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Predicting Attendance at Dementia Family Support Groups

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Abstract

This longitudinal study examined the predictors of dementia family caregivers' self-reported attendance at support group meetings over 6 months. First-time attendees were contacted by telephone after their first meeting and assessed for (*a*) perceptions of similarity between themselves and other members, (*b*) depressive symptoms, and (*c*) perceptions of social support from the facilitator and other members. Participants (N = 70) were recontacted 6 months later to obtain self-reports of attendance patterns. Self-reported attendance at any meeting during this follow-up period was predicted by perceived similarity in care recipient's stage of dementia and perceived support from group members as assessed at the first interview. Greater perceived support from group members and fewer depressive symptoms at time 1 predicted a higher frequency of support group attendance over the follow-up period. Results have implications for orienting new support group members as well as training and supporting group facilitators.

Keywords

Alzheimer's, caregivers, service utilization, depression, facilitators

Social support deficits have been linked to major and subsyndromal depression in older adults[1]; this has been especially true for chronically stressed populations such as dementia caregivers.[2] With the stigma associated with a dementia diagnosis in many cultures and social environments,[3] in addition to the emotional strain related to managing progressive neuropsychiatric symptoms of dementia,[4,5] family caregivers need additional support to complement what is received from informal networks. Support groups for dementia family caregivers have become a means of supplementary aid for these individuals. Despite growth in telephone[6] and Internet-based support programs,[7] in-person groups continue to be the most common group format for dementia family caregivers. The Alzheimer's Association in the United States estimated 6663 support groups offered by their area chapters attended by 39 551 participants in 2010.[8]

When asked about their participation in support groups, the majority of family caregivers surveyed report benefiting from their experience and being satisfied.[9] Reported benefits are varied, including increased knowledge about dementia and specific illnesses such as Alzheimer's disease, elimination of perceptions of deviance, opportunities to receive and provide emotional support, being part of an understanding/empathic community, opportunities to learn specific care skills and coping strategies from similar others, and decreased feelings of burden.[10-12]

In contrast, a different picture emerges of utilization and attendance patterns—one of relatively low utilization rates,[13] unstable attendance patterns, and early attrition. In 1 study, 35% of caregivers who attended a support group once or twice never returned.[12] Goodman[14] found that brief attendees differed from current attendees by (*a*) being less demographically and experientially similar to other group members, (*b*) reporting lower levels of burden and depression, and (*c*) reporting that they received more support outside of the support group. Perception of emotional support during support group meetings did not differentiate the 2 groups. Goodman's[14] findings of a negative association between depression and attrition (eg, lower depressive symptoms related to higher attrition) are also in contrast with a longitudinal study linking attrition to higher levels of depressive symptoms.[15]

Identifying the predictors of support group attendance is important from both an individual and organizational perspective. With such information, caregivers can make informed decisions about the types of services and programs to seek out over different stages of the illness. Moreover, agencies can use this information to implement a stepped model of care by identifying those most likely to benefit from support groups. Alternative or adjunctive interventions can be recommended for those who are likely to terminate prematurely or are less likely to benefit from an open support

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group structure.[16] The goal is to match the individuals with the services that will be most beneficial for them in their present circumstances. Agencies can also use information about variables associated with increased attendance to strengthen support groups (eg, pregroup preparation) or alter aspects of the support group, which are associated with early attrition.

The limited research that has been conducted on predictors of support group attendance has drawn from the Anderson model of service utilization and has primarily focused on physical and demographic variables that function as predisposing, enabling, or need-based factors that influence utilization of support services.[17-19] For example, investigators have examined distance, time and location of the meetings, lack of transportation, lack of respite care, care recipient's cognitive status, age of caregiver, and ethnicity as variables related to attendance.[12,17-19] Although these results have suggested changes in the logistics of support groups (eg, change in time and addition of respite care), few studies have examined the impact of more psychological processes, such as an individual's level of depression or perceptions of emotional support and similarity within the group. If shown to predict attendance, these factors would have implications for the screening of support group members and the training of support group facilitators. Our research group uses Bandura's social-cognitive theory[20] as a conceptual base for hypothesizing variables that might influence support group attendance. From this model describing reciprocal influences of intrapersonal variables and social contexts, caregivers attend support group meetings when they believe that the experience will directly benefit their coping efforts and the ability to manage the many challenges and stressors of dementia caregiving. Thus, attendance at a support group is viewed as first requiring intentionality, forethought, and self-direction. This exercise of personal agency is influenced by emotional factors such as depressed mood and depressive symptomatology, cognitions about the likely helpfulness of the experience, and social contextual factors such as the modeling of effective coping by similar others. Perceived similarity is viewed as more influential than expert status in shaping one's confidence in caregiving abilities and is viewed as a strong reinforcement of the efforts needed to attend a support group meeting.

Thus, the present study aimed to extend this literature by examining depressive symptoms, perceived social support, and perceived experiential similarity as predictors of attendance at Alzheimer's Association sponsored support groups in 2 states within the United States. Specifically, we hypothesized that self-reported support group attendance over a 6-month period would be negatively associated with initial levels of depressive symptoms and positively associated with higher initial levels of perceived support from both support group leader and members and perceived similarity to other group members.

Methods

Participants

Recruitment. Participants were recruited over 3 months from 70 in-person family support groups affiliated with a local Alzheimer's Association chapter, whose territory includes 38 counties in 2 adjoining states of the United States. Copies of attendance sheets from monthly support groups were submitted to the chapter office after each monthly meeting over 3 months and then shared with the research staff who then conducted all eligibility screening and assessment interview over the telephone. Research staff members were also formally registered volunteers for the Alzheimer's Association chapter and had signed confidentiality agreement forms

Eligibility. Participants were included in the study if they met the following criteria: (*a*) had a living family member diagnosed with a dementing illness, (*b*) had not attended a support group for caregivers prior to their initial index meeting, and (*c*) consented to participate in a brief telephone interview. Of the 142 individuals who indicated on an attendance sheet that they were new group members, 105 (74%) were eligible for the first wave of interviews (time 1). The predominant reason for ineligibility was the patient not having a specific diagnosis (ie, individual came to a first meeting with concerns about memory loss in a family member and questions about the process of getting a diagnosis; n = 25). Other reasons for ineligibility (eg, caregiver had attended an Alzheimer's Association support group meeting in the past, declined invitation to participate in study) were less common

Of the 105 participants who completed the first wave of telephone interviews (time 1), 95 (90%) agreed to be recontacted 6 months later (time 2) for a second phone nterview to assess support group attendance patterns. Of these, 70 were successfully recontacted by phone, remained eligible 6 months following the initial assessment (eg, family member was still alive), and completed both time 1 and time 2 interviews, comprising 67% of the initial interview sample. The data presented in this article are drawn from this final sample of 70 family members who participated in both waves of data collection.

Characteristics. Of our sample, 89% were female and their ages ranged from 35 to 82 years, with the mean being 60. On the average, they were well educated (mean = 13.6 years, standard deviation = 2.3). In all, 86% identified themselves as caucasian, 9% as African American, and 5% as another ethnicity. Totally, 61% (n = 43) were adult children of the care recipient, with spouses comprising 30% (n = 21) of our sample; the remaining portion were siblings or grandchildren. Seventy-six percent of participants considered themselves to be the individuals with primary care responsibilities for the individuals with dementia, and the majority reported caring for patients in the middle (41.2%, n = 28) to late (42.6%, n = 29) stages of Alzheimer's disease. A surprising 50% (n = 35) of care recipients were residing in assisted living or skilled nursing facilities at the time of caregivers' first support group meeting. As indicated on the attendance sheets, groups' sizes varied widely (range 3-14) with the number of new members also varying across the groups (range 0-5). New members appeared to be scattered across a large range of the groups, without a noticeable pattern of several groups contributing the greatest number of new members

Measures

New group member designation. All support group meetings sponsored by this particular chapter of the Alzheimer's Association utilized the same attendance form that group facilitators were expected to implement at each monthly meeting. These forms included the name/location of the group, date/time, name of the facilitator(s), and a specific section for group members to write their names and phone numbers. The attendance process made clear that this contact information would be used by the facilitator to contact group members when necessary to follow-up on specific caregiving concerns and by other chapter staff for quality improvement purposes. Following each line for potential group members was the question "Is this your first meeting?" with options of "yes" or "no." The attendance form procedure was already in place for a year prior to the onset of this study; thus, facilitators were familiar with and used to this procedure

For the purposes of this study, participants were considered to be a new support group participant if they circled "yes" on the "new member" question in this attendance sheet and also responded "no" to the time 1 telephone interview question "Prior to the support group meeting at ________ that you attended on the specific date of ________, had you ever attended a support group meeting for family members of individuals with dementia?"

Depressive symptoms. Participants' levels of depressive symptoms were assessed at time 1 using the short form of the Geriatric Depression scale[21] and, similar to its original, has been shown to have good internal consistency and reliability.[22] Consistent with previous research, the Cronbach's α for the present sample was .82

Perceived social support. To assess time 1 perceptions of support received at their first group meeting, participants were given a revised version of the Supportive Behaviors of Group Leaders and Members scales.[14] All questions were answered on a 5-point Likert-type scale and assessed perceptions of emotional and problem-solving supportive behaviors of the support group leader (5 items) and other group members (5 items) during that first group experience. Items reflected both emotional support (ie, showed warmth, listened attentively, encouraged or showed approval, and showed understanding) and problem-solving support (ie, helpful in solving care-related problems). Using time 1 data ($N = 105$), principal components analyses of both subscales reflected a general factor, supporting the inclusion of all items for the 2 subscales. All items had loadings greater than 0.70 on this general factor (Eigenvalue >3 for both subscales) and accounted for more than 70% of the variance. Perceived support subscores for leaders and for group members at time 1 were computed by averaging items, with higher scores indicating higher levels of perceived support. In the present study, items were internally consistent for the 2 subscales representing perceived support from group members (Cronbach's $\alpha = .89$) and perceived support from the group facilitator (Cronbach's $\alpha = .91$)

Perceived similarity. Eight items assessing perceived similarity to other group members at time 1 were constructed using a 5-point Likert-type scale. These items reflected similarity in age, gender, ethnicity, relationship to care recipient, level of care responsibilities, types of care-related problems, stage of dementia, and level of emotional distress due to providing care. Using time 1 ($N = 105$) data, principal components analyses and subsequent factor analyses were unsuccessful in identifying a general similarity factor. Instead, a focus group was held with staff members of the local Alzheimer's Association chapter to select the individual similarity items that had the most immediate implications for support group programming (eg, reflecting chapter and national trends for providing "specialty" support groups, feasibility of screening, and guiding caregivers into specific groups). The 2 items selected by staff were relationship to the patient and stage of dementia. Because these 2 variables were considered representative of the perceived similarity construct and with the highest utility, they were included in the analyses

Procedure

Within a week of each support group meeting and according to regular chapter procedures, group facilitators faxed their group attendance/telephone contact information sheets to the support group coordinator at the local Alzheimer's Association chapter. These sheets were then routinely forwarded by this coordinator to the research project team, all of whom were also formally registered as volunteers of the chapter. Group participants who circled "yes" for the "new member" portion of this form were then contacted by telephone and invited to participate in this study. All data used in the present study were collected via these telephone interviews.

Initial interview (time 1). All telephone interviews were conducted from a research laboratory at the investigators' university. Once participants were determined to be eligible and had given their verbal consent, they were asked for basic demographic and descriptive information and interviewed using the Perceived Similarity Questionnaire, the Geriatric Depression scale–Short Form, and supportive behaviors of group leaders and members subscales

Follow-up interview (time 2). Participants were recontacted by phone, 6 months after their initial interview to be assessed for self-reported attendance patterns. They were asked about their attendance at any family support group sponsored by the Alzheimer's Association (ie, either same or different group than the one initially attended). Those who had not attended any group meetings since their first meeting were asked for

Table 1. Logistic Regression Predicting Future Attendance (N = 70)

Predictor	*B*	SE	Exp (*B*)	Wald statistic
Step 1				
Depressive symptoms	0.15	0.10	1.16	2.13
Step 2				
Perceived similarity				
Stage of dementia	0.55	0.25	1.73	5.01[a]
Relationship to patient	−0.24	0.22	0.79	1.15
Step 3				
Support from leader	−0.19	0.51	0.83	0.14
Support from members	1.05	0.49	2.86	4.54[a]

Abbreviation: SE, standard error.

[a] $P < .05$.

Table 2. Intercorrelations Between Number of Meetings at 6 Months and Predictor Variables (n = 42)

Variable	1	2	3	4	5
1. Number of meetings at 6 months	–				
2. Depressive symptoms	−.35	–			
3. Similarity: stage	−.24	−.02	–		
4. Similarity: relationship	−.22	−.05	.35	–	
5. Support from leaders	.06	−.08	.25	.08	–
6. Support from members	.33	−.16	.26	.19	.45

their perceived reasons for not returning. Study participants were also asked about the living and residential status of the person with dementia. Participants were included in the present analyses if their family member was still living at the time of this 6-month interview

Results

Precisely, 60% of participants (n = 42) reported having returned to a support group at least once during the period following their first index meeting. According to self-reported estimates, the number of meetings attended during this follow-up period ranged from 1 to 9, with the mean being 4.5 meetings. Self-reported reasons for not returning included time conflict (28%), not liking group/not finding the group helpful (17%), feeling dissimilar to group members (13%), reduced caregiver stress due to care recipient having been placed in nursing home (6%), among others.

To examine the predictors of brief versus repeated attendance, 2 groups of participants were formed: (1) family members who did not attend any dementia family support group meetings after their first time (n = 28; 40%) and (2) those who reported attending a support group meeting at least once during the time following their first group meeting (n = 42; 60%). A hierarchical logistic regression was conducted using time 1 depressive symptoms (block 1), time 1 perceived similarity in stage of dementia and relationship to care recipient (block 2), and time 1 perceived social support from the group facilitator and group members (block 3). The model containing depressive symptoms alone did not differ significantly from a null model $\chi^2(1) = 1.26$, $P = .26$. Depressive symptoms accounted for 2% of the variance in this model, Nagelkerke $R^2 = .02$. The addition of the 2 perceived similarity items (stage of dementia, relationship to patient) resulted in a model fit that differed significantly from null, $\chi^2(3) = 8.43$, $P = .04$, Nagelkerke $R^2 = .15$. Adding the final variables of perceived support from the group leader and perceived support from the group members also improved the model fit to, $\chi^2(5) = 14.40$, $P = .01$, Nagelkerke $R^2 = .25$; blocks 2 and 3 each produced a significant improvement over the previous step. Table 1 shows the regression weights, odds ratios, and Wald statistics for the predictors. Based on these statistics, the significant predictors of returning to a group following a first meeting were perceived similarity in stage of dementia and perceived support from group members. This analysis was sufficiently powered for large effects but not for medium to small effects.

We next examined whether this same set of variables would predict the number of meetings attended by those caregivers (n = 42) who returned at least once following their indexed meeting. A hierarchical linear regression was conducted with time 1 depressive symptoms (blok 1), time 1 perceived similarity in stage of dementia and relationship to care recipient (block 2), and time 1 perceived social support from the group facilitator and group members (block 3) as predictor variables. This analysis met Cohen's[23] sample size recommendations for large effects (n = 42). Intercorrelations between the variables of interest are displayed in Table 2. Level of time 1 depressive symptoms, as measured by the Geriatric Depression scale, was a significant negative predictor of the number of meetings, $F_{1,40} = 6.44$, $P = .02$, $R^2 = .15$. The predictive ability of the model was not significantly improved after entry of perceived similarity in stage of dementia and relationship to patient, $F\Delta_{2,38} = 2.08$, $P = .14$. Finally, block 3 variables of social support from both members and the group leader also predicted the number of meetings attended, $F\Delta_{2,36} = 3.94$, $P = .03$, $R^2\Delta = .14$, after controlling for the effects of the previous blocks. This was due to the impact of perceived support from group members; perceived support from the leader was not a significant predictor. As a whole, the model was significant, $F_{5,36} = 4.13$, $P < .01$, and accounted for 38% of the variance in the number of meetings attended. Table 3 displays the standardized (β) regression coefficients, R^2 and $R^2\Delta$ after entry of each group of independent variables.

Discussion

This study prospectively examined the variables associated with attendance by new participants of dementia family support groups, from the perspective of social cognitive theory.[20] Overall, the data suggest that both individual factors (lower levels of depression) and social contextual factors (experiential similarity, perceptions of support from group members) may be longitudinally associated with family members' increased attendance at support groups.

Table 3. Hierarchical Regression Predicting Number of Meetings Attended Over 6 Months (n = 42)

Predictor	R^2	ΔR^2	β
Step 1	.15[a]	.15[a]	
Depressive symptoms			−.38[a]
Step 2	.23[a]	.09	
Similarity: stage			−.23
Similarity: relationship			−.12
Step 3	.38[a]	.14[a]	
Support from leader			−.09
Support from members			.43[a]

[a] $P < .05$.

Participants who perceived other group members as warm, interested, and good at problem solving in their first meeting were more likely to return to the support group and showed improved attendance patterns compared to those who reported less positive first impressions. This finding dovetails nicely with social-cognitive theory[20] and with the literature on support groups and other therapeutic groups for older adults.[24] Indeed, the opportunity for group members to receive and provide support has been cited as one of the most important benefits of participation in support groups for family members[9,11,17] and individuals with early stage dementia.[25,26] Results of the current study highlight that who provides the support is important. In contrast to the significant findings for support from group members, perceptions of social support from the support group leader were not related to the decision to return to the group after the first meeting. This lack of predictive power could be because the caregivers gave disproportionately high ratings for support group leaders, which reduced our ability to detect significant differences between groups. An equally viable reason consistent with social-cognitive theory is that family members weighed the importance of the support received from other caregivers more heavily than that received from the support group leader. Other caregivers are perceived as exhibiting a more accurate understanding of the stresses associated with providing care and thus deemed more empathic and credible.[27] The opportunity to be useful to others may also be a strong incentive for these caregivers to continue their attendance at support groups.[28]

This does not discount the importance of support group leaders being emotionally supportive in their interactions with caregivers. However, our findings may indicate that the support group leader's ultimate importance lies in her or his ability to help other group members support each other. Thus, in addition to possessing characteristics of good therapists, support group facilitators also need to be trained in group processes and interventions.[24,29] In short, facilitators need to be trained to facilitate, and readers are referred to some excellent resources available to assist with this process.[10,29]

In contrast to some previous research, perceived similarity was not significantly related to the number of support group meetings attended. Consistent with predictions, however, participants who perceived that other group members were caring for patients in a similar stage of dementia were more likely to return a second time to a support group than those who perceived that others were less similar on this factor. Thus, the results of this study lend modest support to the practice of offering specialty groups that target specific populations (ie, adult children vs spouses and groups varying by stage of dementia).

We find it interesting that although perception of similarity differentiated the caregivers who returned to a second group meeting from those who did not, perceived similarity did not predict the total number of meetings attended. This could be explained by our low sample size and, thus, low power to find relatively small effects (ie, 6% of the variance). On the other hand, there are also conceptually based explanations available in the group therapy literature; the importance of observed differences may fade over time as the overarching commonality among group members becomes more prominent. In this case, it may be that as cohesion within a group develops, caregivers become less concerned with their dissimilarities (ie, what stage other patients are in or the nature of the familial relationship between patient and caregiver) and more focused on the one characteristic that all share—their role as caregiver. This is supported by the work of Sabir and colleagues[30] who did not find similarity to be important in a peer support intervention for dementia family caregivers. Again, this has direct implications for the training of facilitators and the implementation of support groups. One of the main tasks of facilitators, particularly during the early stages of the group, is to highlight the universal characteristics that all members share. This may be particularly important for support group meetings held at assisted and long-term care facilities, where the dissimilarities between caregivers caring for early to middle stage patients and those caring for more advanced patients are most apparent.

In contrast to Goodman's study,[14] but similar to other research,[15] higher levels of depressive symptoms were associated with lower rates of attendance over the 6 months of the study. Results of the present study are consistent with social-cognitive theory and echo trends found within the support group and therapy literature; individuals who are more depressed attend fewer meetings than those reporting lower levels of depression. We know that depressed individuals report more fatigue and more pessimism; both of these correlates of depression reduce the likelihood that caregivers have the planning skills and efficacy beliefs needed to attend a meeting. Depression may also make it more difficult to perceive the group as helpful. In light of the possibility that clinically depressed individuals experience the support group environment as nontherapeutic, support group facilitators should screen out more severely depressed individuals using available assessment tools[31,32] and refer them for individual or family interventions prior to or instead of entering a support group. Family caregivers providing in-home supervision and assistance may need groups to meet twice a month; additional options for attending would maximize the likelihood that caregivers could attend least 1 meeting each month. Also, those involved in providing in-home care are likely to benefit from consideration of more intensive community supports such as adult day care services or periodic short-term residential care.

Despite the positive findings, a number of limitations of the study deserve mention. Our identification of new group members depended upon the accuracy of the sign in sheets, which may have varied for a number of reasons (eg, hesitancy of new attendees to identify themselves in this way and differences among facilitators in the emphasis they placed on these attendance sheets). Participants made their initial ratings about the first support group meeting retrospectively, which may have led to a recall bias. We believe that accuracy would be significantly improved by assessing individuals' impressions of the support group meetings immediately (ie, the same day). Similar to the majority of studies in this field, the measures were based solely on self-report and dependent upon participants' abilities and willingness to accurately report their experiences. We would have ideally wished to verify these self-reports using attendance forms over the 6 months of follow-up, but changes at the chapter office led to less consistent access to these data after completion of the time 1 interviews. The size of our longitudinal sample was smaller than ideal, leading to analyses powered to find large effects but not medium to smaller effects; expanding our study to a longer period of time would have been useful for increasing sample size and power. Sampling the groups across a longer period of time would have also increased our ability to conduct subanalyses across small-, medium-, and large-sized groups to determine whether our conclusions apply equally to groups of various sizes.

Another concern for the generalizability of the present study is that the percentage of individuals who reported being moderately or severely depressed is inconsistent with other research on caregiver's psychological functioning.[2] The finding that so few of our participants reported being moderately or severely depressed suggests at least 3 possibilities. One, individuals who were more depressed refused to be interviewed and were not a part of our sample. Two, social pressures (eg, stigma of depression and wanting the Alzheimer's Association to hear they were doing well) may have affected participants' abilities and willingness to honestly report their experiences. Finally, it may be that the most distressed caregivers are not attending support groups at any time. Thus, some method for random sampling of dementia caregivers in the community would lead to a better picture of whether depression affects utilization of services beyond the context of the current study.

In addition to highlighting the importance of leaders receiving training in the area of group facilitation skills, the present findings support the benefits of screening and pregroup preparation. It requires only a brief phone conversation with a prospective group member to determine whether a formal diagnosis of Alzheimer's disease or another dementing illness has already been made, and the level of psychosocial distress experienced by the family caregiver. Prior to diagnosis, families will be better served by telephone helpline information and referrals for dementia assessment. Immediately postdiagnosis, families may feel flooded by a variety of needs and are likely to require more assistance than is feasible in a monthly support group format.[33] Similarly, caregivers disclosing extremely high levels of distress and depressive symptoms may need individualized consultation and assistance with care management, before being ready to participate in a support group setting. Even those who are appropriate for support groups will benefit from role induction and additional information about what to expect; caregivers may enter support groups expecting immediate relief and become discouraged when support groups fail to provide the magic remedy they desire. Facilitators are encouraged to provide potential members with information about group practices, common topics, and how group participation interacts with individual efforts to address caregiving issues.[34,35] Examples of such role inductions are widely used in the therapeutic literature and have been positively associated with positive treatment outcomes and reduced attrition. Support groups have been a mainstay of core services provided by the Alzheimer's Association and have much to offer families living with the challenges of dementia.

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