collected information on demographic characteristics, care history, functional and cognitive status, and measures of well-being including mood, distress, well-being, and confidence. These Memory Club surveys took place immediately prior to the first session of the Memory Club (T1) and at the conclusion of the Memory Club (T2). The T2 surveys also included ratings of satisfaction with the Memory Club. Moderators administered all surveys in-person. Following completion of the surveys, PWMLs and their care partners were consented to provide de-identified information for subsequent analysis (IRB# 0710S18221). The evaluation took place from 2008 to 2010. Across the 3 sites, a total of 61 care partners and 63 PWMLs participated in the pre- and post- Memory Club evaluation. Four care partners participated in the Memory Club but did not provide any evaluation data at the pre- or post-Memory Club assessment intervals.

Table 1 provides a list of sessions that occurred at each Memory Club site in the evaluation. As suggested in Table 1, session topics and order of sessions varied across the sites due to clinical expertise of the facilitators, available community speakers to present on various topics, and logistical issues unique to each site. In order to ensure consistency in clinical objectives and delivery of sessions, the Memory Club moderators, Alzheimer's Association Minnesota-North Dakota Regional Office staff, and the evaluator met via telephone conference calls quarterly or on an as-needed basis to discuss issues of clinical concern, scheduling challenges, recruitment and retention of Memory Club participants, and similar issues. This helped to preserve the "organic" nature of the Memory Club at each site while at the same time maintaining a strong focus on the initial goals and objectives of the Memory Club protocol.

Measures: Care Partner

Context of care. Care partners were asked about care context during the pre-Memory Club survey. Measures of context of care included care partner and PWML sociodemographic information (age, gender, race/ethnicity, martial status, education, and income), kin relationship to the PWML, number of living children of the PWML, and where the PWML currently lived. Additional items asked care partners about how long ago they recognized memory problems in the PWML, whether they provided care to the PWML because she/he needed it, duration of care, whether the care partner indicated they spent the most time helping the PWML, whether the PWML saw a doctor for memory problems and how long ago this occurred, and whether the PWML was diagnosed with dementia.

Person with early-stage dementia instrumental activity of daily living dependence. Care partners were asked how much help PWMLs required to complete 9 instrumental activities of daily living (IADL) or similar tasks.[26]Tasks included taking medications, housework/housecleaning, shopping for food, cooking/preparing food, laundry, driving, using the telephone, managing the finances, and participating in leisure activities. Item responses ranged from (1) "does by self or needs no help;" (2) "needs reminders or a little help;" (3) "needs a lot of help;" and (4) "unable to do without help." The reliability of the IADL assessment measure was high at the pre- and post-Memory Club assessment intervals ($\alpha = .86$; $\alpha = .89$).

Care partner stress. Care partners also reported on their feelings of exhaustion, worry, strain, and feelings of being trapped in care responsibilities during the pre- and post-Memory Club assessments.[24,27] Response categories ranged from (1) "never;" (2) "some of the time;" (3) "most of the time;" and (4) "all of the time." Reliability for the care partner stress measure at the T1 and T2 assessments was high ($\alpha = .83$; $\alpha = .86$, respectively).

Care partner effectiveness. Care partners were asked to rate their effectiveness in dealing with various care tasks and issues.[24] The care partner effectiveness measure showed good reliability at the pre- and post-Memory Club assessments ($\alpha = .91$; $\alpha = .93$). Example items included "When your relative is sad or blue;" "Understanding the choices available for treating your relative's illness;" and "Talking to your relative about why he/she has trouble remembering." Item responses included (1) "poor;" (2) "fair;" (3) "good;" (4) "very good;" and (5) "excellent" and were averaged.

Depressive symptoms. Depressive symptoms of the care partner were measured using the Geriatric Depression Scale (GDS) at the pre- and post-Memory Club surveys ($\alpha = .89$; $\alpha = .87$, respectively). The 15-item GDS has demonstrated strong psychometric properties to assess depressive symptomatology.[28-30]

Preparation checklist. A 13-item preparation checklist was administered to care partners during the pre- and post-Memory Club assessments to determine whether care partners were engaging in or had completed activities to maintain the PWML's memory and prepare for the future. Activities included "I have obtained a diagnosis for my RELATIVE'S memory loss;" "My RELATIVE is taking medications and/or vitamins to help their memory (eg, Aricept, Namenda, Razadyne, Vitamin E);" and "We have read books and/or brochures on memory loss and the maintenance of memory." The number of completed activities was summed at pre- and post-Memory Club assessment intervals.

Anticipation of care. Three subscales, based on Sörensen and colleagues' research,[31,32] were administered during the pre- and post-Memory Club surveys to determine care partners' preparation for care. Four yes/no items were administered to assess whether care partners' were anticipating the provision of various types of care to PWMLs. Example items included "Have you ever thought about what would happen if your relative needed help with household tasks like cooking or doing laundry or shopping;" and "Have you and your family ever talked about what might happen if your relative needs help with personal care or household tasks." The *preparation for care needs* items were summed and showed good reliability at the pre- and post-Memory Club assessments. Two additional items were included to measure care partners' *satisfaction with preparation for care.* Care partners' were asked to answer the following questions with item responses ranging from 1 to 5, with (1) meaning "not at all," and (5) meaning "very:" "How satisfied are you with the amount of discussion in your family about how to care for your relative if she/he ever needed it;" and "How satisfied are you with the amount of planning in your family about how to care for your relative if she/he ever needed it?" The average of both items was used to create a summary satisfaction with preparation for care score. Twelve additional items determined care partners' *preparation for future care* of PWMLs during pre- and post-Memory Club surveys ($\alpha = .87$; $\alpha = .86$, respectively). Items included "Thinking more seriously about a relative's needs," "Learning more about a relative's difficulty with personal care," and "Realization that the relative is having difficulty with things." Responses ranged from (5) "Strongly agree;" (4) "Agree;" (3) "Feel neutral;" (2) "Disagree;" and (1) "Strongly disagree."

Satisfaction. Care partners were administered a 13-item measure of satisfaction with the Memory Club during the post-Memory Club survey ($\alpha = .92$).[24]The satisfaction measure assessed the skill of Memory Club group leaders, the information given, how well the group leaders understood the care partner, learning how others managed their situation, and similar items. Item responses included (4) "very good;" (3) "good;" (2) "neutral;" (1) "poor;" and (0) "very poor." Care partners were also asked whether they would recommend the Memory Club to others, with item responses of (5) "definitely;"

Table 2. Descriptive and Context of Care Information, Care Partners (N = 61) and Persons with Memory Loss (N = 63)

Variable Mini-mental status exam	Person With Memory Loss M = 24.67 (SD = 3.26)	Care Partner –
Site		
Park Nicollet	55.6%	59.0%
Rochester-Mayo	19.0%	19.7%
Wilder	25.4%	21.3%
Age (in years)	M = 74.25 (SD = 9.41)	M = 69.16 (SD = 11.10)
Gender (female)	52.5%	58.5%
Race/ethnicity (Caucasian)	96.7%	96.7%
Married/with partner	95.1%	88.5%
Number of living children	M = 3.03 (SD = 1.80)	M = 3.07 (SD = 2.23)
Education (Bachelor's degree or higher)	58.3%	57.4%
Annual household income (over $40,000 per year)	64.0%	78.4%
Employment status (retired)	–	56.7%
Kin relationship to PWML (spouse)	–	85.2%
PWML lives with care partner	82.0%	–
Did care partner recognize memory problems in PWML?	–	96.7%
How long ago were these problems recognized? (in months)	–	M = 42.37 (SD = 27.30)
Did the care partner ever see a doctor for the PWML's memory problems?	–	86.7%
How long ago was the first visit to the doctor? (in months)	–	M = 28.99 (SD = 30.36)
Did PWML receive a diagnosis of dementia?	–	95.1%
Does care partner provide help to PWML?	–	81.4%
How long ago did care partner first start helping PWML? (in months)	–	M = 25.17 (SD = 16.81)
Is care partner the person who spends most time helping PWML?	–	98.0%
Does the PWML suffer from other serious health conditions?	56.9%	–

Abbreviations: PWML, person with memory loss; M, mean; SD, standard deviation

(4) "probably;" (3) "not sure;" (2) "probably not;" and (1) "definitely not."

Measures: Person With Memory Loss

Ratings of effectiveness. During the pre- and post-Memory Club surveys, PWMLs provided ratings of effectiveness when completing certain activities.[24,33] This measure asked PWMLs to judge how effective they were when dealing with forgetfulness, task completion, frustration and similar emotions, planning for the future, interacting with friends and family, and managing memory issues. Item responses include (5) "very good;" (4) "good;" (3) "neutral;" (2) "poor;" and (1) "very poor." The ratings of effectiveness measure showed good reliability at T1 ($\alpha = .81$) and T2 ($\alpha = .83$).

Depressive symptoms. Depressive symptoms were measured at the pre- and post-Memory Club assessments using the Geriatric Depression Scale (GDS; $\alpha = .78$; $\alpha = .74$, respectively).

Satisfaction. Similar to the post-Memory Club care partner survey, PWMLs were administered a 12-item satisfaction survey during the post-Memory Club survey ($\alpha = .99$). The items were the same as the care partner satisfaction measure with the exception of the item "How well the group leaders understood your relative," which was excluded.

Analysis

Following a descriptive analysis of the care partner and PWML samples, paired T-tests were conducted to compare statistically significant ($p < .05$) changes on pre-Memory Club and post-Memory Club scores for the measures described above. Descriptive, univariate statistics were used to summarize satisfaction items related to Memory Club participation following the post-Memory Club surveys. A series of bivariate correlations and one-way analyses of variance (ANOVAs) were also conducted to determine whether background characteristics of PWMLs or care partners were significantly associated with change in key Memory Club outcomes.

Results

Sample Characteristics

Table 2 presents descriptive information for the care partner (N = 61) and PWML (N = 63) samples. On average, PWMLs scored near the mildly impaired range on the MMSE (*M* = 24.67, with scores from 19-24 generally considered "mildly cognitively impaired").[34]Over half of all Memory Club participants were from the Park Nicollet site. Most Memory Club participants were women, held a Bachelor's degree, were retired, and reported an annual household income of over $40 000 per year. Almost all Memory Club participants were Caucasian and married. Over 80% of care partners were the spouse of the PWML and also lived with the PWML. Over half

Table 3. Change Analysis: Memory Club Outcomes

Variable	Pre-Memory Club Assessment	Post-Memory Club Assessment
Care partner (N = 61)		
Care partner report of PWMLs' IADLs[a]	M = 2.07 (SD = .61)	M = 2.19 (SD = .65)
Stress	M = 2.10 (SD = .56)	M = 2.14 (SD = .57)
Care partner task effectiveness[a]	M = 2.80 (SD = .72)	M = 2.99 (SD = .77)
Depressive symptoms	M = 3.27 (SD = 3.27)	M = 3.04 (SD = 2.94)
Preparation checklist***	M = 8.28 (SD = 1.82)	M = 9.21 (SD = 1.55)
Preparation for care needs[a]	M = 2.56 (SD = 1.01)	M = 2.87 (SD = .97)
Satisfaction with preparation for care	M = 3.18 (SD = 1.14)	M = 3.34 (SD = 1.14)
Preparation for future care	M = 3.33 (SD = .69)	M = 3.44 (SD = .67)
Satisfaction with Memory Club	–	M = 4.53 (SD = .49)
"Definitely" recommend Memory Club to others	–	90.6%
Person with Memory Loss		
Ratings of effectiveness	M = 3.09 (SD = .50)	M = 2.99 (SD = .56)
Depressive symptoms	M = 2.84 (SD = 2.56)	M = 2.79 (SD = 2.48)
Satisfaction with Memory Club	–	M = 3.10 (SD = 1.48)
"Definitely" recommend Memory Club to others	–	83.3%

Abbreviations: PWML, person with memory loss; IADLs, instrumental activities of daily living; M, mean; SD, standard deviation.
[a] $p < .05$, *** $p < .001$.

of PWMLs suffered from serious health conditions in addition to memory loss. Over 95% of PWMLs had recognizable memory problems and received a diagnosis of dementia, and among care partners who provided help to the PWML (81.4%) almost all considered themselves most responsible for caring for the PWML.

Change Analysis

Table 3 presents mean values on key Memory Club outcome variables during the T1 and T2 assessment intervals. A series of paired *T*-tests were conducted to determine whether statistically significant change occurred on key variables during Memory Club participation; these results are also presented in Table 3. *T*-test results revealed that PWML IADL dependency significantly increased during Memory Club participation (T1 M = 2.07 to T2 M = 2.19, *P* = .04). Care partners also reported a statistically significant increase in their perceived effectiveness (T1 M = 2.80 to T2 M = 2.99, *P* = .02). The average number of preparation activities reported by care partners increased from the pre- to post-Memory Club assessment period (T1 M = 8.28 to T2 M = 9.21, *P* = .00). Care partners' reports of preparation for care needs also increased significantly during Memory Club participation (T1 M = 2.56 to T2 M = 2.87, *P* = .04).

Care partners' satisfaction with the Memory Club was high, with an average rating of 4.52 on the satisfaction scale. Almost the entire sample of care partners responded "definitely" when asked whether they would recommend the Memory Club to someone in a similar situation (n = 58; 90.6%). Persons with early-stage dementia indicated more moderate satisfaction, with an average of 3.1. Over 80% of the PWML sample indicated they would "definitely" recommend the Memory Club to someone in a similar situation (n = 50; 83.3%). No outcome variables were found to change significantly in the PWML Memory Club assessments.

Correlates of Change

Persons with memory loss who reported a higher MMSE score prior to participation were more likely to indicate increases in activity effectiveness ($r = .28$, $P = .03$). Persons with memory loss at the Wilder Memory Club site also reported higher satisfaction (M = 4.34) when compared to participants at the Rochester-Mayo (M = 2.58) or the Park Nicollet (M = 2.69) sites ($p < .001$). Care partners with more living children indicated a significant increase in depressive symptoms (GDS; $r = .28$, $P = .03$). Care partners who assisted older PWMLs also reported increased preparation for care needs ($r = .27$, $P = .04$). Site differences in care partner outcomes occurred as well; care partners at Wilder reported a greater increase in stress when compared to those at the Park-Nicollet or Rochester sites (M = .42, −.08, −.01, respectively; *P* = .002).

In order to examine the role of PWML cognitive impairment on activity effectiveness, an ANOVA was conducted segregating MMSE scores into 1 of 3 clinical categories: moderately impaired (score of 10-19 on MMSE; n = 6), mildly impaired (20-24 on MMSE; n = 17), and normal (25 or higher on MMSE; n = 37). As the small sample size precluded statistical power, the findings only approached statistical significance ($p = .09$). However, when comparing mean change in activity effectiveness across the moderate, mild, and normal categories, those in the moderate impairment category reported a decrease in activity effectiveness of −.52, whereas those in the normal MMSE category indicated a slight increase (M = −.05). Those in the mildly impaired category indicated a very slight decline (M = .05). A similar ANOVA was conducted on PWML age categories (65 years of age and under, n = 21; 66 to 80 years of age, n = 32; over 80 years of age, n = 7) and care partners' reported preparation for care needs. As with the MMSE analysis of variance, statistical power precluded findings of significance, but mean trends supported the correlation results: care partners of PWMLs over the age of 80 indicated a greater increase in preparation for care needs (M = .93) when compared to care partners of PWMLs aged 66 to 80 (M = .34) or 65 years of age and under (M = .05).

Discussion

The goal of this study was to implement The Memory Club in 3 diverse sites in Minnesota to determine whether PWMLs and care partners reported significant changes in feelings of effectiveness, preparation, stress, and depressive symptoms. The findings here include multiple sites and contribute further empirical evidence to the potential efficacy of psychosocial services for persons with early-stage dementia and their families. Prior to interpreting the findings, however, there are several important limitations to note. Variations occurred in Memory Club delivery across the sites, perhaps contributing to the site-level differences found. Specifically, the diverse ordering of topics across the 3 sites may have limited momentum and synergy in improving the outcomes of both care partners and PWMLs who participated in the Memory Club. Establishing a sequence of topics that builds to program goals is required for most effective implementation across sites; due to logistical issues, this did not occur across the 3 sites in Minnesota. Subsequent implementation efforts here in Minnesota are attempting to rectify this issue and generate a recommended ordering of topics in order to best achieve the stated objectives of the Memory Club program. Conclusions related to the efficacy of the Memory Club are speculative due to the lack of a comparison group. Another limitation was the lack of significant change detected in the PWML assessment measures. Standardized measures may not capture the specific benefits of Memory Club participation for PWMLs and may call for the development of more appropriate tools that assess the psychosocial effects of early-stage support protocols. For example, observational protocols may offer better assessment of Memory Club benefits for PWMLs than self-report instruments. Longer term follow-up of participants, in contrast to a pre-/post-test design, may have also demonstrated how the Memory Club helped PWMLs and care partners plan and prepare during the progression of dementia.

The Memory Club's most apparent benefits were in offering information and education to care partners in preparing for the future. Following diagnosis, many families and persons in the early stages of dementia may feel adrift, as there is a paucity of stage-appropriate services for both care partners and PWMLs who are still able to take part in decision-making and planning. For example, following diagnosis, a care partner may be referred to a standard support group, but such services often include caregivers of relatives in the middle to later stages of dementia (if not already bereaved). Similarly, a PWML may be referred to a community-based long-term care service (such as an adult day program) that specializes in caring for persons in the middle to later stages of dementia. What the results of this study suggest is that a program such as the Memory Club can help fill an important service gap and meet potential unmet needs that occur solely during the early stages of dementia. One of the major benefits of the Memory Club was its ability to motivate and engage care partners in preparing for the future needs of relatives suffering from early-stage dementia, and that including PWMLs in such deliberations may have helped facilitate this preparation.

Participation in the Memory Club also appeared to improve care partners' perceptions of effectiveness when dealing with and managing various tasks related to memory loss. Specifically, care partners reported greater confidence in dealing with the various mood problems, memory concerns, and daily tasks that many PWMLs may struggle with (or begin to struggle with) during the early stages of dementia. The potential positive effects of the Memory Club thus appeared to extend beyond preparation to the care and supervision actually performed by families. It is possible that the sessions focusing on coping with memory loss in a relative and how to address the challenges related to cognitive impairment helped care partners in their own day-to-day lives with the PWML.

The satisfaction results revealed that care partners appeared to experience considerable benefit. However, the satisfaction findings for PWMLs were less positive, and may provide some insights as to why PWMLs did not report statistically significant benefits following Memory Club participation. These results suggest the need to review Memory Club modules to ensure that both members of the care partner-PWML dyads receive similar benefits in the joint support group format. It appears that little change occurred in PWMLs' perceptions of depressive symptoms or feelings of efficacy dealing with everyday tasks. As alluded to above, the lack of significant findings may have been due to inadequate measurement, but it is also possible that the Memory Club as currently designed may require refinement in content and structure (ie, creating activities and discussion periods that are less care partner-focused and where PWMLs can gain more insights and benefits).

Bivariate analyses implied that several characteristics were related to change in key Memory Club outcomes. Persons with memory loss who were less cognitively impaired were more likely to report increased confidence in carrying out day-to-day tasks. It is possible that Memory Club participants with less cognitive impairment were more likely to participate in and engage with the presentations and activities offered in the joint support group format, and thus were able to obtain greater benefit in terms of day-to-day management of dementia-related challenges when compared to PWMLs with more severe memory problems. Several site differences also occurred; while PWMLs indicated higher satisfaction at the Wilder site, care partners were more likely to indicate increased stress at the Wilder site when compared to care partners at the Park Nicollet or Rochester sites. These findings imply that differences in organization and delivery of Memory Club sessions (see Table 1) may have led to varying outcomes over time, particularly when related to the benefits for PWMLs and care partners. Care partners who assisted older PWMLs also appeared more prepared for future care. It is possible that in addition to dementia, assisting older PWMLs may have led care partners to view the Memory Club content as more pressing and thus felt more prepared as a result. A final bivariate association was difficult to interpret: care partners with more living children were also more likely to report increased depressive symptoms. It is possible that care partners may have more difficulty explaining or communicating the experience of assisting someone with early-stage dementia to adult children, thus leading to an increase in depressive symptoms.

The findings of this study have important implications for future practice and research. There is a lack of available psychosocial services for persons with early-stage dementia and their care partners. The preliminary findings of this evaluation imply that a joint psychosocial approach such as the Memory Club (along with other protocols)[22,23] can help to fill this gap. However, for such approaches to gain greater traction in clinical practice, evaluations that adhere to high-quality evidence standards (eg, randomized controlled trials) and more refined measurement for PWMLs are required. Moreover, the results here highlight possible challenges of crafting beneficial activities and services for persons with early stage dementia, and it is critical that providers acknowledge the likely diverse needs and preferences of PWMLs when delivering joint psychosocial support programs. Nonetheless, with the increasing emphasis on early-stage detection and diagnosis of AD, the potential benefits of programs such as the Memory Club support their use in comprehensive care planning for PWMLs and families who must navigate the onset of dementia.

Authors' Note

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Disclosure

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Declaration of Conflicting Interests

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