

Families Filling the Gap: Comparing Family Involvement for Assisted Living and Nursing Home Residents With Dementia

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Purpose: The purpose of this study was to compare the sociodemographics, self-rated health, and involvement levels of family caregivers of residents with dementia in residential care/assisted living (RC/AL) versus nursing home settings. **Design and Methods:** We conducted telephone interviews with the family caregivers most involved with 353 residents of 34 residential care and 10 nursing home facilities. We measured involvement by caregiver self-report of monthly out-of-pocket spending, involvement and burden ratings, and the frequency of engaging in eight specific care activities. Open-ended questions elicited areas in which caregivers preferred different involvement and ways the facility could facilitate involvement. **Results:** Nursing home caregivers rated their health poorer than RC/AL caregivers, but there were no sociodemographic differences between the two. RC/AL caregivers rated both their perception of involvement and burden higher and engaged more frequently in monitoring the resident's health, well-being, and finances than did nursing home caregivers, although the reported time spent per week on

care did not differ. **Implications:** RC/AL and nursing home caregivers to residents with dementia may tailor their care to fit the needs of the resident and setting. Results are discussed in relation to the Congruence Model of Person-Environment Fit.

Key Words: Long-term care, Assisted living, Social support

Introduction

Families play an important role in the quality of care and quality of life of America's institutionalized elders. Among nursing home residents, family involvement has been associated with better psychological and psychosocial well-being (Greene & Monahan, 1982; McCallion, Toseland, & Freeman, 1999) and higher provision of certain types of treatment (Anderson, Lyons, & West, 2001). Higher life satisfaction has been reported for residential care-assisted living (RC/AL) residents who receive at least monthly visits from family (Mitchell & Kemp, 2000), and the quality of the social environment is important to resident satisfaction and feeling "at home" (Cutchin, Owen, & Chang, 2003; Sikorska, 1999).

Research suggests that it is especially vital to keep family members involved in the care of residents with dementia because they provide the historical background for residents, make care decisions, provide personal and social care, and are advocates for elders with dementia (McCallion et al., 1999; Port et al., 2001; Tornatore & Grant, 2002; Yamamoto-Mitani, Aneshensel, & Levy-Storms, 2002). However, many families try to avoid or delay nursing home care for their relatives with dementia by use of alternative forms of long-term care (Meyer, 1998), such as RC/AL settings. Given the value of family involvement for residents with dementia, an important component

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in the placement decision should be the degree to which families are involved in care.

There is reason to expect family involvement to differ between RC/AL settings and nursing homes. Resident demographics, health care needs, and financing differ between these settings, with RC/AL facilities generally offering less intensive care to healthier and younger residents (Zimmerman et al., 2003) who are more commonly private pay than their nursing home counterparts. RC/AL facilities also market themselves as more homelike, permitting greater autonomy, choice, and privacy than nursing homes. Finally, the definition of assisted living of the Assisted Living Federation of America (ALFA, 1998) includes involvement of "the resident's family, neighbors, and friends" (p. 6). Thus RC/AL facilities may attract a different sociodemographic sector, include families to a greater degree in care, or include them in ways that are different than the involvement of families in nursing homes.

The current study addresses the need for basic information about family involvement for RC/AL residents with dementia and also how it compares to family involvement in nursing homes. Comparisons are made in terms of caregiver sociodemographics, self-reported health, and involvement. Involvement in care encompasses a wide range of activities, including hands-on care, financial monitoring, advocacy, care planning and decision making, family events and councils, interaction with facility staff, providing a connection with the past, social visits, and other forms of personal contact. While most previous research on family involvement in long-term care has used a single snapshot measure of involvement, namely visitation frequency (Port et al., 2003), this study includes a broad range of general and specific measures of involvement in order to provide a clearer picture of the similarities and differences for family caregivers in these settings. Because family involvement relates to resident needs and abilities (Barry & Miller, 1980; Yamamoto-Mitani et al., 2002), we conducted comparisons of involvement with and without controlling for resident and caregiver characteristics. We have also presented a comparison of areas in which caregivers would like more involvement and caregivers' suggestions for facilitating involvement.

Design and Methods

Sample

Participants in the Dementia Care project, a study of individuals with a diagnosis of dementia living in 35 RC/AL facilities and 10 nursing homes in four states (Florida, Maryland, New Jersey, and North Carolina), comprised the sample. Using the typology of the Collaborative Studies of Long-Term Care (CS-LTC), four types of facilities were enrolled: RC/AL facilities with fewer than 16 beds, traditional

facilities, new-model facilities that tend to provide nursing care and/or cater to an impaired population, and nursing homes. RC/AL referred to all facilities licensed by the states at a nonnursing home level of care that provide room and board, assistance with activities of daily living (ADLs), personal care, medication administration, and 24-hour supervision or oversight. For purposes of efficiency, CS-LTC facilities with fewer than 2 eligible residents (in facilities with fewer than 16 beds) or 13 eligible residents (in all other facilities) were excluded. Eligible facilities were enrolled in a manner that maintained stratification across states and by facility type and that maximized the number of residents from smaller facilities. Twenty-two facilities (33%) declined to participate. These facilities did not differ from participating facilities in reference to type, size, or state. Of the final sample of 45 facilities, 14 (31%) had fewer than 16 beds, 11 (24%) were traditional facilities, 10 (22%) were new-model facilities, and 10 (22%) were nursing homes. Twelve facilities were from North Carolina, and all other states had 11 facilities.

Within study facilities, participants were randomly selected from residents aged 65 and older with a dementia diagnosis, to a maximum of four for smaller RC/AL facilities and 19 for all other facilities. Of 575 eligible residents approached for consent, 421 (73%) agreed to participate, 66 (11%) refused, and 88 (15%) could not provide consent and had unreachable family members. If available, one family member or friend who was most involved in care decisions for the resident and who visited or spoke with the resident or staff on his or her behalf was recruited by the study. These analyses were limited to the 353 participants for whom a family caregiver completed an interview and who resided in 34 RC/AL facilities and all 10 nursing homes. There was a mean of 11.9 caregivers from each nursing home (range 3–18) and a mean of 6.9 caregivers from each residential care facility (range 2–18). Data from residents and staff also were collected, as noted below. Further details about the CS-LTC and the sample and data collection for this study are provided in the introduction to this issue (Zimmerman, Sloane, Heck, Maslow, & Schulz, 2005).

Family Caregiver Interview

Family caregiver interviews lasted about 20 minutes and were conducted over the telephone between September 2001 and February 2003. In addition to providing sociodemographics (age, gender, race, kinship status, work status, education, income, number of dependents, months providing care, minutes to the facility), caregivers rated their current health (1 = poor, 2 = fair, 3 = good, 4 = very good, 5 = excellent). We rated income on a 1 to 5 scale ($\leq 10,000$; $> 10,000$ to $< 20,000$; $> 20,000$ to $< 30,000$;

> 30,000 to < 40,000; and > 40,000). In analyses, we dichotomized kinship into immediate kin (spouse, sibling, or child) versus extended kin and friends.

We measured involvement by having caregivers estimate the following:

1. Monthly out-of-pocket expenses spent toward resident care. These included facility rates, medical care costs, extras, transportation costs, and any additional services paid for, but did not include the resident's own out-of-pocket costs.
2. How much time per week the family caregiver spent visiting or talking with the resident for primarily social reasons.
3. Their current involvement, self-rated (1 = very high, 2 = high, 3 = average, 4 = low, 5 = very low).
4. Whether they preferred a different level of involvement than they had currently (1 = prefer to be much more involved, 2 = more involved, 3 = no change, 4 = less involved, 5 = much less involved).
5. How burdened they felt in caring for the resident (0 = not at all, 1 = a little bit, 2 = moderately, 3 = quite a bit, 4 = extremely).
6. Involvement in eight specific activities: visiting in person or taking the resident out; making phone calls or writing letters to the resident; doing the resident's laundry; assisting with ADLs (e.g., bathing, toileting, eating, dressing); assisting with instrumental ADLs (IADLs; e.g., shopping, errands, and cleaning); monitoring medical care (talking to staff, physician, or nurses about diet, medications, and health problems); monitoring well-being (speaking with staff about the resident's nonmedical care); and monitoring the resident's finances. Participants provided answers in terms of the number of times per day, week, month, or year, which were converted to monthly rates for analyses.

For caregivers who preferred a different level of involvement, we asked a follow-up, open-ended question: "In what way would you like to be more/less involved? What specific activities would you prefer to be doing more/less of?" Caregivers also were asked whether the facility should help them to be more involved in care. Of those who responded positively, we asked, "If the facility wanted to help you to be more involved in care, what could they do to help you with this?" Four coders placed responses to these open-ended questions into various categories. Initial coder agreement was 95% for the first question and 93% for the second question, and 100% consensus was obtained following coder discussion.

Resident Variables

We obtained functional status via interview with the care supervisor using the Minimum Data Set-

ADL (MDS-ADL; Morris, Fries, & Morris, 1999), as the number of seven activities in which the resident was not independent (bed mobility, transfer, locomotion, dressing, eating, toilet use, hygiene). Comorbidities was a count of the number of 11 conditions a resident had, including 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; and schizophrenia, manic-depressive disorder, or mental retardation. We assessed resident cognition by interview with the resident using the Mini-Mental State Exam (MMSE; Folstein, Folstein, & McHugh, 1975) and by interview with the care supervisor using the MDS Cognition Scale (MDS-COGS; Hartmaier, Sloane, Guess, & Koch, 1994). We classified cognitive deficits using established MMSE cutpoints (≥ 17 , 10–16, 3–9, 0–2) or MDS-COGS cutpoints if the MMSE was missing (0–1, 2–4, 5–6, 7–10).

Analytic Framework

We computed descriptive statistics of caregiver and resident characteristics separately for RC/AL facilities and nursing homes. We conducted statistical comparison of settings for population means (or proportions) of these characteristics using the generalized estimating equations (GEE) procedure to fit linear (or logistic) models for continuous (or binary) characteristics (Liang & Zeger, 1986; Preisser & Koch, 1997). Specifically, we used GEE based on an exchangeable correlation structure within facilities (clusters) to estimate means (and empirical or "robust" standard errors) by facility type while accounting for the correlation of outcomes among residents who cluster in facilities. It is well known that for a cluster-level covariate, such as facility type, failure to account for positive intracluster correlation in statistical comparisons of individual-level (resident-level) data results in inflation of Type I error (and p values that tend to be too small; Liang & Zeger, 1993). In a similar spirit, we conducted population-averaged comparison of measures of family involvement between residential care facilities and nursing homes with the general linear model with correlated errors (Diggle, Heagerty, Liang, & Zeger, 2002), specifying a compound symmetric correlation structure within facilities. We constructed two regression models for each involvement measure. The first model included only a fixed effect for facility type; we adjusted the second model for resident (cognitive function, ADL impairment, number of comorbid conditions, and age) and

Table 1. Characteristics of Family Caregivers in Residential Care/Assisted Living and Nursing Home Settings

Variable	RC/AL		NH	
	<i>n</i> (%)	<i>X</i> (<i>SD</i> ; Range)	<i>n</i> (%)	<i>X</i> (<i>SD</i> ; Range)
Caregivers				
Age	234	59.1 (12.0; 28–95)	119	58.7 (11.4; 37–87)
Gender				
Male	81 (34.6)		40 (33.6)	
Female	153 (65.4)		79 (66.4)	
Race				
Black	11 (4.7)		19 (16.0)	
White	222 (95.3)		100 (84.0)	
Kinship				
Non-1 st degree	54 (23.1)		25 (21.0)	
1 st degree	180 (76.9)		94 (79.0)	
Work				
Full or part time	135 (57.7)		67 (56.3)	
Not working	99 (42.3)		52 (43.7)	
Years of education	234	15.5 (2.8; 4–26)	119	14.8 (3.0; 4–24)
Income	193	4.4 (.96; 1–5)	104	4.1 (1.31; 1–5)
Self-rated health*	234	3.8 (1.04; 1–5)	119	3.5 (0.91; 1–5)
No. of dependents	234	.67 (1.11; 0–5)	118	.59 (0.91; 0–3)
Months providing care	215	81.8 (75.3; 2–468)	119	103.4 (94.7; 3–504)
Minutes to the facility	232	55.4 (114.2; 1–500)	119	52.1 (93.1; 1–500)

Notes: RC/AL = residential care/assisted living; NH = nursing home. For RC/AL, *n* = 193–234; for NH, *n* = 104–119.
**p* < .05.

caregiver (health, income, education, age, and race) characteristics. Based on each fit, we computed model-predicted means of involvement measures and their cluster-adjusted standard errors for RC/AL and nursing homes to provide statistical comparisons of facility type. Because a substantial number of caregivers (*n* = 45) were missing data for family income but had data for all other residents and caregiver covariates, we used stochastic regression imputation based on a proportional odds regression model to generate an imputed value for income for these caregivers (Little & Ruben, 2002).

Results

Comparisons of Residents Included and Excluded From Analyses

Of the total sample enrolled in the Dementia Care project (*n* = 421), there were no significant differences between residents who did (353) and did not (68) have a family interview in terms of age, functional status, cognitive function, comorbidity, or facility type.

Caregiver Characteristics

Table 1 displays sample characteristics separately for RC/AL and nursing home caregivers. For the entire sample, the majority were female (65.7%) and White (91.5%), and the mean age was close to 60. The largest group was daughters or daughters-in-

law (43.3%), followed by sons or sons-in-law (24.7%) and spouses (9.3%), and a small proportion (1.4%) was friends or neighbors. The RC/AL and nursing home caregivers differed significantly only in self-rated health, with RC/AL caregivers rating their health higher than nursing home caregivers (*p* = .026).

Resident Characteristics

There were no differences in resident age or number of comorbidities. RC/AL residents had a mean age of 85.1 (*SD* = 6.9; range 67–100), and nursing home residents had a mean age of 84.2 (*SD* = 7.1; range 67–101). RC/AL residents averaged 2.0 (*SD* = 1.5, range 0–7) comorbidities, compared to 2.4 (*SD* = 1.6, range 0–7) for nursing home residents. However, facility residents had significantly fewer areas of ADL impairment (3.4; *SD* = 2.4, range 0–7) than did nursing home residents (2.4; *SD* = 1.8, 0–7; *p* = .001). RC/AL residents were also significantly less cognitively impaired, having 13.3% mild, 28.8% moderate, 23.8% severe, and 29.2% very severe compared to nursing home residents with 8.0% mild, 13.3% moderate, 22.1% severe, and 56.6% very severe (*p* = .003).

General and Financial Involvement.—As shown in Table 2, RC/AL and nursing home caregivers reported spending approximately \$500 and \$400 dollars per month, respectively, on out-of-pocket costs. They also spent an average of 259 minutes

Table 2. Involvement for Family Caregivers of Residential Care/Assisted Living and Nursing Home Residents

Involvement Type	Unadjusted				Adjusted ^a			
	<i>M</i>	(<i>SE</i>)	<i>t</i> stat	<i>p</i>	<i>M</i>	(<i>SE</i>)	<i>t</i> stat	<i>p</i>
General measures of involvement								
Monthly out-of-pocket costs								
RC/AL	501.94	114.39	−0.47	.643	356.14	166.04	−0.65	.521
NH	401.33	182.67			215.51	213.13		
Weekly minutes spent visiting or talking								
RC/AL	259.12	23.94	−0.51	.616	283.53	41.87	−0.55	.582
NH	237.53	35.34			257.77	48.23		
Self-rated involvement								
RC/AL	2.31	0.05	4.46	< .001	2.12	0.16	2.82	.005
NH	2.72	0.08			2.62	0.18		
Involvement preference								
RC/AL	2.80	0.04	−3.57	< .001	2.73	0.07	−1.37	.177
NH	2.57	0.05			2.64	0.07		
Overall burden								
RC/AL	1.15	0.05	−2.48	.018	1.13	0.13	−2.55	.015
NH	0.92	0.08			0.80	0.14		
Involvement in specific activities (times per month)								
Visit or take resident out of facility								
RC/AL	9.72	0.68	−0.73	.473	10.82	1.30	−1.36	.182
NH	8.85	0.98			8.94	1.45		
Call on phone or write letters								
RC/AL	4.69	0.86	−2.16	.037	6.32	1.27	−0.96	.344
NH	1.37	1.28			5.05	1.41		
Laundry								
RC/AL	1.58	0.39	0.50	.620	2.38	0.61	0.26	.798
NH	1.93	0.58			2.55	0.68		
ADL assistance								
RC/AL	2.10	0.56	1.70	.097	2.02	0.94	0.55	.584
NH	3.82	0.84			2.62	1.11		
IADL assistance								
RC/AL	2.14	0.25	−2.20	.034	2.44	0.41	−1.54	.131
NH	1.12	0.39			1.70	0.49		
Medical monitoring								
RC/AL	5.81	0.86	−1.62	.114	6.26	1.70	−2.12	.040
NH	3.38	1.23			2.49	1.87		
Monitor well-being								
RC/AL	6.25	0.53	−1.31	.198	6.91	0.94	−2.32	.026
NH	5.04	0.76			4.55	1.06		
Monitor Finances								
RC/AL	5.27	0.44	−3.98	< .001	5.20	0.88	−3.98	< .001
NH	2.24	0.63			1.80	0.94		

Notes: RC/AL = residential care/assisted living; NH = nursing home; ADL = activity of daily living; IADL = instrumental activity of daily living. For the table, *n* = 280–290. Income values were imputed using stochastic regression imputation based on a proportional odds regression model (Little & Rubin, 2002).

^aAdjustment for resident cognitive function, ADL impairment, number of comorbid conditions and age, and for caregiver health, income, education, age, and race.

(roughly 4.2 hr) and 237 min (4.0 hr) a week visiting or talking with the resident, respectively. These differences were not statistically significant. RC/AL caregivers rated their involvement and burden significantly higher than nursing home caregivers, and this difference persisted with adjustment for caregiver and resident characteristics. Finally, without adjustment, nursing home caregivers were more likely to prefer increased involvement; however this difference no longer reached significance following adjustment.

Frequency of Engagement in Specific Care Activities.—Prior to adjustment, the RC/AL caregivers made more phone calls to residents and more frequently assisted with IADLs; however, these differences were no longer statistically significant following adjustment for resident and caregiver characteristics. After adjustment, the caregivers to RC/AL residents engaged more frequently in medical monitoring, financial monitoring, and monitoring of the resident’s well-being. We found no differences before or after adjustment for assisting with ADLs, visiting, or doing laundry. The unadjusted percent-

age of RC/AL and nursing home caregivers (respectively) who reported ever engaging in each specific activity was: visit or take out, 98.3% and 96.6%; phone call or letter, 42.4% and 28.6%; do laundry, 25.4% and 26.1%; assist with ADLs, 29.7% and 36.2%; assist with IADLs, 77.4% and 58.1%; monitor medical care, 90.8% and 92.4%; monitor well-being, 92.1% and 88.1%; and monitor finances, 90.4% and 75.4%.

Areas in Which Different Involvement is Desired.—Of the total sample, 4.3% preferred less involvement, 27.2% preferred more, and the remainder (68.6%) preferred no change. We asked those preferring greater involvement to specify the areas in which they would like to be more involved. For RC/AL caregivers, the largest group (41%) wanted to take the resident out more often to visit friends and family or for entertainment (e.g., shopping, dining). Typical responses were, “I’d like to take her places more if I had the time” and “Getting her out more, talking to her sisters.” The next largest group (36%) stated only that they wanted to spend more time with the resident and did not specify further. Less frequent responses included monitoring care (7%), providing personal care (7%), having the resident come home to live with them (7%), and involvement in facility-offered activities (2%). For nursing home caregivers, the largest group (41%) wanted to spend more time with the resident without specifying further. The two next largest groups, at 22% each, wanted more involvement in monitoring care or taking the resident out of the facility. Less frequently cited responses included taking part in more activities (14%) and involvement in personal care (3%). Fifteen caregivers desired less involvement. When asked in what areas they sought to decrease involvement, we obtained 11 responses. Due to the low number of responses, we have not presented percentages; however, there appeared to be a trend for nursing home caregivers to prefer less involvement in personal care, while RC/AL caregivers preferred less involvement in paperwork and financial monitoring.

Areas in Which Caregivers Desire Assistance in Being Involved.—Approximately one quarter of the sample (22.4%) felt that the facility could do more to help them be more involved in care. Sixty-eight caregivers provided responses when we asked them to identify specific ways facilities could assist them; because the categories were identical and the proportions highly similar between the 44 RC/AL and 24 nursing home caregivers, we combined the results. Close to one half of respondents (44%) sought more frequent communication from the facility in terms of regular meetings, phone calls, or more consistent notification of change in the resident’s status (e.g., “Call once or twice a week,

or some kind of contact that is more often”; “Better communication about his behavior—more information regarding his physical health”). One fifth of these requests specifically asked for a regular newsletter. The next largest group (13%) wanted organizational or administration changes such as more responsive staff, greater continuity of care among staff, improvements in staff numbers or qualifications, and more openness with families about problems at the facility. The same proportion (13%) felt the facility could be doing more, but did not have a specific suggestion. Other recommendations included greater involvement in activities at the facility (7%), opportunities to meet with other residents’ families (7%), advice and encouragement regarding how they could be more involved (e.g., “Tell me what I need to do more because I don’t know,” “Maybe they could encourage me a little more”; 7%), more convenient scheduling of meetings (4%), and more interaction with physicians (3%).

Discussion

With the exception of self-rated health, we found no differences between the family caregivers to RC/AL and nursing home residents across several health and sociodemographic characteristics. Whether RC/AL caregivers actually have better health than their nursing home counterparts or tend to rate their health more positively, a relationship between the caregiver’s self-perceived health and the long-term care setting is understandable. In most cases, and especially when the resident has dementia, family members conduct the search for and ultimately select the long-term care setting (Castle, 2003). The higher level of care in nursing homes may be preferred when the family caregiver’s own health limits his or her ability to assist the resident with IADLs and other tasks provided for less in RC/AL care.

Examining the more detailed level of specific activity engagement suggests that these caregivers were tailoring their involvement to the specific abilities of the resident in his or her setting. For example, RC/AL caregivers more frequently contacted the resident via telephone or letter, provided assistance with IADLs, and monitored finances. Higher rates of calling and writing and assisting with IADLs likely reflect the higher functional ability of RC/AL residents, an interpretation supported by the finding that these comparisons lost significance after adjustment for resident health and function. The higher proportion of private pay clients in RC/AL and the variable cost structures of many facilities no doubt increase the amount of attention that families must give to the resident’s financial situation.

We were particularly struck by the finding that RC/AL caregivers monitored the residents’ medical status and well-being more frequently, despite a lack

of differences in visitation or time spent caring. By design, nursing homes provide more monitoring than RC/AL facilities. Thus, a resident placed in a nursing home may be viewed by family as receiving sufficient, or nearly sufficient, monitoring; leaving the family caregiver to devote more effort to other aspects of caring, such as providing entertainment or simply being with the resident. The same resident placed in an RC/AL facility may be viewed by family as receiving insufficient monitoring to maintain safety and/or well-being. In these instances, our data suggest that the caregiver steps in to make up the difference, checking the resident's medications, safety, mood, or other care needs depending on the resident's particular area(s) of vulnerability.

This does not imply that RC/AL facilities need to increase their monitoring role. This would defeat the purpose of these facilities as less restrictive alternatives to nursing homes; further, most residents probably prefer family, rather than staff, oversight. Research comparing RC/AL facilities and nursing homes on important clinical outcomes such as health and mental health, well-being, pain and discomfort, functioning, and staff-resident interaction has generally found few differences (Frytak, Kane, Finch, Kane, Maude-Griffin, 2001; Pruchno & Rose, 2000; Rose & Pruchno, 1999; Sloane et al., 2005, this issue). While additional research is needed, our findings support a view that the apparent lack of differences in clinical outcomes between RC/AL and nursing homes can be at least partially attributed to the diligent efforts of caregiving families. Likewise, to the extent that the lower costs of RC/AL are attributable to fewer staff and regulations, families may help make those lower costs possible.

This leads to an interesting twist on the well-known congruence model of person-environment fit (Kahana, 1982). The congruence model posits that individuals function optimally when environmental demands are appropriate to a person's abilities. The nursing home environment provides a high level of care that minimizes demands on the resident. In the RC/AL environment, the bar is set higher, so to speak, placing more demands on the resident. While the person-environment fit may be ideal for a proportion of residents in each facility type, there are likely nursing home residents who could function adequately with more environmental demands and RC/AL residents who need extra assistance. Families and staff in nursing homes report tensions when families interfere to too great a degree in the resident's care (Duncan & Morgan, 1994; Friedemann, Montgomery, Maiberger, & Smith, 1997), but the more flexible system of care provided by RC/AL facilities may tolerate (and perhaps even welcome) family "interference." As a result, RC/AL residents may enjoy the benefits of more independent living without assuming all of the additional risk such freedoms entail. In the context of RC/AL settings,

person-environment fit may more accurately be described as "person-family-environment fit."

However, the higher level of monitoring provided by RC/AL caregivers appears to come at a price. Both with and without adjustment, these caregivers rate their involvement and burden higher than nursing home caregivers. Prior to adjustment, they were also less likely than nursing home caregivers to prefer greater involvement. Again, even though these caregiver groups report spending similar amounts of time on visits, they seem to experience that time differently. The RC/AL caregivers in our study felt more involved and more burdened than the nursing home caregivers, probably as a function of the greater personal responsibility they assume in order to maintain the resident's safety, well-being, and financial stability.

This is not to say that RC/AL caregivers want less involvement. When asked, only a very small percentage of the total sample (4.3%) preferred less involvement. But even if most wanted to increase (27.2%) or maintain (68.6%) their current level of involvement it should not be concluded that the caring situation for these families could not be improved. Most family caregivers in this and other samples have jobs, many have additional dependents, and some have their own serious health concerns (Brody, Dempsey, & Pruchno, 1990; Dempsey & Pruchno, 1993; Duncan & Morgan, 1994; Farber, Brod, & Feinbloom, 1991). Previous research has identified several factors related to higher family involvement, including closer kinship status, nonuse of Medicaid, and shorter duration of stay in the facility (Bitzan & Kruzich, 1990; Greene & Monahan, 1982; Port et al., 2001; Yamamoto-Mitani et al., 2002). Noting that these factors do not lend themselves well to improvement through intervention, recent research has identified more changeable barriers to involvement, including transportation difficulties, problematic family and staff relationships, and inadequate social support networks for caregivers (Port, 2004).

The open-ended questions in our study provide some direction for assisting family caregivers who desire greater involvement in care. As a group, nursing home caregivers were more focused on increasing involvement in facility-directed ways (e.g., facility-based activities and monitoring care) while RC/AL caregivers sought less facility-directed involvement, such as taking the resident out and providing care at home. At the same time, it is clear that the overall desire among these caregivers, regardless of setting, is to spend more time with the resident. Many caregivers acknowledged a need for more assistance from the facility but could not define that need. This finding, combined with those family caregivers who requested more advice and encouragement from the facility, attests to the need for families to receive more appreciation and education concerning the important role they play

in preserving the well-being of their loved ones (Laitinen & Isola, 1996). Additional research is needed toward understanding caregiver's desires for more and less involvement.

As with all studies, limitations must be acknowledged. Caregivers who agreed to participate may have been those who were more involved (Farber et al., 1991). However, there is no reason to suspect participation biases by facility type, as caregiver participation rates for RC/AL facilities and nursing homes did not differ. Therefore the comparison of involvement between facilities should be not be affected by the issue of participation. Self-reports of involvement could also lead to inflated estimates. While staff and resident reports of family involvement could have been used to collect these data, self-reported family involvement is the most commonly used approach (Port et al., 2003). Staff is not necessarily aware of family caregiver activities due to busy case loads and shift changes, and resident reporting is dependent on cognitive function, a critical issue in any study of residents with dementia. Also, neither staff nor residents could report accurately on caregiver tasks that take place away from the resident and facility, such as monitoring finances. Finally, the study may have had inadequate power to detect differences in variables that tended to cluster within facilities. Race may be one of those variables, considering that the p value approached statistical significance and differences have been found in the racial composition of RC/AL facilities versus nursing homes (Howard et al., 2002). Other possible examples for which a variable may have clinical significance even though it did not reach statistical significance include differences in out-of-pocket costs and minutes per week spent visiting or talking with the resident.

Despite these limitations, we note that the demographics as well as the visitation rates and duration of the nursing home caregivers in this sample are highly similar to previous nursing home family caregiver samples (Duncan & Morgan, 1994; Farber et al., 1991; Greene & Monahan, 1982; Ross, Carswell, & Dalziel, 2001; Whitlatch, Schur, Noelker, Ejaz, & Looman, 2001; Yamamoto-Mitani et al., 2002). The overall impression from this study is that while RC/AL residents with dementia may have more freedom than nursing home residents with dementia, their family caregivers feel somewhat less freedom compared to their nursing home counterparts. To the extent, then, that RC/AL facilities are successful in assisting America's elders to age in place, the families of these residents may be playing a critical role. Given willing and able family caregivers, this arrangement is probably the most desirable for all concerned. However, the contribution of families to these and other long-term care settings deserves more recognition and value within the larger society.

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