Early stage dementia group: An innovative model of support for individuals in the early stages of dementia

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Abstract

Traditionally, supports and services for people diagnosed with Alzheimer's disease have focused on the caregivers. The increase in early diagnosis of Alzheimer's disease has resulted in greater numbers of older adults that have some insight and awareness of their deficits and are capable of dealing with the ramifications of their illness. Yet there are few places to turn for support and education. Circle of Care, a community-based home support agency in Toronto, has developed a support group for individuals with early stage dementia. Comprehensive Rehabilitation and Mental Health Services (COTA), a community-based rehabilitation agency, was invited to provide a co-facilitator for this group. To date, three groups have been held, each one having a fixed membership and meeting for eight sessions of one and a quarter hours. Topics focused on causation, coping with memory problems, loss, grief, and daily living skills. Positive themes emerged to reveal feelings of affirmation, camaraderie, and improved confidence, while feelings of helplessness and frustration were also raised. Implications for future planning and interventions also will be discussed in this paper.

Key words: early dementia, early-stage Alzheimer's disease, support group

Introduction

Since 1987, Circle of Care, a community-based home support agency, has provided counseling and case management services to help individuals and families cope with the stress of caring for a loved one with a progressive dementia. Psychogeriatric services, including assessment, treatment, and long-term case management, have been provided through Comprehensive Rehabilitation and Mental Health Services (COTA) since 1979.

Approximately 20,000 people diagnosed with dementia reside in the greater Toronto area. At present, an estimated 300,000 to 500,000 Canadians have a form of dementia. Larger numbers of older adults are being diagnosed with dementia much earlier in the disease process, due to the increased public awareness of the illness and the availability of specialized geriatric assessment services. According to the Alzheimer Society of Toronto, in the past year, approximately 5 percent of telephone calls received in its telephone counseling program concerned individuals in the early stages of the disease. The needs of caregivers have been well recognized, and resources for this population have become more available in recent years. However, few support services have been developed for those individuals that have some insight and awareness into their deficits and want to be involved in preparing for their future needs. It is often difficult and uncomfortable for families and friends to respond to questions posed by individuals about their future. Yale noted that a support group for people recently diagnosed with dementia has the "potential to facilitate emotional adjustment to coping with and planning for the disease as it progresses."[1] She further believes that this type of support group also benefits caregivers. After much research and discussion, Circle of Care and COTA decided to fill the gap in service by developing a support group for this population in the greater Toronto area.

Outreach and promotion

Our experience has been that whenever a new program is

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introduced, education of potential referral sources as well as possible clients is vital to success. In the fall of 1995, initial outreach for this support group consisted of a large mailing to community professionals and family physicians, introducing the group and specifying the eligibility criteria. This mailing was followed by an interview on a local radio station. The outreach continued with the posting of flyers to announce the group in seniors' buildings, churches, synagogues, and community centers, and the distribution of 900 flyers at the Alzheimer Society's Open Forum and Walk for Memories. Information about the group was circulated to the staff members at Circle of Care with a request for referrals. Despite this effort, only three referrals were received and we decided that a group was not feasible at this time. Staff examined the process and determined that dedicated staff time was required to move this idea forward.

In 1996, a proposal was submitted to the Ministry of Health, long-term care division of the Ontario government and funding was received to develop a group for individuals in the early stage of dementia. In July 1997, the second wave of outreach and recruitment for this support group began. We felt that face-to-face recruitment might prove more effective than the conventional mass mailing and flyer distribution. Over the course of four months, 16 meetings were held with community professionals that were targeted as being potential referral sources. These presentations also provided an opportunity for a question and answer period, which served to clarify many issues related to the new support group.

As the support group was being developed, we felt that expertise from another discipline would be beneficial in working with this client population. Circle of Care invited COTA to become a partner in this new initiative and to co-facilitate the support group.

Assessment of group participants

Following the active recruitment and outreach, several referrals were received from a variety of sources, including community psychogeriatric teams, adult day programs, senior centers, social workers, a memory clinic, community professionals, and private individuals. The largest number of referrals (64 percent) was received from community professionals, while a hospital memory clinic provided approximately one-fifth of the group referrals (19 percent). The remaining referrals were from family members (7 percent), the Alzheimer Society (5 percent), physicians (2.5 percent), and a stroke recovery group (2.5 percent). Potential participants were then contacted by the social worker and assessment visits were booked. These visits took place at the Circle of Care office or in the individual's home, depending on what best suited the individual and his or her family. The majority of individuals referred to the support group had a diagnosis of Alzheimer's disease or dementia. Individuals referred ranged in age from 57 to 90.

Initial interviews were conducted primarily by the social worker, and, when possible, the occupational therapist was also present. The potential group members' level of functioning and cognitive status was assessed by means of an unstructured personal interview and the Folstein Mini Mental State Examination (MMSE). The interview consisted of an overview of the program, the criteria for joining the group, personal demographics, responses to questions, and concerns raised by the individual and his or her family members. The interview allowed us to determine the individual's capability of attending to a discussion and their level of interest in the support group.

The Folstein MMSE was administered near the end of the interview. Participants' scores ranged from 18 to 30, with the majority scoring between 21 and 24. To varying degrees, they shared orientation deficits, language difficulties, and perceptual problems. Insight and judgement were also somewhat diminished. All of the individuals were keenly aware of their memory deficits. If the individual was assessed as appropriate, the interview concluded with an invitation to join the support group. A printed schedule of meeting dates, times, and location was provided. If transportation was required, volunteer drivers from Circle of Care were available. In some cases, participants traveled on their own and others relied on family members. For those individuals who did not meet the necessary group criteria, other resources were suggested.

A total of 42 referrals were received for the three support groups. Thirty-one individuals were assessed as suitable and the remaining 11 were not. Reasons that precluded their appropriateness included denial or a lack of insight into their illness, medical crisis, vacation plans, and resistance or disinterest in attending the group. Of the 42 referrals to the support group, 31 percent (13) were male and 69 percent (29) were female. Note that the referrals did not represent the ethnic diversity of Toronto. In fact, 57 percent of the individuals referred to the support group were Jewish with the remainder being of Anglo-Saxon (40 percent) and Italian (3 percent) backgrounds.

Development of the group format

As is well recognized, individuals in the early stage of dementia require some level of structure, support, and consistency. We therefore designed the group format in keeping with these parameters. Eight weekly meetings were scheduled, each one lasting for one and a quarter hours. We decided upon a closed group format to encourage cohesiveness of the members. We chose a late morning time slot, as it seemed to be the most convenient for the prospective participants. The group size was limited to 12 people. Meetings were held in a community facility, which was easily accessible by public transportation. To encourage commitment to the group and to recover some of the costs, a nominal fee was charged with subsidies available as needed.

A social worker and an occupational therapist facilitated all groups, using a structured format. The room was set with chairs in a circular configuration to encourage group interaction. At the beginning of each session, the facilitators reviewed the purpose and norms of the group. Norms included a statement about confidentiality, the use of first names, available refreshments, and orientation to the date and session number. Topics for discussion were suggested by the facilitators and were chosen for their interest and educational value. Examples of topics included the brain and behavior, energy conservation, reminiscence, coping with loss, and strategies to improve memory. Fun activities such as warm-up exercises and mental aerobics were also used as appropriate by the group.

Group members were given printed handouts after each session and were encouraged to share them with their caregivers. Feedback from group members on the usefulness of the handouts has been positive.

Role of the facilitators

As with many support groups, the facilitator's role in a group for individuals with early-stage dementia is multifaceted. For the group to be successful, the facilitators must establish a supportive and nurturing relationship with the participants. They need to feel safe and comfortable if they are to share and express themselves openly. Yale states that "the facilitator sets the stage for self-disclosure, girded by mutual respect, by communicating interest, empathy and acceptance."[2] This process begins at the assessment interview and continues throughout the group's work. When working with this population, facilitators need to recognize that group members may present differently at each meeting. Fluctuations in the affect, behavior, communication, and cognitive functioning are variables that group facilitators can anticipate and need to be prepared to accommodate within the group process. Changes in behavior or functioning are not viewed as deliberate or disruptive, rather as normative within this population. When members move off in different directions, the role of the facilitator is to gently support the members and redirect them back to the group discussion. The extent to which the facilitators need to intervene is dependent upon the group dynamics and the abilities of the individual members.

The facilitator may also be seen as both an educator and a resource person for the group. To have a solid knowledge base and to stay current with changing trends in the treatment of Alzheimer's disease are important. At times, the facilitators were seen as authorities, and group members needed to be reminded to discuss all medical concerns with their physicians.

Group process

The early stage dementia group was designed to help individuals connect to one another, gain an understanding of their illness, and develop coping techniques. On the basis of these criteria, the theoretical model most applicable to the group is the *mainstream model*, which "emphasizes the interaction of four group components: the member, the group, the worker and group activity. Each of these areas, although important in themselves, cannot be isolated from the others and are interactive with one another."[3] Members are encouraged to participate actively; role differentiation is an accepted norm within this model. In one group, the most cognitively intact and articulate member assumed the role of group leader. She listened to the other members, reflected their needs and interests, and others looked to her for decision-making. In another group, one member who suffered severe visual deficits in addition to his cognitive deficits was pursuing a ceramics hobby. The other members supported his interest and encouraged him to bring his ceramic pieces to a meeting where they could view them; ultimately, two members made purchases.

Group development occurs through a democratic process, where each member is treated equally. The needs and interests of the group are met with careful consideration of the individual members. In the early stage dementia group, forgetfulness is a group norm that is accepted among the members. Further, members gave each other permission to forget, and sometimes shared with humor, jokes and anecdotes relating to poor memory. During many of the group sessions, colleagues walking past the closed doors of the meeting room would remark on the laughter coming from inside. "The changes or variations in the worker's role will be determined by the ability of the group...[T]he use of authority by the worker will be inversely related to the capacity of the members and the group."[4] In the mainstream model, the facilitator's role varies and flexibility is essential. At the first meeting of a newly formed group, two members recognized each other from elementary school. They delighted in their rediscovery of each other, and at each of the following seven sessions they "rediscovered" each other as if for the first time. As group facilitators, we were prepared to intervene each time they replayed their recognition. However, we took our cues from the other group members, who accepted their behavior without stigma and, in fact, seemed to derive a sense of satisfaction and joy from their interplay.

Group activities, an integral part of the process, are task-centered and related to the needs of the members. We concluded most of the group meetings with *mental aerobics*, an intellectually and mentally challenging group activity in which individuals of varying cognitive ability could participate. These memory games provided positive encouragement, as members shared information and friendly competition while facilitating their memories. In a recent support group, many of the members began to look at Mr. S as "the intellect," while Mrs. B was referred to as "the numbers expert." The other members bestowed these labels with a sense of warmth and pride.

Caregiver involvement

With an early stage dementia group, caregivers are often an integral part of the process. In some cases, the caregiver is the one who makes the initial inquiry regarding the support group. Often, the caregiver is the one with whom the assessment visit is scheduled. The majority of caregivers are also present during the initial interview. They provide important information, which can help to determine the individual's appropriateness for the group. The ability of caregivers to deal with their relative's illness and their approach to the support group can directly influence interest and attendance in the group. Mr. and Mrs. H, who were both candidates for the group, received positive encouragement and support from their son and daughter, whereas Mrs. S's daughter's high anxiety around her mother's illness negatively impacted on the mother's group attendance.

Throughout the course of the support group, the needs of caregivers are also addressed. Caregivers are encouraged to contact group facilitators with questions and concerns as they arise. In addition, facilitators notify caregivers when there are significant changes in mood, behavior, or physical status. These contacts are usually via telephone; however, office appointments with the facilitators are available if necessary. It is made clear to caregivers that general information is readily shared, but specific details of group discussion and process are not. During the course of one support group, a social worker was made available to meet with caregivers who remained at the agency during their family members' sessions.

At the conclusion of the group meetings, an evening meeting is scheduled for the caregivers of the participants. Group members are informed of this meeting and are reassured of group confidentiality. The purpose of the caregiver meeting is to provide information, education, and support. Facilitators respond to concerns and questions, and offer suggestions about management of the illness and community resources that may be appropriate. Caregivers are asked to complete a self-reporting evaluation form at the conclusion of this meeting.

Evaluation

During the last session of each group meeting, a self-reporting evaluation form is distributed to the group members. The members are requested to complete the forms to help the facilitators plan for future groups. Anonymity is ensured, although some individuals prefer to sign their evaluation forms. In some cases, assistance in completing the forms is required.

For 80 percent of the participants, this was their first support group experience. Member satisfaction generally rated very high with a few exceptions. A few participants would have preferred a larger group, while others indicated that additional sessions and a longer meeting time would have been beneficial. Seventy-four percent of the respondents felt that the group helped them deal with their problems more effectively. In particular, one member wrote, "the group gave me some good ideas which worked for me"; another shared that "the group helped me to relax when I found myself in difficult circumstances"; and a third participant wrote that "the group helped me think things out more clearly and decide." One member felt that the group was not useful in dealing with his or her particular problem and two other individuals wrote that being with people who have the same problem was not helpful. Eighty-eight percent found the educational component useful. One participant reported that "learning about the functioning of the brain and how it affects daily living" was helpful. However, one individual wrote, "it doesn't help much to know what is wrong without knowing how to deal with it." Two members felt that the information provided on the brain and its function was too technical. Ninety-six percent of the participants found the group experience satisfying and would recommend this type of group to others in similar circumstances. One member noted that she "experienced a certain amount of camaraderie and discovered kindred spirits." Another member was "amazed at how well we bonded and how we were open to each other," and yet another participant "found affirmation and pleasure from total strangers." However, there were some members that described the group as interesting rather than satisfying.

An analysis of the evaluation forms completed by the caregivers revealed that they learned about the support group in a number of ways: 42 percent from community professionals, 26 percent by word of mouth, 16 percent from other family members, 11 percent from the Alzheimer Society, and 5 percent from the media. Caregivers indicated that feedback from their relatives about the group was minimal, but positive for the most part. "My mother felt wonderful participating in the group - she felt validated as an intelligent adult." The majority of caregivers (69 percent) did not observe changes in their relatives' behavior during the course of the support group. For those who did observe changes, some comments were: "for 24 hours my mother experienced lightheartedness"; "he was able to find the confidence to retrieve his natural ability of imaginative innovation and creativity [his pottery]"; and "she seemed to remember who was picking her up and some of the individuals in the group - she felt she had a purpose on Mondays." When asked if attendance in the group made an impact on their life or their relative's, 55 percent responded affirmatively. One caregiver stated that her mother felt "that she was doing something normal—being part of a discussion group." Overall comments indicated that their relatives looked forward to the social interaction.

Discussion and recommendations

People in the early stages of dementia have had few places to turn for support. The majority of existing programs are either geared to support caregivers or for those in the more advanced stages of the illness. For individuals who are not suitable for the group, the lack of appropriate community programs continues to be a major problem. Once a diagnosis of dementia is made, the focus becomes centered on the disability, rather than capability. It is quickly forgotten how capable and functional individuals with early stage dementia are. Equally important, there has been no place for this population to express their concerns, fears, and emotions in a safe, supportive, nonjudgmental environment. One caregiver summed it up best when she wrote in her evaluation: "my mother is not ready for Day Care and there are no services available such as this one." In *Living in the Labyrinth*, Diana Friel McGowin, who began a group for individuals with early onset dementia, stated: "No matter how caring our friends and family members are, we *still need each other*—people walking through the same maze as ourselves. There were already support groups for caregivers, but until now, nothing for us. 'We, the People.'"[5]

Recruitment is a multifaceted task, which comprises outreach, intake, and individual client assessment. When working with this population, the facilitators' active involvement is necessary in both the intake and assessment processes. This type of involvement is different from the intake process of other support groups (*i.e.*, caregiver support), where most screening is done via telephone contact. Our experience has demonstrated that telephone screening and referral information is often not a reliable indicator of the client's appropriateness for the group; a face-to-face interview is required. Consequently, active recruitment for this group requires considerable time and attention, and it is labor-intensive.

In order to sustain a support group for this population, outreach and promotional activities need to be ongoing. As potential group members are often hidden and do not come forward on their own initiative, we have relied upon professional referral sources. Necessary outreach activities include mailings, press releases, public service announcements, telephone follow-up, and face-to-face presentations. The community has a number of potential referral sources that remain untapped due to time restrictions.

The need for, and potential benefit of, this type of support group seem to be analogous to those of other types of group support. People with memory loss can and do express their concerns in a group setting. Members of our groups expressed a sense of success and satisfaction from their participation, and experienced relief in talking with others with similar problems. Participants were articulate, attentive, insightful, and empathetic in the group setting.

Group process issues are unique with the dementia population, requiring facilitation techniques that accommodate participants' impairments and emotional reactions. Facilitators must have a flexible range of group skills and be ready for the unexpected. Positive evaluations from members indicate that this type of support group is important and necessary. Both participants and their caregivers requested continued group involvement following the conclusion of the structured group. On the basis of our experiences in working with this population and the feedback from the members and their caregivers, we realize that these groups have played a vital role in the lives of the members and their families. We strongly recommend that a short-term support group followed by ongoing support be the starting point on the continuum of dementia care.

In the future, we would like to see the development of additional time-limited groups and the expansion of services to include opportunities for individuals to receive mutual support in an informal, open-ended, continuous group.

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Suggestions for additional reading

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