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The Gerontologist
Vol. 45, Special Issue I, 81–86

BRIEF REPORT

Characteristics Associated With Lower Activity Involvement in Long-Term Care Residents With Dementia

Debra Dobbs, PhD,[1] Jean Munn, MSW,[2] Sheryl Zimmerman, PhD,[2] Malaz Boustani, MD, MPH,[3] Christianna S. Williams, PhD,[4] Philip D. Sloane, MD, MPH,[5] and Peter S. Reed, PhD[6]

This article describes the characteristics associated with activity involvement in 400 residents with dementia in 45 assisted living facilities and nursing homes. Activity involvement was related to family involvement in care and staff encouragement, after adjusting for resident age, gender, race, cognitive and functional status, and comorbidity.

Key Words: Nursing homes, Assisted living, Residential care

There is evidence that engagement in meaningful social activities is related to quality of life for individuals residing in long-term care facilities (Gonzalez-Salvador et al., 2000; Hagen, Armstrong-Esther, & Sandilands, 2003). For example, participation in activities such as music, exercise, or cooking is associated with less depression, better cognition, mobility, and balance, and lower mortality rates (Kiely, Simon, Jones, & Morris, 2000; Koh et al., 1994; Marsden, Meehan, & Calkins, 2002; Mitchell & Kemp, 2000; Turner, 1993). Further, allowing residents choice in activity programming is associated with their involvement (Hedley, Wikstrom, Gunnarsson, & Sjoqvist, 1994). It is often a challenge, however, to involve persons with dementia in activities and for them to be able to inform facility staff of their preferences. This challenge may be especially notable in residential care/assisted living (RC/AL) facilities, which have become a predominant provider of long-term care. RC/AL facilities are nonnursing home residential settings that provide or arrange supportive and health care services for individuals who require assistance with daily activities (Kane & Wilson, 1993). Traditionally, they differ from nursing homes in that they promote a more social model of care (e.g., resident autonomy and choice in a home-like environment). Further, this social model of care, to which activity involvement clearly relates, is important to resident quality of life (Dobbs, 2004; Mitchell & Kemp, 2000; Zimmerman, Sloane, & Eckert, 2001). Given the difference in the RC/AL philosophy compared to nursing homes, these residents may have, and their families may expect them to have, higher activity involvement than residents in nursing homes (after adjusting for functional, cognitive, and health status). Thus, it is useful to understand resident involvement in activities and facility care related to resident involvement, both overall and separately, for each type of setting. Findings related to activity involvement, assessment for and availability of activities, and what resident and facility characteristics are associated with activity involvement may provide suggestions to improve care.

Research Design and Methods

Sample and Recruitment

The sample comprised participants in the Dementia Care project of the Collaborative Studies of Long-Term

This research was supported by grants from the National Alzheimer's Association, Program and Community Services Division and Medical Scientific Division (Grant No. IIRG-00-2222). The authors express appreciation for the cooperation of the staff, residents, and families participating in the Collaborative Studies of Long-Term Care (CS-LTC). Gratitude also is extended to Ms. Jane Darter for expert data management.

Address correspondence to Debra Dobbs, PhD, Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill, 725 Martin Luther King Jr. Blvd., Chapel Hill, NC 27599-7590. E-mail: Debra_Dobbs@unc.edu

[1]Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill.

[2]Cecil G. Sheps Center for Health Services Research and the School of Social Work, University of North Carolina at Chapel Hill.

[3]Regenstrief Institute, Inc. and Indiana University Center for Aging Research, Indianapolis, IN.

[4]Cecil G. Sheps Center for Health Services Research and the Department of Epidemiology, School of Public Health, University of North Carolina at Chapel Hill.

[5]Cecil G. Sheps Center for Health Services Research and the School of Medicine, University of North Carolina at Chapel Hill.

[6]Alzheimer's Association, National Office, Chicago, IL.

Care (CS-LTC), living in a stratified sample of 35 RC/AL facilities and 10 nursing homes in Florida, Maryland, New Jersey, and North Carolina. In this study, RC/AL facilities included those facilities with fewer than 16 beds ($n = 14$); larger, traditional facilities ($n = 11$); and new-model facilities that tend to provide nursing care and/or cater to an impaired population ($n = 10$). Details of this typology can be found elsewhere (Zimmerman et al., 2001).

We randomly selected residents from among those aged 65 years or older who had a diagnosis of dementia. A total of 575 eligible residents were approached for enrollment. Of these, 421 (73%) agreed to participate, 66 (11%) refused, and 88 (15%) were unable to provide consent and had family members who were unreachable.

Data Collection

Data collection occurred between September 2001 and February 2003. For each resident, we conducted on-site interviews with the resident, the direct care provider who provided the most hands-on care and knew the most about the resident's care, health, mood, and daily activities, and the supervisor (i.e., staff member above a direct care provider level who knew the most about the resident). The facility administrator provided facility-level data, and the family provided information about their level of involvement in care. Further details about the Dementia Care sample and data collection procedures can be found in the introduction to this issue.

Measures

Activity involvement.—We measured activity involvement using the Patient Activity Scale–Alzheimer's Disease (PAS-AD; Albert et al., 1996), which was reported for each resident by the direct care provider ($n = 400$) as well as by self-report for residents ($n = 99$) scoring 10 or higher on the Mini-Mental State Exam (MMSE; Folstein, Folstein, & McHugh, 1975). We selected the PAS-AD because it includes activities judged to be within the capacity of demented individuals who receive supervision and aid in daily activities (Albert et al.; Logsdon, Gibbons, McCurry, & Teri, 1999). The 15 items include 5 that involve travel outside of the facility (e.g., going shopping, to church, for a car ride, to the movies, and to see family and friends) and 10 that can be carried out in the facility (e.g., being with pets, exercising). Each activity is rated for opportunity (yes/no) and engagement during a one-week time frame. Response categories for engagement are frequently (≥ 3 times/week = 2), occasionally (1–2 times/week = 1), or never (0). Responses are aggregated into a summary activity measure, (range = 0–30), with higher scores indicating more activity. Because norms for the frequency of such activities among demented people do not exist, Albert and colleagues recommends defining "higher" and "lower" activity based on those above and below the median of the distribution. Hence, lower activity involvement is defined here as less than 9.0 for both care provider and resident respondents, which is the same cutpoint used by Albert and colleagues. Internal consistency for the PAS-AD was very good ($\alpha = 0.79$ and 0.80 for care provider and resident, respectively) and interrater reliability (care provider only, $n = 18$ pairs) was excellent (0.95 intraclass correlation coefficient for continuous measure and $K = 1.00$ for dichotomous measure of lower activity involvement).

Resident characteristics.—We categorized dementia severity as mild, moderate, severe, and very severe based on scores from the MMSE and Minimum Data Set Cognition Scale (MDS-COGS; Hartmaier, Sloane, Guess, & Koch, 1994). MMSE category ranges are $\geq$ 18, 11–17, 3–10, 0–2 respectively; MDS-COGS cutpoints are 0–1, 2–3, 5–8, 9–10. We measured depression using the Cornell Scale for Depression in Dementia (CSDD; Alexopoulos, Abrams, Young, & Shamoian, 1988); behavioral symptoms with the Cohen-Mansfield Agitation Inventory (CMAI; Cohen-Mansfield, 1986); and pain using the Philadelphia Geriatric Center Pain Intensity Scale (PGC-PIS; Parmelee, Katz, & Lawton, 1991). We measured immobility by direct observation (Williams et al., 2005, this issue). We measured low food intake using the Structured Meal Observation (SMO; Reed, Zimmerman, Sloane, Williams, & Boustani, 2005, this issue). We measured functional status using the Minimum Data Set–Activities of Daily Living (MDS-ADL; Morris, Fries, & Morris, 1999) as a count of the number of disabilities (range = 0–7).

Facility characteristics.—We obtained facility type, ownership (nonprofit, for-profit), bed size, and activity provision on a facility level from the administrator. We asked administrators to what degree the facility provides and encourages resident participation in 10 activities common to long-term care (exercise, personal care, social, housekeeping, meal preparation, crafts, work-oriented, special events, sensory, and intellectual; Zgola, 1987), and we coded responses as either not/rarely (less than one day/week) or regularly.

We asked supervisors three resident-level questions related to assessment: whether or not the resident's ability to participate and preferences for participation were assessed by an activity director; or by a written assessment; and how involved family members were in determining resident activities (from 0 = not at all to 4 = extremely). Supervisors also reported whether anything was done to encourage involvement in activities that the resident preferred and was able to do (yes/no); how well they feel the facility has been able to involve the resident in activities suited to his or her abilities and preferences (from 0 = not at all to 4 = extremely); and how well trained they feel in identifying residents' preferences and abilities to participate in activities, and helping residents participate in activities, as well as to actually help residents participate in activities. Finally, families reported their own involvement in care (number of

hours/week spent visiting with or talking to the resident for social reasons).

Analysis

We computed simple descriptive statistics separately for RC/AL facilities and nursing homes. We used generalized estimating equations (GEE; Diggle, Heagerty, Liang, & Zeger, 2002) for the statistical comparison of these characteristics by setting, applied to linear or logistic (for continuous and binary characteristics, respectively) models and an exchangeable correlation structure with facility as the clustering variable. *P* values were based on score statistics (Boos, 1992). To examine the association between resident and facility characteristics and care provider report of activity involvement, we estimated odds ratios and 95% confidence intervals using a separate binary logistic regression model for each characteristic, controlling for clustering using GEE empirical standard error estimates and an exchangeable correlation matrix. We estimated adjusted odds ratios controlling for gender, race, age, cognitive status, number of comorbid conditions, and ADL dependencies. We repeated analyses using linear regression with the continuous PAS-AD as the dependent variable; results were very similar, and only the logistic regression results are reported. We also tested interactions of predictors with setting.

Results

The mean age of the 400 residents was 84.7 years (range = 66–101 years), 20.0% were male, 9.5% were non-White, and 64.4% had severe or very severe cognitive impairment. Ninety-nine of the 400 residents with complete data on the outcome (24.7%) were sufficiently cognitively intact (scored ≥10 on MMSE) to report their own activity preferences and involvement. Based on supervisor report, slightly more nursing home residents exhibited lower activity involvement (56% vs 43%); this situation was reversed when reported by the 99 residents who could self-report (43% vs 55%); neither difference was statistically significant. As shown in Table 1, RC/AL residents enjoyed more activities than did nursing home residents based on staff report (10.7 vs 9.3, $p = .025$); no such difference was found for the 99 residents who could self-report (12.4 vs 13.0, $p = .319$). Based on staff report, the activities with the highest mean for both RC/AL and nursing home residents were (not shown) listening to radio, tapes or watching TV (1.49 and 1.62, respectively, on a scale of 0–3). Going shopping had the lowest mean (0.16 and 0.04), and 86.6% of RC/AL residents and 95.5% of nursing home residents had not gone shopping at all in the last week. Staff reported a high percentage of residents in both RC/AL facilities and nursing homes getting together with family and friends at least once in the last week (78.5% and 70.5%), but relatively few (33.6% of RC/AL residents and 16.2% of nursing home residents) had spoken on the telephone. Further, 31.5% of RC/AL residents versus 12.0% of nursing home residents had been outside often in the last week. The differences between RC/AL and nursing home residents for this finding was significant ($p = 0.021$).

The percentage of residents assessed for ability and preferences were similar, with roughly one half of residents professionally assessed in RC/AL facilities and two thirds in nursing homes. Families were more involved in assessment in nursing homes compared to RC/AL facilities (2.0 vs 1.6, $p = .037$). RC/AL facilities and nursing homes were similar in the number of activities available (7.5 vs 8.2 out of 10), and while staff encouragement (as reported by supervisors) of resident involvement was slightly greater in nursing homes ($p = .078$), RC/AL staff believed treatment was successful for a higher proportion of residents (63% vs 50%), ($p = .067$). The majority of staff in both settings felt adequately trained.

Table 2 shows the distribution of characteristics related to lower activity involvement and the associated odds ratios and 95% confidence intervals. Lower activity involvement was more common in those with severe or very severe cognitive impairment, but this association was limited to nursing home residents and remained significant with adjustment for other resident characteristics (OR = 3.83; 95% CI = 2.69–5.45). Behavioral symptoms, depression, and ADL impairment were other resident characteristics associated with lower activity involvement, but the effects diminished in the adjusted model. Family involvement in assessing activities (OR = 0.86; 95% CI = 0.75–0.98), family social involvement (OR = 0.92; 95% CI = 0.87–0.97), and staff encouragement of activity involvement (OR = 0.32; 95% CI = 0.15–0.69) were all related to more activity involvement. Aside from cognitive impairment, there were no significant interactions between resident or facility characteristics and facility type (all were $p > .05$).

Discussion

The RC/AL facilities and nursing homes in this study did not differ in the number of activity types offered or in the level of involvement of residents with dementia. However, residents who self-reported were significantly more likely to indicate a higher number of activities *enjoyed* in RC/AL. In both settings, the residents who self-reported indicate a higher number of activities enjoyed compared to when staff reported for the larger sample. Other work has noted similarity in activity availability across settings (Zimmerman et al., 2003), but this is the first study to examine resident preferences, actual involvement of residents with dementia, and correlates of that involvement in both RC/AL facilities and nursing homes.

There were significant differences by facility type for activity involvement among residents who were more cognitively impaired: A higher percentage of

Table 1. Prevalence of Lower Activity Involvement and Relevant Components of Care in the Dementia Care Study Sample, by Setting

Activity Involvement	RC/AL ($N = 266$) % or M (SD)	NH ($N = 134$) % or M (SD)	p[a]
Prevalence of lower involvement			
Direct care provider report			
Involvement at or below median (9.0)	42.9%	56.0%	.125
PAS-AD score	9.8 (5.3)	8.3 (4.2)	.081
No. of 15 activities enjoyed	10.7 (3.4)	9.3 (4.2)	.025
Resident Report			
Involvement at or below median (9.0)	55.1%	42.9%	.491
PAS-AD score	9.1 (5.5)	10.0 (4.2)	.690
No. of 15 activities enjoyed	12.4 (2.7)	13.0 (2.0)	.319
Assessment			
Activity ability			
Activity director assessment	50.7%	77.1%	.355
Written or standardized assessment	34.3%	66.7%	.009
Activity preferences			
Professional assessment	53.1%	74.3%	.340
Written or standardized assessment	33.2%	54.3%	.062
Family involved in assessment	1.6 (1.4)	2.0 (1.3)	.037
Provisions and treatment			
No. of 10 types of available activities	7.5 (2.2)	8.2 (1.7)	.364
Staff encourages resident involvement	90.2%	97.6%	.078
Family involvement, social (hr/week)	4.3 (5.3)	4.7 (5.9)	.612
Perceived success (quite a bit or extremely)	63.2%	49.5%	.067
Training to facilitate activity participation[b]			
Staff feels adequately trained to assess preferences and abilities	77.5%	81.3%	.856
Staff feels adequately trained to help with participation	81.7%	82.1%	.378

Notes: RC/AL = residential care/assisted living; NH = nursing home; PAS-AD = Patient Activity Scale–Alzheimer's Disease. Lower activity involvement is defined based on a score below the median (9.0) on the PAS-AD. Except for number of activities available, all data are resident level and are for those residents for whom outcome data (i.e., activity involvement) are available. Direct care providers and residents (MMSE $\geq$ 10) provided data for the PAS-AD; supervisors reported on assessment, encouragement, and perceived success; administrators reported on activities available; feelings of training adequacy were reported by the one supervisor (or direct care provider, if supervisor data were missing) who was most involved in the resident's care; and level of family involvement (hr/week) was reported by resident's family. Due to missing data, N varies from 266 to 183 for residential care and assisted living and from 134 to 83 for nursing homes for care provider responses; for resident responses, $n = 78$ and $n = 21$, respectively.

[a]Adjusted for facility-level clustering using generalized estimating equations (exchangeable correlation matrix); p values are based on score statistics (Boos, 1992).

[b]Adequately is quite or extremely well trained.

nursing home residents compared to RC/AL residents with more severe cognitive impairment had lower activity involvement. Recognizing that these are adjusted activities, nursing home providers may gain insight from RC/AL facilities about how they are engaging these individuals in activities. Perhaps it is related to the social model of care philosophy that RC/AL facilities incorporate in their care practices.

Increased resident activity participation was associated with two measures of family involvement: the amount of time the family reports being socially engaged with the resident and the family's degree of involvement in assessing resident preferences as reported by the supervisor. Nursing home families were more likely to be involved in the assessment process (2.0 vs 1.6, $p = .037$). There is indication that it may be worthwhile to include families in the assessment process. In addition, when staff reported encouraging resident participation, the odds were higher that residents were more involved in activities. Of course, in a cross-sectional study such as this, a causal ordering of events cannot be established. It is possible that staff encouragement and family involvement correlates with more social residents. The fact that family involvement and staff encouragement relate to activity involvement could be tested to target resident participation in some of the activities with low involvement mentioned in this article (going outside, shopping, and talking on the telephone with family and friends). That this effort might be worthwhile is supported by reports that these are viewed by many residents as key to quality of life (Dobbs, 2004).

Nonetheless, one limitation of this study is worth reporting. It relied on staff data for the outcome variable (because only a small number of residents were able to respond for themselves). While the measure used was designed for proxy report, and while proxies are useful when participants cannot respond for themselves, there is no gold standard against which to compare their reports.

Table 2. Characteristics Associated With Lower Activity Involvement, Unadjusted and Adjusted

Characteristics	Distribution of Characteristic as % or *M* (*SD*)		Relationship Between Characteristic and Presence of Lower Activity	
	Higher Activity Involvement ($n = 174$)	Lower Activity Involvement ($n = 155$)	Unadjusted OR (95% CI)	Adjusted[a] OR (95% CI)
Resident[b]				
Cognitive status				
Mildly impaired	17.8%	5.8%	1.00	1.00
Moderately impaired	28.7%	22.6%	1.64 (0.66–4.07)	1.37 (0.48–3.88)
Severe or very severe				
Cognitive impairment[c]				
RC/AL	50.0%	61.9%	1.42 (0.77–2.63)	1.09 (0.61–1.93)
Nursing home	62.5%	87.9%	4.82 (3.74–6.22)	3.83 (2.69–5.45)
Behavioral symptoms	55.0%	63.0%	1.65 (1.09–2.49)	1.35 (0.84–2.16)
Depressed	21.9%	26.7%	1.61 (1.08–2.40)	1.31 (0.85–2.02)
High pain	25.7%	15.2%	0.69 (0.40–1.19)	0.69 (0.39–1.23)
Immobile	12.8%	12.5%	0.97 (0.46–2.09)	0.76 (0.31–1.84)
Low food intake	52.9%	53.6%	0.80 (0.55–1.17)	0.81 (0.54–1.23)
Low fluid intake	50.9%	53.6%	0.83 (0.58–1.21)	0.80 (0.56–1.16)
ADL limitations	3.4 (2.5)	4.6 (2.3)	1.20 (1.07–1.35)	1.14 (1.00–1.28)
Facility				
Facility type				
Nursing home	27.6%	37.4%	1.00	
RC/AL				
< 16 beds	16.1%	12.3%	0.56 (0.23–1.41)	0.79 (0.31–1.96)
Traditional	25.9%	17.4%	0.47 (0.16–1.39)	0.68 (0.21–2.26)
New-model	30.5%	37.4%	0.85 (0.35–2.06)	1.16 (0.46–2.91)
For-profit ownership	77.0%	60.6%	0.53 (0.25–1.10)	0.58 (0.28–1.22)
Size (per 10 beds)	83.0 (48.9)	83.6 (58.4)	1.01 (0.94–1.07)	1.00 (0.93–1.06)
Assessment of activity involvement				
Activity ability assessed				
Professional	58.3%	61.4%	1.06 (0.63–1.78)	1.13 (0.60–2.13)
Written or standardized	41.7%	49.0%	1.07 (0.56–2.04)	1.13 (0.57–2.25)
Activity preferences assessed				
Professional	61.3%	59.7%	0.81 (0.44–1.49)	0.87 (0.44–1.71)
Written or standardized	36.9%	44.4%	1.10 (0.64–1.88)	1.12 (0.63–1.97)
Family involved in assessment	1.8 (1.4)	1.6 (1.4)	0.89 (0.78–1.01)	0.86 (0.75–0.98)
Provisions and treatment for activity involvement				
No. of 10 types of activities available	7.8 (1.9)	8.0 (1.8)	1.01 (0.81–1.27)	0.97 (0.77–1.22)
Staff encourages resident involvement	95.6%	89.0%	0.31 (0.13–0.74)	0.32 (0.15–0.69)
Family involvement, social (hr/week)	4.9 (6.0)	3.2 (4.1)	0.93 (0.88–0.98)	0.92 (0.87–0.97)
Perceived success	62.7%	54.5%	0.75 (0.42–1.35)	0.84 (0.47–1.50)
Training to facilitate activity participation[d]				
Staff feels adequately trained to assess preferences and abilities	82.2%	81.2%	0.77 (0.41–1.47)	0.82 (0.44–1.53)
Staff feels adequately trained to help with participation	84.5%	81.8%	0.78 (0.42–1.42)	0.87 (0.43–1.76)

Notes: RC/AL = residential care/assisted living; ADL = activity of daily living. For the table, $N = 329$. Lower activity involvement is assessed by direct care provider report on the Patient Activity Scale–Alzheimer's Disease and is based on the median value in the distribution (< 9). Except for facility demographics and number of activities, all data are resident level and are of those residents for whom outcome data (i.e., lower activity involvement) and supervisor data (required for adjustment) are available. Due to missing data, n varies from 137 to 174 for higher activity involvement and from 127 to 155 for lower activity involvement.

[a]Adjusted for gender, race, age, cognitive status, 11 comorbidities (congestive heart failure; high blood pressure or hypertension; myocardial infarction, heart attack, angina, arrhythmias, or other heart problem; diabetes; kidney disease or renal insufficiency; arthritis, rheumatism, degenerative joint disease, lupus, erythematosis, or scleroderma; fractured bones or osteoporosis; cerebrovascular disease, stroke, TIA, or CVA; hemiplegia or paraplegia; asthma, emphysema, bronchitis, or COPD; schizophrenia, manic-depressive disorder, or mental retardation), and impairments in 7 activities in daily living (bed mobility, transferring, locomotion, dressing, eating, toilet use, and hygiene), unless that is the predictor under study.

[b]Cognitive status is based on the Mini-Mental State Exam (MMSE) or Minimum Data Set–Cognition (MDS-COGS) scores, if the MMSE is missing ($N = 54$). Cutpoints for mild, moderate, severe, and very severe (MMSE) are ≥ 18, 11–17, 3–10, 0–2, respectively; MDS-COGS cutpoints are 0–1, 2–3, 5–8, 9–10. Behavioral symptoms: any behaviors at least weekly on the Cohen-Mansfield Agitation Inventory; depression: ≥ 7 on the Cornell Scale for Depression in Dementia; pain: ≥ 2 on the Philadelphia Geriatric Center Pain Intensity Scale; immobility: no position or location changes observed during 3 hr of observation; low food intake and low fluid intake: consumed ≤ 1/4 of meal and drank ≤ 8 oz. on Structured Meal Observation. Cognitive status and the MMSE are from resident report; depression, behavioral symptoms, pain, and ADL function are from supervisor report; and immobility and intake are based on direct observation.

[c]The association between cognitive impairment and activity involvement is reported separately for residential care and /assisted-living facilities and nursing homes because there is a significant Facility type × Cognitive impairment interaction ($p = .007$).

[d]Staff feelings of training adequacy are reported by the one supervisor (or direct care provider, if supervisor data are missing) who is most involved in the resident's care; "adequately" is quite or extremely well trained.

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Received June 24, 2004
Accepted April 15, 2005
Decision Editor: Richard Schulz, PhD