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Dying with Dementia in Long-Term Care

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Abstract

Purpose—To better understand the experiences and potential unmet need of persons with dementia who die in long-term care.

Design and Methods—After-death interviews were conducted with staff who had cared for 422 persons with dementia and 159 persons who were cognitively intact who received terminal care in US nursing homes (NHs) or residential care / assisted living (RC/AL) settings. Family caregiver interviews were conducted for 293 decedents.

Results—No differences were noted between decedents with and without dementia in terms of pain, psychosocial status, family involvement in care, advance care planning, use of most life-prolonging interventions, and hospice use. Dying residents with dementia, in comparison with nondemented, tended to die less often in a hospital, have less shortness of breath, receive more physical restraints and sedative medication, and use emergency services less frequently on the last day of life. Persons with dementia dying in RC/AL tended to have more skin ulcers and poorer hygiene care than nondemented persons in RC/AL. In comparison with persons dying with dementia in NHs, those in RC/AL settings tended to be restrained less often, to have emergency services called more often on the day of death, and to have family more satisfied with physician communication.

Implications—Overall, care for persons dying with dementia is not inferior to that of dying persons who are cognitively intact, and care for dying persons with dementia in RC/AL facilities is not inferior to that provided in NHs. However numerous specific areas for care improvement were noted.

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Keywords

End-of-life care; palliative care; nursing homes; assisted living; residential care facilities

INTRODUCTION

Each day approximately 1,000 nursing home (NH) residents and 500 residential care / assisted living (RC/AL) residents die (Centers for Disease Control, 2002; National Center for Assisted Living, 2001; Zimmerman et al, 2005). Given that more than one-half of NH and RC/AL residents have dementia (Magaziner et al., 2000; Zimmerman et al., 2007), long-term care facilities are a major site for end-of-life care of persons with dementia. Indeed, because of their prolonged need for high levels of care, it is estimated that 70% of persons with dementia spend their last days in residential long-term care (Mitchell et al., 2005). Therefore, the provision of end-of-life services for persons with dementia is a major component of long-term care.

It is likely that the end-of-life services required by persons with dementia differ from those of persons who die from other conditions. Dementia is slowly progressive over many years, and family and health care providers may not always view it as a terminal illness. Caregivers may overlook prognostic signs that otherwise could trigger end-of-life planning (Sachs et al., 2005), and even Medicare hospice guidelines may fall short of the prognostic information needed to understand the course of dementia (Schonwetter et al, 2003) Furthermore, persons with dementia often die from acute illnesses superimposed on dementia (e.g., pneumonia), rather than from the dementia alone. Thus, planning and preparation for end-of-life care for patients with dementia differs from illnesses better understood as terminal, such as end-stage organ failure or metastatic cancer. In addition, the presence of prolonged cognitive impairment can result in surrogate decision-makers who have varying levels of familiarity with individual patient preferences (Bradley et al., 1998).

Given the relative paucity of research data on this highly prevalent and complex population, a better understanding of the experience of persons with dementia who die in long-term care facilities is critical to providing optimal end-of-life care in these settings. A recent systematic review yielded only four clinical trials of palliative care approaches for this population (Sampson et al., 2005). Since then, Engel and colleagues have reported a study of end-of-life care for nursing home residents with advanced dementia in 13 Boston facilities, reporting that better family communication, improved comfort, avoidance of tube feeding and specialized dementia care were associated with greater family caregiver satisfaction (Engel et al., 2006). However, no large studies have examined the quality of end of life care in long-term care for dementia patients compared to those who die without dementia. Furthermore, studies of end-of-life care in RC/AL facilities are largely absent, in spite of the growing importance of this facility type in providing both dementia care and end-of-life care (Sloane et al., 2003).

Therefore, to better understand the experiences and potential unmet needs of persons with dementia who die in long-term care, and of the family members who care for them, we conducted and analyzed data from staff and family caregiver interviews regarding 581 persons who had lived in a NH or RC/AL community. Our conceptual and analytical framework represents expert opinion on the essential domains of the experience of dying and the provision of palliative care. Domains and variables represented by this framework are drawn from the work of the Alzheimer’s Association (2007), Ferrell (2005), Mitchell (2004), the National Consensus Project for Quality Palliative Care (2004), and Volicer et al. (2001). Table 1 summarizes the domains we evaluated.

Analyses sought to address two primary research questions: 1) How does the experience of dying and the provision of palliative care for long-term care residents with dementia and their families differ from that of those without dementia? 2) How does the experience of dying and the provision of palliative care for persons with dementia and their families differ depending on whether the decedent resides in a NH or RC/AL community?

METHODS

Study Sample

The data for these analyses were derived from a stratified random sample of 199 RC/AL communities and 31 NHs recruited from four states (Florida, Maryland, North Carolina, New Jersey). The facility cohort, known as the Collaborative Studies of Long-Term Care (CS-LTC), was initially established in 1996 and refreshed for this study to reflect attrition of old facilities and opening of new facilities between 1996 and 2002. The four study states were chosen to reflect the diversity of state policies towards RC/AL, in terms of licensure, structure, and process of care. Within each state, participating facilities were selected in four strata: NHs, RC/AL facilities with fewer than 16 beds, "new-model" RC/AL facilities (≥16 beds, built after 1987, and having one or more features suggesting the ability to care for an impaired population), and traditional RC/AL facilities (≥16 beds, not new-model). Further details on the facility categorization process in the CS-LTC are published elsewhere (Zimmerman et al., 2001).

Between July 2002 and January 2005, research staff telephoned participating facilities monthly to identify residents who had died. To achieve a sample size balance across facility sizes and types, the sample accrual period varied by facility type (shortest for NHs, longest for RC/AL facilities with <16 beds). These monthly telephone contacts identified all former facility residents who had died in the past month and met the study's inclusion criteria: a) having spent 15 of the last 30 days of life in a study facility, and b) having died no more than three days after leaving the facility.

For each identified death, research staff asked the participating facility to identify two individuals who would be approached for interviews: a) a staff respondent – defined as the facility staff member who had known the resident best and either provided or supervised direct care; and b) the family respondent – defined as the blood relative, legal guardian or friend who was most involved in care during the last month of life and had visited and/or spoken with the resident or a staff member at least once during the last month of life.

To recruit staff respondents, the project office contacted them by telephone and requested participation in the study interview. If the contacted staff member agreed to be interviewed, the interview was scheduled at a time that was convenient for the staff member. To recruit family respondents, letters were sent to family members approximately eight weeks following the resident's death, after which time the family respondent was contacted by telephone to schedule an interview.

Of the 1020 eligible deaths identified, interview data were collected on 792 decedents. These included staff interviews for 677 decedents and family interviews for 451. Both participating staff and family informants provided informed consent by telephone at the beginning of their interviews, using procedures approved by the Institutional Review Board of the University of North Carolina at Chapel Hill. Interviews lasted 45 to 90 minutes for family members and 30 to 45 minutes for staff members.

A decedent was defined as having died with dementia if the NH or RC/AL staff member who knew the individual best responded "yes" to both of the following questions: a) "Three months prior to death was [the decedent] an Alzheimer's type resident?" and b) "Was dementia a contributing factor to [the decedent's] death?" A decedent was defined as having died without dementia if the staff respondent answered "no" to both of the above questions. The 84 respondents (12.6%) for whom one question was answered "yes" and the other "no" (i.e., for whom dementia status was uncertain) were excluded from analyses, as were 12 for whom this information was incomplete. Thus, this paper reports staff-reported results on 581 decedents, of whom 422 are defined as having had dementia and 159 as having been cognitively intact during the last months of life. Family interview data were available for 293 (50.4%) of these residents.

Study Measures

Because the study sought to gather data on both the experience of dying and the provision of palliative care, our data collection strategy sought to obtain data from the source (i.e., staff or family respondent) who would be most capable of providing valid data in a given domain. Thus, staff interviews were used to characterize the following aspects of decedent end-of-life status: illness course, physical symptoms, behavioral symptoms and treatment, psychosocial status, care provision, and care of the imminently dying patient. Similarly, family interviews were the source of data on family involvement, communication with the residents and family, decision-making (including advance care planning), and satisfaction with care. In addition, data on demographic characteristics of the decedents (age, gender, race/ethnicity, marital status, religion, Medicaid status, and relationship to the family respondent) were also gathered from family interviews or facility staff, as appropriate. Table 1 provides an overview of the domains, variables, and sources used to gather data.

An established scale was used to evaluate physician-family communication, the seven-item Family Perception of Physician-Family Caregiver Communication (FPPCC) score (Biola et al., 2007). Items in the FPPCC include whether the family was kept informed, received information about what to expect, understood what the doctor was saying, discussed wishes for medical treatment, had the opportunity to ask questions, felt listened to, and felt understood; responses ranged from 0 (poor) to 3 (excellent) and had a Cronbach's alpha of 0.96.

Analytical Methods

We used simple descriptive statistics to characterize the sample with respect to facility type and state, resident demographics and relationship of family respondent, both overall and by dementia status. In order to compare those with and without dementia, we used logistic regression with dementia status as the binary dependent variable and the characteristic of interest as the single independent variable. Generalized estimating equations (GEE) were applied to the logistic regression in order to account for the clustering of residents within facilities (Diggle, Liang & Zeger 2002). We specified an exchangeable correlation matrix as the working correlation structure as is commonly done in clustered cross-sectional data such as these (Preisser & Koch 1997); the empirical "sandwich" estimators are robust to misspecification of the correlation matrix (Liang & Zeger 1986). Further, because the study design was stratified by facility type and because important aspects of dementia care may differ between NHs and RC/AL, we also compared the same factors for decedents with dementia and their families by type of long-term care setting. These analyses were also conducted using GEE applied to logistic regression models; however, here the measures of the end-of-life experience were the dependent variables (with a separate model for each), and dementia status and facility type (NH vs. RC/AL) were the two independent variables included in all models, with the models comparing facility type limited to the dementia group.

Because the relationship between dementia status and end-of-life care and family experiences may differ depending on the setting, we also tested a facility type by dementia status interaction term in each model. In almost all cases, this was not significant (p>0.05) and the interaction was dropped. Where there was evidence for interaction, the comparisons for dementia status were made separately for NH and RC/AL decedents.

To account for policy variation among states, and key resident characteristics that vary between NH and RC/AL, our statistical tests for differences were adjusted for state, decedent age, and functional status, with functional status operationalized as the number of ADL tasks (among transferring, walking and eating) in which the resident depended on personal assistance three months before his/her death. Due to our study making multiple comparisons, our discussion only draws conclusions regarding findings whose statistical tests were significant at p<0.01. All analyses were conducted using SAS Version 9.1.3.

RESULTS

Demographics

Table 2 provides demographic data on the 581 decedents in the study sample, overall and by dementia status. Just over half (54%) were from NHs; the mean length of stay in the long-term care facility from which they were recruited was 28.7 months. Study decedents were largely white and unmarried, predominantly female. Approximately three-quarters (73%) had dementia.

Gender, race/ethnicity, marital status, religion, Medicaid status, and length of stay did not differ by dementia status. However, persons with dementia were more likely to have been in a NH (p=0.006) and to have had a family informant who was a spouse or child (p=0.002). In addition, persons with dementia were on average 2.7 years older (p=0.019) and had greater ADL dependency (p<0.001).

Experience of Dying and Palliative Care: Dementia versus Non-Dementia

Table 3 displays data on the dying experience and palliative care received by decedents with and without dementia, as reported by facility staff, stratified by site of care (RC/AL facility or NH); Table 4 displays data from family respondent reports, also stratified by site of care. Within each table the first p-value column displays the adjusted p-value of the comparison between persons who died with dementia and those who died without dementia, regardless of site. The second p-value refers to the adjusted comparison across facility types only for those with dementia.

When staff reports of physical symptoms were examined (Table 3), no difference was noted between persons with and without dementia in reported levels of pain or effectiveness of pain treatment. Shortness of breath, however, was both more often present and more often inadequately treated among decedents without dementia (p=0.014). When reports of hygiene care were examined, an interaction was noted, in that care was reported to be significantly more effective for persons without dementia in RC/AL (p=0.004), whereas the opposite was noted for NHs (p=0.024). An interaction effect was also present in reports of skin ulcer prevalence; in RC/AL, skin ulcers were considerably more prevalent among persons with dementia (27% vs 10%; p=0.003), whereas in NHs no significant difference was present (p=0.566). Finally, it was noted that, across all settings and comparisons, use of physical restraints and sedative medications was more common among persons with dementia than those without.

When the use of life-sustaining and palliative interventions was compared, no significant differences were noted between demented and nondemented residents in use of nutritional supplements, intravenous fluids, feeding tubes, hospitalization, antibiotics, in-facility CPR, special attention to moving and positioning, or hospice use (Table 3). Facilities tended to more frequently call 911 on the last day of life for persons without dementia (p=0.006), and persons without dementia – particularly if RC/AL residents – were more likely to die in hospital than persons with dementia (p=0.005).

Domains reported by family informants (Table 4) demonstrated relatively few differences by dementia status. Across all aspects of interaction and care other than telephone use, family involvement was not different for decedents with dementia, when compared with those who did not have dementia. Although residents with dementia were less able to participate in decisions about care (p>0.001), and death and dying were less frequently discussed with persons with dementia (p=0.030), all other aspects of advance care planning – including prevalence of a living will, of a durable power of attorney (POA) for health care decisions, and decision-making about cardiopulmonary resuscitation (CPR), feeding tubes or comfort measures – did not differ by dementia status. Family familiarity with the physician, and the prevalence of meetings between the family and physician did not differ by dementia status; however, there was a borderline significant trend (p=0.035) for families of decedents without dementia to be more satisfied with physician communication. Finally, overall satisfaction with care did not differ between families of persons dying with dementia and decedents who were cognitively intact.

Dying with Dementia in RC/AL versus NH

When the staff informant reports of experiences of dying and palliative care for persons with dementia in RC/AL facilities are compared with those of persons in NHs, again controlling for state, age, and number of ADL dependencies, several differences are noted. As is displayed in Table 3, physical restraints were far more common in NHs (92% vs 66%, p<0.001), but use of sedative medication was not. Nutritional supplements were used more commonly by NHs (88% vs 68%, p=0.003), and parallel trends are present regarding use of intravenous fluids (11% vs 4%, p=0.014) and feeding tubes (7% vs 1%, p=0.062). Similarly, antibiotic use was reported more frequently in NH residents dying with dementia (50% vs 34%, p=0.003). On the other hand, RC/AL facilities tended to call 911 on the last day of life (18% vs 3%, p<0.010). Also, RC/AL residents more often experienced a disease course that was interpreted as a series of ups and downs (34% vs 20%; p<0.001).

Comparison of family informant data (Table 4) reveals relatively few significant differences between the experience of dying with dementia in NHs and RC/AL settings in terms of family involvement, advance care planning, and decision-making regarding interventions. However, consistent differences are noted in the area of physician communication, with RC/AL respondents being more often familiar with the resident’s physician (95% vs 84%, p=0.015), having been more likely to have met face-to-face with the physician (79% vs 62%, p=0.010), and to report more favorable family-MD communication scores (mean of 1.78 vs 1.52, p=0.009).

DISCUSSION

Prior to beginning this study, one of our concerns was that persons with dementia in long-term care settings might receive lower quality end-of-life care, since they are often unable to advocate for themselves or to effectively communicate with staff and family. Sachs and colleagues (2004), for example, reported that inadequate pain treatment, reduced hospice use, and overuse of feeding tubes are common among persons with dementia. While persons with dementia were less likely to participate in decisions about care, our overall results suggest that the quality of palliative care provided may not differ by dementia status. Facility staff reported no significant differences in rates of use of nutritional supplements, intravenous fluids, feeding tubes, and attention to moving and positioning; and families reported a similar frequency of discussions and decisions regarding palliative care measures. The reported prevalence of ineffectively treated pain, though slightly higher among persons with dementia, was not significantly different between groups, and inadequately treated shortness of breath was more common among cognitively intact decedents. Furthermore, family visitation rates did not differ by dementia status; persons with dementia were no more likely to die alone; and hospice use did not differ between the two groups. Finally, family assessments of the overall quality of care did not differ by dementia status, a finding that is similar to the recent report of Engel et al. (2006).

Our findings are in contrast to those of Mitchell and colleagues (2004), who identified a consistent pattern for New York NH residents with dementia to be receiving less palliative care than a comparison group of residents with advanced cancer. They found that residents with advanced dementia had a lower prevalence of orders not to resuscitate, hospitalize, or tube feed, and higher levels of feeding tube use, test performance, and restraint use. None of these patterns were evident in our data, however, and several explanations are possible for this inconsistency. First of all, it is possible that care patterns have changed, since Mitchell's data are eight years older than ours, and palliative care for end-stage dementia has become more commonplace in recent years. Additionally, Mitchell's choice of persons dying of cancer as the comparison group affects her findings, since cancer tends to have a more recognized terminal disease trajectory than dementia (Chen, et al, 2007), thereby magnifying differences in care. Furthermore, life-sustaining treatments, such as antibiotics or intravenous fluids, tend to be effective in the short-run in persons with dementia but not in terminal cancer, further complicating decision-making (Sachs, et al, 2004). Therefore, we feel that, in both NH and RC/AL facilities, differences in palliative care between persons with dementia and those who are cognitively intact may be far less prominent than has been previously reported.

The high rates of hospice service use we observed among persons dying with dementia in both RC/AL settings (65%) and NHs (55%) is particularly refreshing, as this indicates a marked trend upward from the virtual nonuse by persons with dementia reported by Hanrahan and Luchins in 1995 (Hanrahan & Luchins, 1995) and the lower rates that we identified five years prior to the current study (Sloane, et al, 2003). An unresolved question is whether hospice services are initiated early enough in dementia; indeed, some of the differences noted by Mitchell et al. (2004) but not by our study could have reflected earlier initiation of palliative care in cancer than in dementia. Thus, the issue in quality end-stage dementia care is no longer whether or not to use hospice, but instead may be whether to initiate palliative care earlier and more gradually, issues that are a major point of emphasis of the clinical practice guidelines developed by the National Consensus Project for Quality Palliative Care (National Consensus Project, 2004).

The high reported rates of physical restraint and sedative use by persons with dementia is troublesome. Indeed, the rates of non-bedrail physical restraint use for all subgroups studied (46% and 68% for persons with dementia in RC/AL and NHs, and 17% and 48% for persons without dementia in RC/AL and NHs, respectively), merits further study. Given that physical restraint use in NHs has been strongly discouraged since the Nursing Home Reform Act of 1987, and that rates of approximately 10% have been reported in general studies of NH residents (Phillips, et al, 2000; Castle, et al, 2005), both demented and nondemented patients who are dying appear to disproportionately be physically restrained, with dementia patients significantly more at risk (p=0.002). This issue merits further investigation. Reported rates of sedative use were also higher among persons with dementia than among those who were nondemented; however, these medications are often considered appropriate for symptom relief as part of the care of persons who are imminently dying (National

Consensus Project, 2004), and so these rates and differences are difficult to interpret. Therefore, further, case-specific research is needed in this area.

As is noted in the new End-of-Life care guidelines from the Alzheimer's Association (2007) and in the article by Sachs and colleagues (2004), the role of family in decision-making and communication with health care providers are elements that most strongly distinguish end-of-life care of persons with dementia from those who are cognitively intact. Thus, it was encouraging to see that family participation in, and the frequency of completion of, discussions involving life-sustaining treatments and palliative care interventions appeared to be just as frequent among decedents with dementia as those who were cognitively intact. Levels of physician-family communication also appeared to be similar (Table 4), although in this context perhaps greater communication with family overall would be preferred, and the comparatively low family-physician communication scores suggest need for improvement.

Decisions to use a palliative care approach were more common among persons who had dementia. Thus, persons who were cognitively intact were more likely to have died in the hospital and to have had emergency services called on the day of death. Quite possibly, such a difference in use of life-prolonging care may be medically appropriate, as many dementia care experts have advocated for a palliative focus to care of end-stage Alzheimer's disease (Volicer, 2001; Wolf-Klein et al., 2007). Furthermore, unexpected acute events may have occurred more frequently among persons who were cognitively intact, since our study noted a nonsignificant trend for staff caring for persons dying with dementia to report stable health, followed by a relatively sudden terminal event (unadjusted p=0.025; adjusted p=0.212).

Another concern we had prior to initiating the study was that the quality of end-of-life care in RC/AL facilities might be lower than that provided in NHs, since RC/AL facilities tend to have fewer professional staff and to be designed largely for less impaired residents. Differences in end-of-life care by facility type were indeed noted, some of which are expected because of the different care environments, but no pattern of differences in quality is evident. RC/AL caters more to a private pay clientele and less-impaired residents, and provides fewer medical services, so the findings (Table 3) that decedents with dementia in RC/AL facilities more often had private rooms and received fewer non-palliative medical services (i.e., nutritional supplements, antibiotics, and 911 calls on the last day of life) are not new observations (Sloane et al., 2003). RC/AL residents with dementia were also less frequently physically restrained, and family members of RC/AL decedents reported better communication with physicians. Symptom care did not seem to differ, however, with the striking exception of skin ulcers, which were significantly more common among demented than nondemented persons in RC/AL facilities (p=0.003) but not in NHs (p=0.566). In summary, these data suggest a tradeoff between settings related to various components of care, and that neither is clearly superior to the other.

A number of potential limitations of the study should be noted. Our method of determining who did and did not have dementia was indirect, excluded approximately 14 percent of the sample, and could have led to some misclassification. However, since terminal delirium is common in dying persons, the questions that we asked, including inquiring about status three months before death, represent a valid (albeit indirect) method of identifying persons who died with Alzheimer's disease or another dementia. Furthermore, even expert, in-person assessments fail to classify the dementia status of as many as 20 percent of long-term care residents, so excluding 14 percent is in line with established evidence (Magaziner et al., 2000). Finally, although misclassification is never preferred, such a bias will tend to reduce rather than inflate the statistical significance of findings, and therefore does not threaten the validity of the positive associations noted. Another potential limitation of the study is nonresponse. Since family interview data were available for only about half of enrolled decedents, responses could have been biased toward, for example, family members who were more involved in care. The data available to us suggest that this is true, as family were present at death for 44% of those with a family interview, compared to 34% of those without (p=0.026). Also, NH decedents and African American decedents were less likely to have a family interview. In addition, we should note that we have conducted multiple statistical tests, and that therefore the likelihood of identifying spuriously “significant” results is high; for this reason we focused our discussion on relationships that were significant at the p<0.01 level and/or that demonstrated consistent trends across multiple measures within a domain. Other potential limitations of the study include the possibility that staff could have under-reported the prevalence of inadequate care, particularly in discussing symptoms, a situation that, if present, would have tended to reduce the likelihood of finding significant differences. Finally, unmeasured or uncontrolled sources of confounding between the dementia-nondementia or the NH-RC/AL samples could have been present, which underscores the hypothesis-generating nature of these analyses.

Nevertheless, the results presented here represent the largest and most comprehensive study of dying with dementia in long-term care reported to date. They provide reassurance that, in general, both NHs and RC/AL settings appear to provide quality, appropriate care to dying persons with dementia, and that this care is generally provided in the facility. They also identify potential foci for care improvement initiatives and further research, such as the use of physical restraints, prevention of skin ulcers in RC/AL, and physician-family communication.

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Table 1

Domains and Variables Evaluated

Domains[*]	**Sample Variables or Variable Categories**	**Source**
Descriptive data	Course of Illness	Staff
Family involvement [a]	Family involvement Family involvement in basic care Most influential person in care decisions	Family
Communication with residents and family [a]	Physician contact with family Physician communication with family	Family
Decision-making [a,b,c,d]	Advance care planning Decision-making regarding interventions	Family
Satisfaction with care [e]	Family Global impressions of care	Family
Physical symptoms [a,b,c,d,e]	Pain, shortness of breath, hygiene, and skin ulcers	Staff
Behavioral symptoms and treatment [a,b,c,d]	Management of behavioral symptoms	Staff
Psychosocial status [a,b,c,d]	Appeared at peace, received compassionate touch, dignity maintained, attached to staff	Staff
Care provision [a,b,c,d]	Life-sustaining interventions (IV fluids, feeding tube, hospitalization, antibiotics, CPR, 911 on last day of life) Palliative interventions (moving/positioning, hospice services) Symptom-directed care	Staff
Care of the imminently dying patient [d]	Circumstances of death	Staff

[*] Sources for the domains of end-of-life experience and care evaluated:

[a] . Alzheimer's Association,

[b] . Ferrell, 2005;

[c] . Mitchell, 2004.

[d] . National Consensus Project, 2004.

[e] . Volicer, 2001

Table 2

Description of the Study Sample, Overall and According to Dementia Status of the Decedent (N=581)[a]

	Overall n (%)	**Decedents with Dementia (N=422) n (%)**	**Decedents without Dementia (N=159) n (%)**	**p-value**[b]
Facility type				
RC/AL	267 (46.0)	175 (41.5)	92 (57.9)	0.006
Nursing home	314 (54.0)	247 (58.5)	67 (42.1)	
State				
Florida	141 (24.3)	93 (22.0)	48 (30.2)	0.543
Maryland	131 (22.5)	100 (23.7)	31 (19.5)	
North Carolina	147 (25.3)	106 (25.1)	41 (25.8)	
New Jersey	162 (27.9)	123 (29.1)	39 (24.5)	
Gender				
Male	181 (31.2)	132 (31.3)	49 (30.8)	0.747
Female	400 (68.8)	290 (68.7)	110 (69.2)	
Age, mean (SD)	85.7 (9.1)	86.5 (7.8)	83.6 (11.7)	0.019
Race/Ethnicity				
White, non-Hispanic	517 (89.1)	381 (90.3)	136 (86.1)	0.304
White, Hispanic	12 (2.1)	9 (2.1)	3 (1.9)	
African American	49 (8.4)	30 (7.1)	19 (12.0)	
Other	2 (0.3)	2 (0.5)	0 (0.0)	
Marital status				
Married	49 (17.3)	39 (19.1)	10 (12.5)	0.170
Unmarried	235 (82.7)	165 (80.9)	70 (87.5)	
Religion				
Protestant	156 (55.5)	108 (53.7)	48 (60.0)	0.610
Catholic	80 (28.5)	58 (28.9)	22 (27.5)	
Jewish	21 (7.5)	16 (8.0)	5 (6.3)	
Other	8 (2.8)	7 (3.5)	1 (1.3)	
None	16 (5.7)	12 (6.0)	4 (5.0)	
On Medicaid during last year				
No	172 (61.0)	121 (58.7)	51 (67.1)	0.128
Yes	110 (39.0)	85 (41.3)	25 (32.9)	
Relationship of family respondent				
Spouse	24 (8.3)	22 (10.5)	2 (2.5)	0.002
Adult child (or in-law)	195 (67.2)	147 (70.3)	48 (59.3)	
Other	71 (24.5)	40 (19.1)	31 (38.3)	
Length of stay in months, mean (SD)	28.7 (33.1)	29.4 (33.7)	26.8 (31.2)	0.216
ADL dependencies (of 3)[c]**, mean (SD)**	1.7 (1.2)	1.9 (1.2)	1.0 (1.1)	<0.001

[a] Missing data: race/ethnicity (n=1); marital status (n=297); religion (n=300); Medicaid status (n=299); and family relationship (n=291). All those with large numbers of missing data are from the family interview, which is unavailable for 288 (49.6% of sample), including 211 with dementia and 77 without. The proportion having family data available does not differ between those with (211/422=50.0%) and without (82/159=51.6%) dementia, p=0.472.

[b] Type 3 Score test p-value for comparison of decedents with and without dementia, based on logistic regression, using generalized estimating equations to account for clustering of residents within facilities.

[c] Dependence in walking, transferring, and eating.

Table 3

Experience of Dying and Palliative Care Reported by Staff of Residents (N=581) who Died With and Without Dementia in Residential Care / Assisted Living (RC/AL) Communities and Nursing Homes (NH)

	RC/AL		Nursing home		p-value[a]	
	Decedents with Dementia	Decedents without Dementia	Decedents with Dementia	Decedents without Dementia		
	N (%)	N (%)	N (%)	N (%)	Dementia	Facility type (among those with dementia)
Course of illness during last months of life						
Stable health	22 (12.6)	25 (27.2)	20 (8.1)	6 (9.0)	0.212	0.136
Steady decline	93 (53.4)	43 (46.7)	177 (71.7)	48 (71.6)	ref	ref
Series of ups and downs	59 (33.9)	24 (26.1)	50 (20.2)	13 (19.4)	0.225	<0.001
Physical symptoms and symptom-directed care during last month of life						
Pain						
Not effectively treated	17 (10.2)	4 (4.5)	13 (5.5)	3 (4.6)	0.078[b]	0.186[b]
Treatment effective	69 (41.3)	44 (49.4)	133 (55.9)	44 (67.7)		
None, never an issue	81 (48.5)	41 (46.1)	92 (38.7)	18 (27.7)	0.206[c]	0.249[c]
Shortness of breath						
Not effectively treated	8 (5.0)	13 (15.7)	13 (5.3)	8 (12.3)	0.014[b]	0.570[b]
Treatment effective	60 (37.3)	34 (41.0)	108 (44.4)	29 (44.6)		
None, never an issue	93 (57.8)	36 (43.4)	122 (50.2)	28 (43.1)	0.014[c]	0.218[c]
Hygiene care very effective	153 (89.5)	87 (96.7)	224 (90.7)	52 (77.6)	*	*
One or more skin ulcers	47 (26.9)	9 (9.9)	55 (22.6)	17 (25.4)	*	*
Management of behavioral Symptoms						
Any restraints used	115 (65.7)	35 (38.0)	226 (91.5)	49 (73.1)	0.004	<0.001
Any restraints other than partial bed rails used	81 (46.3)	16 (17.4)	167 (67.6)	32 (47.8)	0.002	0.031
Sedative used frequently	33 (21.0)	10 (11.0)	68 (29.2)	9 (14.1)	0.010	0.592
Sedative used at least sometimes	47 (29.9)	11 (12.1)	87 (37.3)	14 (21.9)	0.002	0.792
Psychosocial status during last month of life						
Resident appeared to be at peace	122 (70.1)	73 (82.0)	158 (64.2)	42 (62.7)	0.163	0.304

	RC/AL		Nursing home		p-value[a]	
	Decedents with Dementia	Decedents without Dementia	Decedents with Dementia	Decedents without Dementia		
	N (%)	N (%)	N (%)	N (%)	Dementia	Facility type (among those with dementia)
Resident received compassionate touch daily	168 (96.6)	82 (90.1)	233 (95.1)	60 (89.6)	0.035	0.399
Resident’s dignity maintained	156 (90.2)	82 (90.1)	219 (89.4)	57 (85.1)	0.676	0.847
At least one staff had close attachment to resident	144 (82.8)	77 (85.6)	176 (72.1)	55 (83.3)	0.220	0.528
Life-sustaining interventions during the last month of life						
Nutritional supplement	98 (68.1)	34 (58.6)	184 (87.6)	43 (87.8)	0.170	0.003
IV fluids[d]	6 (4.2)	3 (5.2)	24 (11.4)	5 (10.2)	0.499	0.014
Feeding tube[d]	2 (1.4)	2 (3.4)	16 (7.5)	6 (12.0)	0.067	0.062
Hospitalized	69 (39.7)	45 (50.6)	57 (23.6)	23 (34.3)	0.214	0.149
Received antibiotics in facility	55 (33.7)	24 (28.6)	114 (50.0)	28 (45.2)	0.150	0.003
Received CPR in facility	5 (2.9)	3 (3.3)	4 (1.6)	3 (4.6)	0.941	0.921
911 called on last day of life	30 (18.0)	31 (35.6)	8 (3.3)	9 (13.6)	0.006	0.010
Palliative interventions during the last month of life						
Special attention to moving and positioning	56 (32.0)	26 (28.3)	102 (41.6)	29 (43.3)	0.903	0.956
Received hospice services	109 (64.5)	46 (51.7)	120 (55.0)	28 (45.2)	0.123	0.183
Circumstances of death						
Location of death						
Facility, private room	109 (63.0)	44 (47.8)	43 (17.6)	17 (26.2)	0.198[e]	<0.001[e]
Facility, shared room	37 (21.4)	17 (18.5)	184 (75.1)	38 (58.5)		
Hospital	24 (13.9)	29 (31.5)	17 (6.9)	9 (13.8)	0.005[f]	0.509[f]
Other	3 (1.7)	2 (2.2)	1 (0.4)	1 (1.5)		
Companionship at death						
Someone else present	103 (60.9)	53 (59.6)	156 (66.4)	42 (65.6)	0.635[g]	0.180[g]
Died alone	41 (24.3)	18 (20.2)	40 (17.0)	11 (17.2)		
Staff did not know	25 (14.8)	18 (20.2)	39 (16.6)	11 (17.2)		

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[*] Dementia by facility type interaction was $p<0.05$ for these characteristics. For effectiveness of hygiene care, the p-value for dementia vs. cognitively intact is 0.004 in RC/AL and 0.024 in NH; for skin ulcer, the p-value for dementia vs. cognitively intact is 0.003 in RC/AL and 0.566 in NH.

[a] P-values for score test from logistic regression with given measure of end-of-life experience as dependent variable and dementia status and facility type (RC/AL vs. NH) as predictors, and controlling for state, decedent age, and number of ADL dependencies, using GEE and specifying exchangeable correlation matrix to account for clustering of residents within facilities.

[b] Ineffective treatment compared to combination of treatment effective and never an issue.

[c] Any pain/shortness of breath (combination of treatment effective and ineffective treatment) compared to never an issue.

[d] Because of change in skip pattern partway through data collection, IV fluids and use of feeding tube unknown for 115/581 = 19.7% of sample; other items missing for <5% of sample.

[e] For facility, private room vs. shared room; those who died in hospital or other location excluded for this comparison.

[f] For died in hospital vs. died in facility (shared room or private room); those who died in other location excluded for this comparison.

[g] For died alone vs. someone present at death; those for whom the staff did not know if resident was alone at time of death excluded for this comparison.

Table 4

Experience of Dying and Palliative Care Reported by Family Members of Residents (N=293) who Died With and Without Dementia in Residential Care / Assisted Living (RC/AL) Communities and Nursing Homes (NH)

	RC/AL		Nursing home		p-value[a]	
	Decedents with Dementia	Decedents without Dementia	Decedents with Dementia	Decedents without Dementia		Facility type (among those with dementia)
	N (%) or Mean (SD)				Dementia	
Family involvement in last month of life						
Days visited in last month	16.2 (10.9)	13.3 (9.7)	15.5 (10.7)	17.4 (10.5)	0.684	0.218
Ever spoke to resident by phone	9 (9.0)	31 (62.0)	10 (9.3)	14 (45.2)	<0.001	0.702
Days spoke w/staff about resident	17.4 (10.4)	12.0 (9.7)	16.2 (10.6)	16.1 (10.8)	0.178	0.144
Family present at death	38 (40.4)	20 (43.5)	40 (40.8)	7 (23.3)	0.314	0.732
Most influential person in care decisions						
Resident[b]	27 (27.0)	22 (45.8)	24 (22.4)	7 (24.1)	0.047	0.152
Family	68 (68.0)	23 (47.9)	79 (73.8)	22 (75.9)		
Physician	2 (2.0)	0 (0.0)	0 (0.0)	0 (0.0)		
Non-physician staff	3 (3.0)	3 (6.3)	4 (3.7)	0 (0.0)		
Family involvement in care (at least once a week)						
Helped with bathing, toileting, or dressing	17 (16.8)	11 (22.4)	17 (16.0)	6 (20.0)	0.387	0.566
Helped with grooming	27 (27.0)	9 (18.4)	37 (34.9)	13 (43.3)	0.714	0.744
Helped decedent walk in facility	39 (39.0)	18 (36.7)	43 (40.6)	12 (40.0)	0.503	0.764
Was involved at mealtime	61 (61.0)	23 (46.9)	60 (56.6)	16 (53.3)	0.810	0.239
Helped with financial, legal or other management activities	79 (79.0)	34 (69.4)	72 (67.9)	20 (66.7)	0.259	0.011
Monitored/oversaw staff care	86 (86.0)	39 (79.6)	89 (84.0)	23 (76.7)	0.478	0.350
Physician communication with family during the last month of life						
Family familiar with MD	95 (95.0)	45 (90.0)	91 (84.3)	26 (86.7)	0.704	0.015
Family ever met MD	79 (79.0)	41 (82.0)	66 (61.7)	17 (56.7)	0.640	0.010
Family-MD communication score	1.78 (1.05)	2.19 (0.90)	1.52 (1.01)	1.50 (0.95)	0.035	0.009
Advance care planning						
Resident able to participate in decisions about care	11 (11.0)	25 (50.0)	8 (7.4)	15 (50.0)	<0.001	0.212
Discussed death/dying with resident	57 (57.0)	33 (67.3)	47 (43.5)	22 (73.3)	0.030	0.086

	RC/AL		Nursing home		p-value[a]	
	Decedents with Dementia	Decedents without Dementia	Decedents with Dementia	Decedents without Dementia		Facility type (among those with dementia)
	N (%) or Mean (SD)				Dementia	
Had durable health care POA	96 (96.0)	46 (92.0)	101 (93.5)	27 (90.0)	0.988	0.485
Extent resident preferences known						
Living will	93 (92.1)	43 (87.8)	92 (86.0)	21 (70.0)	0.097[c]	0.252[c]
No document, knew preferences	6 (5.9)	2 (4.1)	9 (8.4)	8 (26.7)		
No document, did not know preferences	2 (2.0)	4 (8.2)	6 (5.6)	1 (3.3)		
Decision-making regarding interventions						
Decision made about:						
CPR	89 (89.0)	44 (91.7)	97 (90.7)	24 (82.8)	0.975	0.837
Decided to do CPR	2 (2.0)	2 (4.2)	3 (2.8)	2 (6.9)	0.291[d]	0. 716 [d]
Feeding tube	82 (82.8)	39 (81.3)	89 (83.2)	21 (72.4)	0.542	0.782
Decided to use feeding tube	3 (3.1)	0 (0.0)	8 (7.6)	2 (6.9)	0.561	0.078
Comfort measures only	85 (85.9)	39 (83.0)	95 (88.8)	22 (75.9)	0.274	0.660
Decided to use comfort measures only	71 (71.7)	35 (74.5)	79 (73.8)	20 (69.0)	0.724	0.974
Family global impressions of care during last month of life						
Assessment of overall quality of care						
Poor/fair	10 (10.0)	7 (14.3)	8 (7.5)	4 (13.3)		
Good	18 (18.0)	5 (10.2)	37 (34.6)	14 (46.7)		
Very good	72 (72.0)	37 (75.5)	62 (57.9)	12 (40.0)	0.288[e]	0.304[e]
Would have preferred more involvement in care	22 (22.0)	14 (28.6)	30 (28.0)	11 (36.7)	0.438	0.235

[a] P-values for score test from logistic regression with given measure of end-of-life experience as dependent variable and dementia status and facility type (RC/AL vs. NH) as predictors, and controlling for state, decedent age, and number of ADL dependencies, using GEE and specifying exchangeable correlation matrix to account for clustering of residents within facilities.

[b] Could be resident by him/herself or through advance directives; statistical comparisons compare this group to all other groups combined.

[c] Because of small number not reporting living will, this group compared to the other two groups combined.

[d] Because of small number of events, adjusted model does not converge; p-value for dementia status is therefore adjusted only for facility type; p-value for facility type among dementia group is unadjusted.

[e] These tests compare those rating care as very good compared to the combination of those rating care poor, fair, or good.