

Impact of an activities-based adult dementia care program

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Abstract: The investigators studied over one year the impact of a newly established once-a-week activity-based day care program for dementia patients combined with 17 educational sessions for caregivers held at the same facility. Outcome measures were patient and caregiver quality of life (QOL), patient behavioral disturbance, and use of community-based resources. Of the 37 enrollees, 3 chose not to start the program and 13 dropped out before the end of one year, largely due to health-related issues. Of the initial group, 21 attended for the entire year. The average patient Mini-Mental State Exam (MMSE) score at entry was 16, indicating a moderate level of dementia. Average score on the CERAD Behavior Rating Scale for Dementia (BRSD) was 30.1, indicating a mild level of behavioral disturbance. Attendance at day care was 91%; at the caregiver educational sessions, 74%. Patient and caregiver enthusiasm for the program was high and all wanted to continue attendance beyond the study period despite the fact that patients reported no change in QOL. Caregivers rated patients as having significantly less QOL, and rated their own QOL as unchanged. Symptomatic patient behaviors, as measured by the BRSD, increased significantly over the period of study. Caregivers reported greater use of community resources.

Keywords: dementia, day care, quality of life, CERAD Behavior Rating Scale

Introduction

BeBe's House is an activities-based, one-day-per-week adult day care/caregiver education and support program. It was established through a gift from donors who wanted their gift to have an immediate impact on the lives of persons with Alzheimer's disease (AD) and other dementing illnesses. A cooperative endeavor between the University of Texas Southwestern Medical Center and the Greater Dallas Chapter of the Alzheimer's Association, it was conceived as a volunteer-staffed, activity-centered day care setting that would provide an inviting, comfortable, and appropriately stimulating environment for persons with dementia and respite and education for caregivers.

The project was undertaken with the understanding that investigators at the University of Texas Southwestern Medical Center would attempt to measure the impact of this program on day care clients and their caregivers.

A review of the psychosocial intervention literature for both AD patients and their caregivers revealed no comparable program. There were uncontrolled reports including an exercise program for patients (Heyn 2003), a weekly art program for patients (Rentz 2002), and a workshop for caregivers (Ostwald et al 2003). A controlled study that included a 3-month exercise program and training of caregivers in behavioral management showed better physical role functioning and improved mood (Teri 2003). With regard to adult day care for dementia, one study found decreased frequency of problem behaviors among patients and less caregiver time spent dealing with problem behaviors (Gaugler et al 2003). Another study, which

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examined a rehabilitative day care program that included cognitively and physically impaired adults, found greater decline in health and greater loss of function among non-day-care users than among matched control patients. There was no difference in caregivers in terms of burden or subjective wellbeing despite patients being in day care for an average of 3.4 days per week (Zank and Schacke 2003). By contrast, Zarit et al (1998) found that caregivers of dementia patients who used day care for their loved ones at least two days per week for at least 3 months experienced less emotional strain, depression, and anger than a comparable group of caregivers who would have used adult day care had it been available and affordable.

Our previous experience with groups providing cognitive stimulation (8 weekly group sessions of one and one-half hours with 6 participants each; total N=53) showed a subsequent modest decrease on the irritability and apathy scales of the Neuropsychiatric Inventory (Cummings et al 1994), and a trend toward greater QOL by patient self report (Chapman et al, in press). We reasoned that a combined activity-based day care and caregiver education and support program conducted for a year might have more discernable effects. Our primary hypothesis was that patients and caregivers would each experience increased QOL. Our secondary hypothesis was that patients would have lowered levels of behavioral symptoms. We also hypothesized that there would be greater use of community resources as a result of the day care experience for patients and the educational experience for caregivers.

Methods

The physical setting for BeBe's House was a new, attractive building designed as a day care facility. It was comfortably furnished and had a living room area (with fireplace), an activity-dining area, and a kitchen area. The Director of BeBe's House (SC) was a Certified Activities Director who had formerly directed an Alzheimer's unit in a long-term care facility. The educational program (biweekly for 8 weeks, then monthly) was conducted by KB, Educational Director of the Greater Dallas Alzheimer's Association. The patient program was carried out with the help of one other employee and with intermittent help from volunteers recruited by the Alzheimer's Association. The daily program is presented in Table 1. The patient activities were designed to promote interaction between patients and also a sense of relatedness. They included the use of overlearned skills in

Table 1 Schedule of program

0930	Arrival
0945	Greet and review events of the week
0955	Word game (often recall of 3 associated words such as hop, skip, and jump)
1000	Set up exercise room to do chair exercises to music
1040	Set up dining area for snacks, serve juice and fruit
1100	Arrange living area for current events, saying days of week and months of year, talking about the weather, and reviewing a few items from the local newspaper
1115	Wash hands, set tables for lunch, serve lunch, clear tables
1245	Outside activities (bean bags, horse shoes) or inside games such as Bingo or puzzles
1315	Return to living area for word games such as opposites, finishing song titles, wheel of fortune
1340	Singing, using audiotape and song sheets
1400	Review of day and adjournment

simple games and stimulation of recent memory, associative processes, and simple socially appropriate motor tasks.

Subjects were recruited from among the patients and caregivers at the Clinic for Alzheimer's Disease and Related Disorders at the University of Texas (UT) Southwestern Medical Center, through the newsletter of the UT Southwestern Alzheimer's Disease Center, from mailings to residents of the retirement community (Presbyterian Village North) that housed the project, and through publicity generated by the Greater Dallas Chapter of the Alzheimer's Association.

Inclusion criteria

Patients were required to have a medical diagnosis of a dementing illness, to be community dwelling, continent, independently mobile, or mobile with assistive devices. Caregivers were required to be fluent in English and able to complete study questionnaires. They were asked to make a 3-month commitment for themselves and their loved ones.

We had planned to randomly assign patients to a 6-month wait list and to compare the treated and untreated groups, but the feeling in the community was that anyone we could accommodate should be enrolled, despite limiting the findings of the study.

Exclusion criteria

These included not having a medical diagnosis, inability to speak English, language impairment sufficient to be unable to respond to the QOL questionnaire, being a physical threat to others, and being enrolled simultaneously in another day care program.

Measures

We adopted as our primary outcome measure the Quality of Life in Alzheimer's Disease Scale (QOL-AD; Logsdon et al 1999), patient and caregiver versions. The scale was administered to patients in an interview format. Caregivers were asked to rate their loved ones' QOL on the same scale and then to rate their own QOL. The QOL-AD is a 13-item instrument that can be administered directly to persons with dementia or their caregivers as surrogates. It can also be used as a QOL measure for caregivers. It has a one-week window of observation, and is reliable and valid for persons with mild to moderate cognitive impairment (Mini-Mental State Exam scores > 10 (Logsdon et al 2002). Each item is rated on a 4-point scale from poor to excellent. The range of scores was 13–52 for patients and 15–156 for caregivers, who were given the additional scoring option of indicating how important specific activities were to them. Higher scores on this scale indicate higher QOL. The scale is not influenced by caregiver or patient education, and has moderate correlation with measures of depression ($r = -0.65$). Caregivers were asked to assess their own QOL using a modified version of this instrument.

Our secondary outcome measure was the CERAD Behavior Rating Scale for Dementia (CBRS; Tariot et al 1995). This 48-item instrument is administered to caregivers and has a one-month window of observation. Items are rated by frequency of occurrence on a 5-point scale; the maximum score is 178 points (we slightly modified the scoring, giving extra points for persistence of patient beliefs despite caregiver attempts to correct them), and higher scores indicate greater behavioral disturbance. The scale is sufficiently sensitive to detect small behavioral changes related to anticholinesterase treatment of AD patients (Weiner et al 2000).

To obtain an estimate of the severity of our patients' cognitive impairment, we employed the Mini-Mental State Exam (MMSE; Folstein et al 1975), a brief (30-point) cognitive screening instrument administered directly to patients. Higher scores indicate better cognitive function.

We also tracked service utilization by means of a standardized questionnaire filled out by caregivers at the end of the study period. The questionnaire asked about use of patient support groups, adult day care, caregiver support group at BeBe's House, caregiver support group elsewhere, housekeeping assistance, in-home patient care assistance, and other services.

All patients and caregivers signed a consent form approved by the institutional review boards at UT Southwestern and Presbyterian Hospital of Dallas. No fees were charged for the program. Enrollment in the study was for a period of 12 months (the day care program was continued). Participants attended one day per week from 9:30 am to 2:00 pm. There were 15 individuals enrolled in one session and 16 in the other. Caregivers were invited to attend periodic educational meetings at the facility that occurred biweekly at first and then monthly.

Test procedures. All measures were administered by an experienced research nurse (KK). The MMSE was administered at baseline and at 12 months. Quality of life scales and the CBRS were administered at baseline, 3 months, 6 months, 9 months, and 12 months (or end of study, when feasible).

Statistical methods. Our projected sample size of 50 patients and 50 caregivers was large enough to detect a 2–2.4 point change (5%–6% in the overall QOL score and a 7-point (26.2%) change in the CERAD BRSD score with 80% power ($\alpha = 0.05$) using repeated measures design (assessment every 3 months) and having patients serve as their own controls.

Results

This report covers the first year of the BeBe's House project. A total of 37 patient/caregiver dyads signed consent forms. Of these, 3 chose not to start the program and 13, including 1 patient who has not yet completed the one-year period of study, have data available for less than one year having dropped out before one year (4 before 3 months, 2 between 3 and 6 months, 6 after 6 months, and 1 after 9 months). The primary reasons for dropouts were medical problems or nursing home placement (7). There were two program-related dropouts: one patient dropped because he and his caregiver thought the program too simple; another because she was unable to keep up with the activities. One patient refused to get out of bed. The first group of 15 began in January, 2003; a second group began in March, 2003.

Beginning and end of study data were available for 21 pairs of patient/caregiver participants who stayed with the program over the first year. Attendance at the day care sessions ranged from 35–50 sessions (average = 44.6; 91.0% attendance). Demographic data concerning the participants is contained in Table 2, which compares those who stayed with the program over the first year (completers) with those

Table 2 Comparison of non-completers and completers

	Non-completers		Completers	
	Mean	SE	Mean	SE
N	13		21	
Female %	46		43	
Age	74.8	3.1	77.3	2.0
Symptom duration (years)	5.1	0.8	4.7	0.7
MMSE (initial)	14.4	1.6	17.0	1.6
CBRS (initial)	39.3	6.7	24.8	2.3
Patient QOL (patient)	38.0	2.1	40.2	1.5
Patient QOL (caregiver)	34.0	1.6	33.7	1.5
Caregiver QOL	115.0	5.6	119.0	3.9

NOTE: Data are given as mean (standard errors) except where noted.

Abbreviations: MMSE, Mini-Mental State Examination; CBRSD, CERAD Behavior Scale for Demetia; QOL, Quality of Life Scale.

who dropped out before then. Those who dropped out did not differ in age from those who continued in attendance, but their longer symptom duration (5.1 vs 4.7) and lower MMSE scores (14.4 vs 17.0) suggested that they were more severely impaired. The mean score for all participants (16.0) indicates that their dementia was of moderate severity.

Both cognitive function and behavioral symptoms worsened significantly over the course of the study. MMSE scores declined by more than 4 points and CERAD Behavioral Rating Scale scores increased by 5 points (Table 3).

Caregivers reported significant decrease in QOL for their loved ones (Table 2), but patients reported essentially no change in QOL over the course of the study. Caregivers rated their own QOL as unchanged.

Of the 19 caregivers, 18 attended some or all of the educational sessions; the mean number of sessions attended was 12.6 or 74% (12.6/17) attendance. At the beginning of the BeBe's House program, some form of additional support was used by 9 of the 19 caregiver/patient dyads. This increased to 12 by the end of the study. Community-based patient support groups were attended by 5 of the patients at

the beginning of the study and 11 at the end. Only one caregiver was attending a community-based support group at the beginning; 4 were attending by the end of the study period. At the beginning, 6 caregivers used housekeeping assistance; at the end, there were 9. In-home assistance with patient care paralleled housekeeping assistance, with 6 users at the beginning and 11 at the end. The total average number of services employed rose from 1.1 to 2.2 (including the BeBe's House support group for caregivers and day care for the patients).

Discussion and conclusions

To obtain a sufficient number of subjects to draw conclusions, our limited resources allowed us to enroll patients for only one day per week. Although the original study design contemplated a 6-month experience and would have given us greater statistical power, the staff were unwilling to disenroll anyone who wanted to continue participation. Of the regular attendees, no one wanted to stop.

Our measures did not support our primary hypothesis that the BeBe's House experience would increase QOL for patients and caregivers. The fact that the trend was in the direction of worse QOL for care recipients goes against our hypothesis, but lack of a control group prevents us from determining if there might have been a difference from an untreated group. We were also not able to support our hypothesis that the level of behavioral disturbance would be decreased; nor was it decreased in relation to a group of community dwelling AD patients with similar MMSE scores who were studied over one year (an approximately 3-point increase) (Patterson et al 1997).

Our third hypothesis was supported. The increase in service utilization could have been related to the patients' enjoyment of BeBe's House, and their use of another patient-centered community-based support group essentially

Table 3 Combined data for all participants

	Visit (months)										p-value
	Baseline		3		6		9		12		
	Mean	SE	Mean	SE	Mean	SE	Mean	SE	Mean	SE	
MMSE score	16.0	1.2							11.4	1.3	<0.0001
CBRS (score)	30.1	2.9	29.4	2.9	35.6	3.0	36.9	3.2	35.3	3.2	0.0073
Patient QOL (patient)	39.4	1.2	39.8	1.2	40.4	1.3	39.5	1.4	41.1	1.4	0.4226
Patient QOL (caregiver)	33.8	1.0	33.0	1.1	32.3	1.1	32.2	1.1	31.0	1.2	0.0423
Caregiver QOL	117.5	3.2	114.6	3.4	117.2	3.4	113.7	3.6	115.0	3.6	0.6537

NOTE: Data are given as mean (standard errors). Patient QOL (caregiver): B vs 3, $p=0.0026$; 3 vs 12, $p=0.0311$. CBRSD score: B vs 6,9,12 (0.0213, 0.0093, 0.0478); 3 vs 6,9,12 (0.0106, 0.0047, 0.0269). **Abbreviations:** MMSE, Mini-Mental State Examination; CBRSD, CERAD Behavior Scale for Demetia; QOL, Quality of Life Scale.

doubled. The increase of housekeeping and in-home patient care could have been related to greater acceptance of support, but could equally well have been related to disease progression, as indicated by the change in MMSE scores over the 12 months.

Like other psychosocial interventions assessed in terms of their subjective value to continuing participants (Schulz et al 2002), BeBe's House was highly valued. Numerous caregivers reported informally that the day care sessions were the high point of their loved ones' week, and also reported that they greatly valued their new-found sense of community and the feedback from their support group leader and the other members.

Although the BeBe's House experience did not affect the course of disease, did not ameliorate disturbing symptoms, and did not improve ratings on a QOL scale, it appeared to increase morale and decrease a sense of isolation for patients and caregivers alike. This should be sufficient justification for continuing this program and others like it.

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