Memory Club: A Group Intervention for People With Early-Stage Dementia and Their Care Partners

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Purpose: Diagnosis of dementia in its early stages presents a window of opportunity for examining the immediate and long-term consequences of the illness at a point when the individual with memory loss can still participate in decision making. Design and Methods: Memory Club is a 10-session group program designed to provide information about memory loss and resources for coping with it in an emotionally supportive atmosphere for people with dementia and their care partners. Memory Club sessions are structured so that dyads meet together, as well as separately with other care partners and people with dementia, respectively. This approach allows for time for the dyad to talk together about issues in a supportive setting, and for the people in the same role (person with dementia or the care partner) to share experiences with one another. Results: A preliminary evaluation indicated that people with dementia and their care partners rated Memory Club very positively. Implications: Facing an inevitable decline, persons with early-stage dementia and their care partners found it helpful to talk with one another and with peers in the same circumstances about the disease and its effects.

Key Words: Early dementia, Psychoeducational treatment, Dyadic treatment

There is increasing emphasis on early diagnosis of Alzheimer’s disease and other dementias, but few programs are available for people at the early stages of the illness or their families. This report describes Memory Club, a structured, time-limited psycho-educational group for people with early symptoms of dementia and their supporting family member (termed “care partner”). Memory Club was developed as a joint project of the Center for Aging, Research and Evaluation (CARE) of Granada Hills Community Hospital and the Alzheimer’s Association at California State University–Northridge of the Los Angeles, Riverside and San Bernardino Chapter of the Alzheimer’s Association. We present an overview of the Memory Club program, and we describe the participants who joined the first three Memory Clubs. We also present how care partners and people with dementia evaluated the Memory Club program.

Most programs and educational materials currently found in the literature focus on family caregivers assisting someone with middle- to late-stage dementia. Many of the issues discussed in these programs may not be appropriate for early-stage caregivers (Kuhn, 1998), and they do not incorporate the perspective of the person with dementia. Proponents of early-stage interventions have identified several needs for people with early-stage illness and their family members, including improving communication between the couple, learning coping strategies for dealing with memory loss, addressing relationships with family and friends, finding ways for the person with dementia to continue to feel useful, experiencing grief and loss, and learning about the disease and treatment options (Clare, 2002; Kuhn, 1998). Clare noted that adaptation efforts have to strike a balance between fighting the disease and coming to terms with it and the limitations it imposes. Several early-stage interventions have been proposed to address these needs. Clare and colleagues (Clare, Wilson, Carter, & Hodges, 2002, 2003) reported considerable success.
by using errorless learning principles for improving memory performance, demonstrating both immediate and long-term gains. Moniz-Cook and colleagues (Moniz-Cook, Agar, Gibson, Win, & Wang, 1998) found that a brief individualized intervention at the time of diagnosis that included information about the disease, attention to coping, memory management, and referral to community agencies resulted in better outcomes for people with dementia and their family caregivers than a control group who received usual services. Perhaps the most widely available intervention has been early-stage support groups (e.g., Goldsliver & Gruneir, 2001; Yale, 1989, 1999). According to Yale (1999), early-stage groups help people with dementia to reduce feelings of isolation, increase knowledge about resources, and facilitate grief work. Early-stage support groups also help the caregiving dyad function as a team and communicate more effectively with each other about current problems and concerns for the future.

The Memory Club Program

The Memory Club is a 10-session program designed for 8 to 10 dyads, with sessions held every other week (see Table 1). Unlike the typical Alzheimer’s disease (AD) support group, the Memory Club seeks to empower both care partners and the people with dementia to participate jointly in managing current problems and planning for the future. The groups are led by a team consisting of a social worker and a neuropsychologist. The social worker provides information on resources available for people with AD and their families, and the neuropsychologist is able to interpret symptoms and diagnostic findings. They are assisted by two co-leaders who work under their supervision.

The goals of the Memory Club include the following. First, it attempts to increase the information that participants have about the illness, symptoms associated with dementia, and care options, including diagnosis, treatment possibilities, current research on the disease, community resources, and legal and financial issues. Second, it tries to strengthen the care dyad by improving communication and maintaining positive aspects of the relationship. Third, it tries to help the care dyad learn how to make plans together for the future, including long-term care and financial planning. Fourth, it attempts to help the dyad reach out to other family members and friends (e.g., learning how to talk to family and friends about the disease; inviting family and friends to sessions with speakers). Fifth, it seeks to build relationships within the group that can be supportive and may buffer the stresses associated with dementia.

Each of the 10 sessions is structured around a topic, as shown in Table 1. The first two sessions build group cohesion and provide an information base to use in later discussions. Sessions 3 through 7 explore more difficult topics such as the emotional and interpersonal consequences of diagnosis, the impact of diagnosis on the dyad, and coping strategies through which participants may gain a sense of comfort or strength. The last three sessions represent a return to informational topics. Of course, participants may bring up concerns off schedule. The leaders are trained to respond flexibly, and devote time to exploring an off-schedule issue, while coming back to the week’s agenda when appropriate. The leaders also show flexibility in responding to an acute problem, should one arise.

Several specific therapeutic strategies are used in the Memory Club groups to facilitate positive changes. A distinct feature of the Memory Club is its emphasis on solving problems through the dyad. Similar to marital therapy, Memory Club emphasizes strengthening the couple’s relationship (whether marital or parent–child). Unlike marital therapy, however, the Memory Club recognizes that the diagnosis of AD carries with it such devastating implications for the relationship that it is necessary to spend some time working separately to strengthen individuals so that they can work more effectively as a couple.

The other main therapeutic approach is to use the group setting and interactions to build cohesion and support. As in typical support groups, there is an emphasis on the unique kind of support that comes from people who understand and are experiencing similar challenges. The leaders encourage and, if necessary, model supportive and nonjudgmental interactions among all the participants so that people may feel understood and accepted. This type of supportive interaction is useful for care partners, who may feel cut off from their social circles, but particularly for the person with dementia who may have very limited opportunities to interact with other people with a similar disorder. Once a supportive atmosphere is fostered, it becomes easier for participants to utilize the information that is provided and to work through difficult personal and interpersonal issues related to the dementia.

The program’s innovation is in how sessions are organized. Each session includes the following: (a) an initial period in which the people with dementia and their care partners interact together; (b) a period in which they meet separately so that each can discuss individual and unique concerns with peers, but apart from their partner; and (c) a concluding period during which everyone gets back together. The topic for that day is the focus in each part of the session. The separate portions of a session provide a safe haven for people to explore normal feelings of anger, frustration, fear, or sadness, and to discuss concerns that an individual might not be ready or able to bring up with his or her partner. Care partners are typically more ready to take advantage of these sessions, though the supportive atmosphere
Table 1. Overview of Memory Club Sessions

<table>
<thead>
<tr>
<th>Session or Topic</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>1. Welcome to the Club!</td>
<td>Set the stage for the Club experience by creating an environment that is comfortable, safe, and friendly through casual discussion of what is to come in the weeks ahead and individual introductions in a small group atmosphere. Learn more about each memory participants’ and care partners’ key stories and concerns related to memory loss.</td>
</tr>
<tr>
<td>2. ADRD in the early stages: Medical information</td>
<td>Provide the most recent information about AD and related disorders in an effort to ensure that all members have equivalent information. Help families begin a dialogue about the symptoms and related questions, concerns, and thoughts. Guest Speaker</td>
</tr>
<tr>
<td>3. ADRD in the early stages: Emotional issues</td>
<td>Provide a supportive and safe environment for members to begin an examination of the impact of memory loss on their sense of self and on their family and circle of friends through small group sharing. Validate the challenges memory loss has created in their daily living, social functioning, and overall wellness.</td>
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<tr>
<td>4. Talking about feelings</td>
<td>Encourage the discussion of feelings related to reactions to the diagnosis, impact on self, family, and friendships. Validate and support each member’s feelings, and identify similarities and differences.</td>
</tr>
<tr>
<td>5. “I get by with a little help from friends…”</td>
<td>Explore issues of trust, communication, task sharing, role changes, and expectations for adjustment to promote increased understanding and expand empathy for what each member is feeling. Work on decreasing the tension around these issues through large and small group sharing by delineating the challenges care partners and memory loss participants are confronted with. Explore issues related to giving and receiving help. Guest Speaker</td>
</tr>
<tr>
<td>6. “It’s hard enough dealing with my own changes!”</td>
<td>Build on Sessions 4 and 5 by continuing to raise awareness of the issues and challenges confronting the other half of the dyad. Expose and validate the concerns, frustrations, and questions members have related to their partner and encourage sharing and thoughtful confrontation of these issues and other related concerns that members identify. Explore issues related to telling friends and co-workers about the diagnosis. Guest Speaker</td>
</tr>
<tr>
<td>7. Keeping the faith—Taking care of yourself</td>
<td>Explore the ways in which members find comfort, peace, and strength. Discuss various coping strategies and the impact of mood and attitude on overall wellness. Discuss the benefits of taking care of yourself and what that means (physically, emotionally, mentally, and spiritually) in relation to each member’s values or goals. Begin preparing members for graduation.</td>
</tr>
<tr>
<td>8. Community resources</td>
<td>Provide information on community resources and planning for the future (legal, financial, medical, etc.) to assist members in making informed decisions. Discuss and explore members’ concerns and feelings related to anticipating the future. Guest Speaker</td>
</tr>
<tr>
<td>9. Looking to the future</td>
<td>Review information covered in previous sessions and discuss implications for the future, the changing nature of the disease, and possible needs for ongoing support or intermittent guidance. Discuss and explore plans for and thoughts about the future. Help members identify possible solutions to concerns or needs. Family consultation (to take place between Sessions 9 and 10)</td>
</tr>
<tr>
<td>10. Graduation</td>
<td>Recognize the completion of the group, their contributions, personal growth, challenges, and willingness to participate and share. Evaluate members’ satisfaction with the group process and overall impact on self and dyad. Close the group with a celebration luncheon.</td>
</tr>
</tbody>
</table>

Note: AD = Alzheimer’s disease; ADRD = Alzheimer’s disease or related disorder.

is essential in helping them overcome their fears about facing the future or discussing their concerns openly. The leaders of the separate sessions for people with dementia must work harder to build trust and communication, but in the end they can create a nonjudgmental and supportive environment in which people can bond with one another and explore their concerns. The separate sessions are also used for discussing and planning what to share or bring back to the dyad.

The role of the leaders is essential for facilitating change. The leaders model a nonjudgmental attitude, and they provide empathy and emotional support as participants explore difficult issues. They draw in people who may be having difficulty participating, and they keep one or two people from dominating a session. They also set a balance between giving sufficient time to explore personal issues and keeping the agenda moving. They serve as resources for the group, providing information on a variety of topics from medications for dementia to long-term care options.

Care partners and people with dementia respond to the topics and issues discussed in the groups in somewhat different ways. Table 2 summarizes how care partners and people with dementia discuss key
Much of the concern of care partners is anticipation of how their relationship will change over time. Considerable emphasis is placed on helping care partners gain insight into why people with dementia behave the way they do, such as learning to view suspiciousness as part of the disease rather than as directed personally at them. Once they understand the impact of the disease, they can move beyond their anger or upset to adopt more flexible coping strategies for these types of behaviors.

The concerns raised by people with dementia are similar to or mirror those of their care partners (Table 2). Many of their concerns, however, revolve around a loss of control (e.g., “What is happening to me?” “Why do I feel so sad? Why don’t I feel like myself?” “What can I do to stay motivated?” “I can’t concentrate. I’m scared.” “I feel so much pressure now.”). The groups empower them by creating an opportunity to express their needs and participate in planning for their future. Giving control in a protected way, even as their care partners must take over some decisions and responsibilities, may reduce the anxiety and uncertainty that people with dementia express about their future. The group may also be helpful to people with dementia by deflecting their anger about loss of independence from the caregiver. As an example, a person who does not want to give up driving, but is being pressured to do so, may gain a better perspective on this issue when someone else in the group talks about having to give up driving. Through this discussion, participants can learn to separate their feelings of anger and loss from their relationship with their care partner.

**Recruitment and Screening**

Recruitment for the Memory Club used a four-tiered strategy. First, geriatric assessment clinics were informed about the project and were asked to identify potential participants. Second, a brochure describing the Memory Club was mailed to a network of gerontological service agencies, to people who previously had been assessed at CARE or attended past educational programs, and to the Alzheimer’s Association. Third, advertisements and articles were placed in local newspapers and in the Alzheimer’s Association newsletter. Fourth, the...
Memory Club staff held several community talks on early-stage dementia for people with the disease and their family members.

Two factors enhanced recruitment: First, staff at CARE and the Memory Club had strong relationships with geriatric assessment programs and aging service programs in the area. Second, grant support meant that the Memory Club could be offered for no charge.

Screening played an essential role in the Memory Club. It was used to determine that the person with dementia had the necessary awareness of his or her illness to benefit from the group discussions and to identify if either the care partner or person with dementia had other characteristics or beliefs that would make it difficult for him or her to benefit from a group treatment. An initial telephone screening was conducted with care partners to determine if the person with dementia had other characteristics or beliefs that would make it difficult for him or her to benefit from a group treatment. An initial telephone screening was conducted with care partners to determine if the person with dementia had other characteristics or beliefs that would make it difficult for him or her to benefit from a group treatment. An initial telephone screening was conducted with care partners to determine if the person with dementia had other characteristics or beliefs that would make it difficult for him or her to benefit from a group treatment.

Preliminary Evaluation of the Memory Club

To provide a preliminary evaluation of the Memory Club, we interviewed care partners and persons with dementia who participated in the first three Memory Club groups prior to and after they completed the groups. The interviews provided information about characteristics of participants, their functioning in key domains, and their evaluation of various features of the Memory Club. During the first group session, participants were told about the evaluation and were asked if they were willing to participate. After giving consent, people with dementia and care partners were interviewed by trained interviewers in different rooms. This was done to ensure confidentiality and independence of responses of the person with dementia and his or her care partner. Following the last group session, a posttreatment questionnaire was administered in the same way. Participation was voluntary and not a requirement of being in the Memory Club.

Characteristics of Participants in the Memory Club

A total of 23 dyads and 1 person with dementia who did not have a care partner completed the evaluation interviews. Eight dyads and the singleton were in the first group, 7 dyads were in the second group, and 8 were in the third group. One other dyad attended the first session of a group and declined to participate after that. All but three dyads attended every session, and those three missed no more than two sessions. Sociodemographic characteristics of participants are shown in Table 3.

To characterize the current functioning of the people with dementia, care partners provided information on their relative’s performance on nine instrumental activities of daily living (IADLs). On average, their relative needed help with nearly five. They were most likely to need help with taking medications, shopping, driving, and managing finances. Care partners were also asked if their relatives had experienced any of 16 memory and behavior problems in the past week. Items appropriate to early dementia were selected from the Revised Memory and Behavior Problems Checklist (Teri et al., 1992). Care partners reported that the person with dementia had experienced, on average, 7.4 of the 16 behavior problems in the past week at baseline. Memory and mood problems were the most commonly reported. Thus, the people with dementia in the Memory Club were already experiencing significant problems that were placing demands on their care partners.
Participants’ Evaluation of Components of the Memory Club

A series of questions reflecting the content of the intervention (gaining information, or learning more about one’s own situation) and the therapeutic processes that were expected to lead to change (the leader’s ability to foster supportive interactions, or learning from other people in the group) were administered at the end of the program. Seven items were identical for care partners and persons with dementia, whereas other items varied slightly, reflecting their different needs. Participants were asked to give performance of the Memory Club a grade for each item ranging from A (excellent, scored 4) to F (poor, scored 0; there was no E rating).

Overall, care partners were very positive about the group (Table 4). Their most positive ratings were for the performance of the group leaders, the information they received, and being with other people in a similar situation. Their lowest scores, which fell in the very good range (~3.0), were on these items: “Learning more about your relative’s feelings” (3.09) and “How well the other members of the group understood you” (3.13). Two thirds of care partners rated the time they spent together in the group with their relative as very helpful or extremely helpful. In addition, all 23 care partners said they would definitely recommend the Memory Club to someone else in a similar situation.

Ratings by persons with dementia were also very positive (Table 4). Their highest scores also pertained to the leaders and the information they received, whereas their lowest scores were on items concerning their interactions with other people in the group.

Qualitative Evaluations of the Memory Club

Responses to a series of open-ended responses supported the quantitative findings. Care partners reported that the most helpful aspects of the Memory Club for them and their relative were being able to learn from and share experiences and feelings with people in the same situation. Care partners felt it was beneficial for their relative to be around other people in the same situation. Several care partners thought that the groups helped their relative become more aware and accepting of memory problems. Only a few care partners mentioned experiences that were not helpful. One care partner, for example, thought her husband did not fit well in the group, because he was the youngest person there and had concerns that were not shared by anyone else.

Many of the people with dementia mentioned that they liked the opportunity to be with friendly, supportive people. They also liked being able to learn from other people in their situation. One person stated, “What is very helpful about the program is that we can very freely talk about our feelings or express them with each other. We cannot do this in other groups. It is a healthy thing when you can go and express things freely.” Another person stated what was helpful about the group was “to know I was not alone. To hear how others were dealing with issues I was struggling over. The support I felt was very important from others in the group and the leaders.” A few persons with dementia identified aspects of the group that were not helpful. Two people noted that someone in their group talked too much. One person thought that the sessions were too short, and another thought that the group should have been a little smaller.

Another important result is that all but three of the care partners have continued to attend follow-up groups that were made available following completion of the 10 planned sessions. Many of the people with dementia also moved on to appropriate supportive programs, such as early-stage day care.
Discussion

The Memory Club appears to be a promising program for people with early-stage AD or other dementia and their care partners. It is similar to typical family support groups in emphasizing information about the disease and resources available and building support among group members. Unlike traditional support groups, the Memory Club aims to strengthen the care dyad by involving both the care partner and the person with dementia. Facing the inevitable decline caused by AD, persons with dementia and their care partners were able to talk with one another and with peers in the same situation and to find the experience to be helpful to them.

The structure of the groups, which provided time for the dyad to be together and time when they were apart with their peers, was a key to the success of the program. In the separate portions of the sessions, issues could be discussed candidly, in ways that probably were not possible in the dyadic portions of the meetings. The separate sessions were also used to build the special support that comes from interacting with people in the same situation, an aspect of the program that both care partners and persons with dementia reported was valuable to them. In the dyadic portions of the sessions, it was then possible to address issues affecting the dyad, and how they were dealing with memory loss and its consequences. In contrast to typical family support groups, there was a constant pressure to go beyond an individual’s expression of needs or concerns that came up in the separate sessions, and to find ways of reshaping those concerns into communications in the joint sessions that could help strengthen the dyad.

The social aspects of the experience may have been most helpful to both care partners and persons with dementia. The Memory Club is about bonding and learning that it is safe to discuss what seemed too hard to talk about. It is about maintaining trust and discussing conflicts. As dyads grow increasingly comfortable talking about their situation, they may even discuss long-standing family problems that may be worsened by AD.

Another feature of the Memory Club was that the dyad was able to plan for their future, both in the separate sessions and when together. The person with dementia was often (though not always) able to take an active role in making decisions. For example, the session of the Memory Club that focused on legal issues prompted couples to discuss their needs for planning in areas such as health care decision making and financial affairs. Many persons with dementia were able to articulate their preferences (in the group and later to their attorney) for what should happen when they were no longer competent to make decisions. Other decisions in which persons with dementia played an active role included leaving a job, trying a medication for memory, enrolling in the Safe Return program, and discussing one’s illness with family and friends. One person with dementia recounted how the group helped him survive having to give up driving. He went on his own to the Department of Motor Vehicles to get his ID card (which replaces the driver license). He has now learned how to use the bus and incorporates regular walks in his routine. The program thus confirms other reports (e.g., Yale, 1999) that people with early symptoms of dementia can participate in programs focused on their illness and can provide meaningful observations of their experiences.

In a preliminary evaluation of the Memory Club, care partners and people with dementia gave high ratings to various features of the Memory Club, indicating that the program was accepted and meeting its objectives. Given the emotionally charged discussions about the implications and course of dementia that care partners and persons with dementia engaged in, it is noteworthy that participants had strong positive opinions about the program.

There are some obvious limitations in this report. The evaluation of the Memory Club has to be viewed as preliminary. There was no possibility of a control group or random assignment, given the resources available to the program. There were no data beyond clinical report on treatment fidelity, that is, how consistently leaders were able to implement various features of the intervention as planned. We also do not know how well the program could be replicated in a different setting or with different leaders. Despite these limitations, the Memory Club has demonstrated that people with dementia can participate in the intervention and also in its evaluation.

Table 4. Care Partner’s and PWD’s Ratings of Features of the Memory Club Program

<table>
<thead>
<tr>
<th>Memory Club Feature</th>
<th>PWD (n = 24)</th>
<th>Care Partner (n = 23)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Skill of group leaders</td>
<td>3.83</td>
<td>3.96</td>
</tr>
<tr>
<td>Information given</td>
<td>3.74</td>
<td>3.78</td>
</tr>
<tr>
<td>How well leaders understood you</td>
<td>3.59</td>
<td>3.74</td>
</tr>
<tr>
<td>How well leaders understood your relative</td>
<td>N/A</td>
<td>3.78</td>
</tr>
<tr>
<td>Being with others in similar situations</td>
<td>3.45</td>
<td>3.83</td>
</tr>
<tr>
<td>Learning how others in your situation manage</td>
<td>3.05</td>
<td>3.65</td>
</tr>
<tr>
<td>How well group members understood you</td>
<td>2.92</td>
<td>3.13</td>
</tr>
<tr>
<td>Learning about your (relative’s) feelings</td>
<td>3.45</td>
<td>3.09</td>
</tr>
<tr>
<td>Learning about your (relative’s) memory problems</td>
<td>3.13</td>
<td>3.43</td>
</tr>
<tr>
<td>Learning about things that can help you (your relative)</td>
<td>3.41</td>
<td></td>
</tr>
<tr>
<td>Overall grade of group</td>
<td>3.64</td>
<td>3.83</td>
</tr>
<tr>
<td>Mean score of all items</td>
<td>3.43</td>
<td>3.60</td>
</tr>
</tbody>
</table>

Note: PWD = people with dementia. Scores ranged from 0 (F = poor) to 4 (A = excellent). Care partners were asked questions using the wording in parentheses.
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