Published in final edited form as:

Am J Hosp Palliat Care. 2018 October ; 35(10): 1314–1322. doi:10.1177/1049909118761094.

End-of-Life Plans for African American Older Adults With Dementia

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Abstract

African Americans are perceived to be least likely of all racial and ethnic groups to prepare for the end of life. However, verbal plans for the end of life are of particular importance to this population and may help understand why they are less likely to possess a formal end-of-life care planning document. The purpose of this study was to determine the number of formal and/or informal end-of-life care plans that existed among a convenience sample of African American older adults with dementia. For this descriptive study, data were collected from African American family caregivers (N = 65) of older adults with dementia. Descriptive statistics were conducted. Caregivers in this sample reported high rates of formal and/or informal end-of-life plans for their care recipients. Agency forms (power of attorney, health-care surrogate, or guardianship forms) had been obtained by 74% of the care recipients, while 63% of them possessed a formal end-of-life care planning document. All combined, 88% of the caregivers possessed at least 1 document or verbal information concerning end-of-life care for their care recipient or at least there was an assigned surrogate. Although limited, these findings reflect more end-of-life planning in this population than previous studies reported and could improve the quality of end-of-life outcomes in this population by giving health-care providers increased understanding of African American end-of-life planning preferences. This may, in turn, help the providers to inform and educate these care recipients and their family caregivers.

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Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Keywords

African American; caregivers; dementia; formal end-of-life plans; informal end-of-life plans; older adults

African Americans are less likely than any other racial group to participate in advanced care planning and often choose intensive life-sustaining treatments near the end of life.¹⁻⁴ In 2013, African American hospice use was 8.4%, but this number decreased to 7.6% in 2014.⁵ In 2015, this number increased to 8.2% but still fall far behind the rates of hospice use by caucasians.⁶ These differences in rates of end-of-life planning among blacks versus whites have been widely reported⁷⁻¹⁷; yet, African American older adults are twice as likely to develop dementia than caucasians.¹⁸ Dementia may add another degree of complexity to disparities in end-of-life decision-making among this population.¹⁹ The low rates of end-of-life planning²⁰⁻²⁶ and high rates of dementia among African Americans¹⁸ indicate the need to address end-of-life planning in this population. In the general US population, a primary diagnosis of dementia in hospice existed in 16.5% of all admissions in 2015, third only to cancer (27.7%) and cardiac/circulatory disease (19.3%).⁶ The 2014 National Academies of Sciences, Engineering, and Medicine report *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* supports a focus on improving quality of life for the culturally diverse and cognitively impaired with serious advanced illness near the end of life and for their families.¹⁹

Family orientation is valued by many African Americans²⁷ and may influence end-of-life decision-making toward more family-oriented approaches.²⁸⁻³⁰ It is important for health-care providers and researchers to focus on such belief systems in addressing and providing end-of-life care.³¹ Respect for differences is also crucial for health-care providers in addressing end-of-life care needs.³² In African American family culture, having trusted family members voice patient wishes, rather than completing an advance directive, is important.^{33,34} There is also a common belief in this population that a distrusted health-care system holds authority for health-care decision-making,^{3,27,35} leading these families to varying degrees of avoidance, lack of information sharing, and apprehension for fear of exploitation.³⁶

Despite the enactment of the Patient Self-Determination Act of 1990 that requires Medicare and Medicaid-funded health-care organizations to empower patients to refuse or accept medical care and execute advance directives,³⁷ and Medicare health-care provider reimbursement for having end-of-life conversations as of January 2016,³⁸ fewer than 40% of Americans have completed an advance directive.³⁹ Formal and informal end-of-life decision-making in patients with serious life-limiting conditions such as dementia should be a core aspect of their care. Informal end-of-life plans involve talking to family members of persons with dementia and others about one's wishes, including values, goals of care, and prognosis,^{40,41} and often include discussions related to hospice, palliative care, venue for dying (eg, home, hospice, and hospital).^{42,43} End-of-life discussions also describe wishes about care an individual would receive when they are dying. These discussions would include conversations inclusive of but not limited to hospice, resuscitation (eg,

cardiopulmonary resuscitation), artificial ventilation (eg, intubation), symptom management (eg, pain control), venue for dying (eg, home, hospice, and hospital), and nutritional supplementation (eg, feeding tube).⁴³ These verbal plans are of particular importance to African Americans.⁴⁴ The fact that high numbers of African American care recipients have informal (verbal) plans, as opposed to formal plans, is supported in the literature and may substantiate decreased likelihood that African Americans prepare for the end of life due to this difference.^{21–26,45,46} Written plans often include end-of-life wishes or treatment decisions written informally, such as on a plain piece of paper (tucked away in a family Bible), and can be legally binding if evidence exists that the individual wrote it themselves, that they were competent to do so at that time, and that there is no evidence that they changed their mind after writing it.⁴⁷ Formal end-of-life plans are legal documents such as advance care directives or living wills.⁴⁰ These documents are widely advocated as a mechanism for individuals to express preferences for life-sustaining treatments, based on the assumption that they will improve caregivers' knowledge and confidence in end-of-life decision-making.⁴⁸ Few studies exist that examine aspects of end-of-life decision-making among dementia caregivers, such as advance care planning and treatment decisions (eg, tube feeding).^{49–51} The purpose of this study was to determine the number of formal and/or informal end-of-life care plans that existed among a convenience sample of African American older adults with dementia.

Methods

Study Design and Sample

This cross-sectional, descriptive study was part of a mixed methods study conducted in 2015 and received institutional review board approval prior to data collection. The qualitative results are reported in a separate article.⁵² Study participants needed to self-identify as an English-speaking African American adult (21 years or older) caring for a community-dwelling African American older adult (> 55 years) diagnosed with dementia. Caregivers were excluded if they reported cognitive impairment for themselves or if their older adult loved one was acutely hospitalized or actively dying. A convenience sample of 91 African American caregivers of African American older adults with dementia was solicited for study participation. Of the 91, 14 caregivers declined to participate, and another 12 did not meet the study inclusion criteria, leaving 65 who were enrolled in the study. Participants (N = 65) were recruited via snowball methods in the community and via Program of All-Inclusive Care for the Elderly (PACE) programs in a southeastern state. Recruitment measures for this study are more fully described in another article.⁵²

Data Collection and Analysis

All data were obtained via face-to-face interviews in person by the lead author. Results reported in this article were collected using 2 basic forms: a demographic form and a documentation form of end-of-life care plans. Either the lead author asked the questions and completed the forms or the caregiver completed the forms in the presence of the lead author, depending on caregiver preference. The presence of the following documents was assessed: advance directives, living wills, do not resuscitate (DNR), physician orders for scope of treatment (POST), power of attorney/health care surrogate (POA/HCS), and guardianship.

All forms, except POA/HCS and guardianship, speak to an individual's plan for care toward the end of life. In this study, these forms are referred to as "formal end-of-life care planning documents." Although POA/HCS and guardianship forms designate a surrogate decision maker, agent, proxy, or surrogate, they do not necessarily include nor are they required to accompany the individual's wishes for the end of life. In this study, the POA/HCS and guardianship forms are referred to as "documents of agency."

Formal end-of-life documents (advance directives and living wills) have long been promoted as a means for persons to obtain desired treatment, and avoid treatment they don't want, as they face advanced illness.⁵³ In this study, having a formal end-of-life care planning document refers to possession of one or more of the following: advance directive, living will, DNR, and/or POST forms. Having an agency document refers to possession of a power of attorney, health-care surrogate, or guardianship form for the care recipient. To obtain this information, this question was asked in 2 ways: "Has your older adult care recipient with memory impairment signed any of the following documents?" and "Have you signed any of the following written documents concerning the care of your older adult care recipient?" To assess if oral/verbal plans existed, this question was also asked in 2 ways: "Has your older adult care recipient expressed verbal/oral wishes or desires for healthcare decisions in the face of serious or life-threatening illness?" and, "Have you and your family discussed verbal wishes or desires for healthcare decisions for your older adult care recipient in the face of serious or life-threatening illness?" The questions were framed in both ways because of the dementia diagnosis, in order to capture whether the plan-making included input from the care recipient, which could have been given prior to a loss of decision-making capacity. Response options for these questions were: "yes," "no," or "don't know." Participants self-reported all data collected; the researchers did not see any of the end-of-life care planning documents. Data analyses were conducted using SPSS statistical software version 23.⁵⁴ Descriptive statistics were used to describe the characteristics of the sample.

Results

Family Caregiver Characteristics

Caregivers all self-identified as African American or black. Caregivers were mostly female (87.7%) and most often daughters (49.2%) caring for a parent with dementia. Participants caring for a spouse represented 13.8% of caregivers. Other caregivers included relatives such as sons (9.2%), nieces (9.2%), and sisters (6.2%). Less frequently, caregivers were granddaughters, great-granddaughters, nephews, cousins, daughters-, or sisters-in-law. Mean family caregiver age was 59.5 years (range: 25-82 years). Over half of the participants were single, widowed, separated, or divorced (60%), and the remaining 40% were married. Just over half (55.5%) of the caregivers were employed in a full- or part-time position. The majority (70.8%) had completed at least some college, graduate, and/or doctoral studies, while 24.6% had only a high school diploma. Only a few (4.6%) did not have a complete high school education. Caregivers resided in rural (26.2%), urban (36.9%), and suburban (36.9%) areas of the southeastern state. The median length of time in their caregiving role was 4 years.

Care Recipient Characteristics

Care recipients were mostly female (73.8%), and their mean age was 82.8 years (range: 62-104 years). Most care recipients were living in home settings and therefore were noninstitutionalized (83.1%). Care recipients enrolled in PACE programs received adult daycare or homecare services through PACE but resided elsewhere. These PACE enrollees represented 24.6% of all care recipients. Caregivers most commonly reported care recipients' dementia diagnoses more specifically as Alzheimer disease (35.4%), followed next by vascular dementia (15.5%). For 40% of care recipients, the family caregiver did not know the specific type of dementia. The median length of time since diagnosis of memory loss was 4 years. Table 1 reports caregiver and care recipient characteristics by possession of a formal or informal end-of-life plan.

Care Recipient or Family Caregiver Signed End-of-Life Care Planning Document

A majority of care recipients (74%) possessed at least a POA/HCS or guardianship form. However, possession of one or both of these documents was not considered having a formal end-of-life care plan because these do not necessarily indicate that plans for the end of life exist but rather that there is an assigned surrogate decision maker. These documents often existed in the absence of a formal end-of-life care planning document. Care recipients often possessed more than 1 formal end-of-life care planning document.⁵⁵ Overall, 63% of caregivers stated possession of formal end-of-life care planning document(s) for the care recipient, signed by themselves, their care recipient, or both.⁵⁶ The remaining 37% of caregivers included 6.2% who reported that they were unaware whether their care recipient had signed a formal end-of-life care planning document or documents of agency. Others in the 37% either did not indicate possession or stated that there were no such signed documents. Care recipients enrolled in a PACE program were more likely to have an end-of-life care plan document than those not enrolled in PACE (75% for PACE enrolled; 59.2% for those not in PACE).

Informal (Verbally Expressed) Care Recipient End-of-Life Care Plans

For the purpose of this study, an informal end-of-life care plan referred to any report of care recipient self-expressed verbal plans regarding wishes for the end of life. Caregivers reported that 57% of care recipients had expressed verbal wishes for the end of their lives. This compared to 40% of caregivers who reported that their care recipients had not verbally expressed such wishes to anyone. Only 3% of caregivers had no knowledge of whether there were verbal end-of-life care plans expressed by their care recipients regarding their wishes toward life's end.

Formal or Informal End-of-Life Care Plans for Care Recipient

In examining care recipients who had formal and/or informal end-of-life care plans, 78% of caregivers reported that there were such care plans in place for their care recipient. The other 22% of caregivers did not report either a formal or an informal end-of-life care plan. These results show that for the majority of care recipients in this study, at least a strategy existed for how health care received at the end of their lives would be executed. When agency documents were included, 88% of caregivers possessed at least some documents or

information concerning end-of-life care for the care recipient or at least had an assigned surrogate. Care recipients were more likely to possess a formal and or informal end-of-life plan if they were female, between the ages of 80 to 89 years, residing in the home setting, and diagnosed with dementia with Lewey Bodies, Wernicke-Korsakoff Syndrome, Mixed, or an unknown form of dementia. Family caregivers of care recipients who possessed a formal or informal end-of-life plan were mostly daughters, between the ages of 60 to 69 years, who were married. They were mostly employed with an annual income of \$25 000 or more with 1 to 3 years of college, possessed private insurance, live in suburban areas, and reported paying for “the basics” as “not difficult at all.” Care recipients enrolled in a PACE program were more likely to have a written or oral end-of-life care plan (87.5%) than those not enrolled in PACE (75.5%), although this difference was not significant ($P = .487$; see Table 1).

Discussion

This study contributes to the growing body of literature on end-of-life planning in African Americans. Findings revealed high completion rates of formal end-of-life care planning documents (advance directives, living will, DNR, and/or POST forms) as well as documents of agency (POA/HCS or guardianship forms). High rates of verbal end-of-life care plans were also observed in this sample. According to the literature, average completion rates of formal advance care planning documents among African Americans are low.^{15,20} For the care recipients and their caregiver participants in this study, a dementia diagnosis may have added another layer of complexity to disparities in medical decision-making faced by racial and ethnic minorities such as African Americans.¹⁹ End-of-life planning among the group of African Americans with dementia referenced in this study contradicts what is often found in health-care literature. Reasons for this finding are possibly multifactorial and include (1) all care recipients had dementia, (2) influence of PACE’s advance care planning policies, (d) only African Americans were studied, as there was no comparison group, and (4) caregivers who self-reported these data generally represented a select group of highly educated individuals with high income levels.

In this current study, 63% of care recipients had signed an advance directive and/or living will DNR and/or POST forms, and many had signed more than one of those, while 57% of care recipients had given verbal wishes. African Americans when compared to non-African Americans, particularly caucasians, seem to prefer to plan for the end of life in different ways, with African Americans being more likely to possess a verbal plan than having a signed advance care planning document.⁴⁴ Therefore, African Americans may continue to seem to fall short in terms of end-of-life planning because of the lack of a formal end-of-life care planning document. Research that only reports on documents may miss an important segment of the population who only give verbal wishes. There is a need to capture outcomes of end-of-life discussions. These results and that of another recent study⁵⁷ provide evidence that there may be improvements in end-of-life planning among African Americans; however, these are not generalizable.

The main contribution of the manuscript is that it demonstrates a high completion rate for end-of-life planning among this high socioeconomic sample of African American older

adults with dementia—a racial group that is generally less likely to demonstrate having a plan for the end of life, and more likely to choose life-sustaining treatment methods, even in the face of terminal illness. Findings of this study support the fact that the participants, which included a number of highly educated African Americans with high socioeconomic status, were more likely than the literature suggests to plan for the end of life in the form of a completed document or verbal discussions with loved ones. However, these verbal discussions, if nothing else, provide a basis on which caregivers can make decisions that are somewhat aligned with the values of their loved ones. Therefore, these verbal plans should not be ignored or seen as not having a plan.

Several limitations of this study should be noted. Data collection was cross sectional. One point-in-time measurement does not capture the dynamic fluctuation of uncertainty across trajectory, and any significance determined in this study must be interpreted with caution.⁵⁸ Data collected in this way also did not allow for assessments of the detailed process of end-of-life planning in this population, including specific details on what was included in the formal end-of-life plan or details on what was included in the verbal plans. Data were self-reported; therefore, accuracy could not be confirmed.⁵⁹ These reported rates were limited by the sample size (N = 65). It is also a limitation of this current study that annual income levels were measured in a very rudimentary way (< \$25 000 or >\$25 000). However, validity threats include the high educational and income levels reported by most of the caregiver participants. According to the 2013 United States Census Report American Community Survey, more than one-third of family caregivers of persons aged 50 years or older have a high school education or less, which is just lower than the percentage who have a college degree (36%). Median household income for these caregivers is \$55 000 compared to the \$53 046 for caregivers in the United States overall.⁶⁰ According to national data, African American caregivers are often high school graduates or have taken some college courses, but have no degree and have an average annual household income of \$37 000.⁶⁰ Pickard et al⁶¹ found a group of African American female caregivers had a wide range of annual income levels from \$187.50 to \$75 000 per person in the home, with an average annual income of \$10 244 (standard deviation = \$10 277), while Bonner et al⁴⁹ reported incomes mostly \$40 000 annually. Pickard et al⁶¹ reported median education levels to be 12 years (range: 1-17 years), while Bonner et al⁴⁹ reported that most had some college education or higher. Another limitation is the inclusion of PACE enrollees. Programs such as PACE are influential in ensuring that end-of-life education and follow through on completion of advance care planning documents (formal end-of-life care plans) are a priority.⁶² Therefore, such programs can be influential in boosting rates of planning among the participants. In the general US population, persons who are institutionalized are more likely to have a plan.^{63,64} These findings support the benefits of the end-of-life planning support offered by a program such as PACE to assist in meeting the wishes of its participants and their loved ones. In a study among African American PACE enrollees with various diagnoses, there was a preference for life-sustaining treatment.⁶² In that study, verbalized end-of-life preferences and advance directives were not always in agreement.⁶² In the current study, although PACE may have an influence, the figure of 75.5% with a written or oral end-of-life plan for those not enrolled in PACE is still quite high.

African American caregivers often lack understanding of values and goals of care for their loved ones,⁶⁵ stressing the importance of the need for caregivers to participate in these end-of-life discussions. In a longitudinal study containing 141 African American patients with renal failure (67.4% of the sample) and 142 of their surrogates, researchers using the Sharing Patients' Illness Representations to Increase Trust (SPIRIT) program educated dialysis dyads and found an association between dyad preparation for end-of-life decision-making and surrogate bereavement outcomes.⁶⁶ This was also observed in a preceding randomized controlled trial of SPIRIT in a population of African Americans.^{66,67} In both of these studies, success of this program was attributed to the fact that the focus was on assisting patients and surrogates to discuss possibilities of end-of-life decision-making and feelings about options near the end of life versus advance directive completion.^{66,67} However, additional work testing a community-based end-of-life education program among persons with dementia is warranted. More important, studies may be required to examine perceptions of end-of-life education further in dementia caregivers longitudinally to determine family caregiver outcomes of end-of-life planning for themselves in relation to the end-of-life experiences of those who they previously served as surrogate decision makers. Additionally, details contained within the formal end-of-life care planning documents and components of end-of-life conversations need to be examined by researchers. Additional research is needed to identify factors that influence end-of-life planning in this population and determine whether similarities exist in a more socioeconomically diverse sample and in other disease states. If these high rates of end-of-life planning reported by caregivers of these African American older adults with dementia hold true in a larger sample, this subset of individuals may serve as exemplars for other groups of African Americans as well as other minority racial or ethnic groups.

Acknowledgments

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported in part by Dr. Moss' appointment as a Jonas Nurse Leader Scholar (2014-2016) through the Jonas Foundation.

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Table 1

Demographics by End-of-Life Plan.

Family Caregiver Characteristic	Care Recipient Formal or Informal End-of-Life Care Plan, N = 65			P Value
	N = 65 n (%)	Yes n = 51 n (%)	No, n = 14 n (%)	
Gender				.675 ^a
Male	8 (12.3%)	7 (13.7%)	1 (7.1%)	
Female	57 (87.7%)	44 (86.3%)	13 (92.9%)	
Age				.047 ^a
21-29 years	2 (3.1%)	1 (2.0%)	1 (7.1%)	
30-39 years	1 (1.5%)	1 (2.0%)	0 (0.0%)	
40-49 years	8 (12.3%)	6 (11.8%)	2 (14.3%)	
50-59 years	16 (24.6%)	11 (21.6%)	5 (35.7%)	
60-69 years	28 (43.1%)	25 (49.0%)	3 (21.4%)	
70-79 years	6 (9.2%)	6 (11.8%)	0 (0.0%)	
80-89 years	4 (6.2%)	1 (2.0%)	3 (21.4%)	
Age, years, Mean (SD)	59.5 (11.5)	59.9 (10.1)	58.1 (15.9)	.683 ^b
Marital status				.149 ^a
Single	17 (26.2%)	13 (25.5%)	4 (28.6%)	
Separated or divorced	17 (26.2%)	15 (29.4%)	2 (14.3%)	
Married	26 (40.0%)	21 (41.2%)	5 (35.7%)	
Widowed	5 (7.7%)	2 (3.9%)	3 (21.4%)	
Annual income				.270 ^a
\$25 000 or less	20 (30.8%)	14 (27.5%)	6 (42.9%)	
Above \$25 000	43 (66.2%)	36 (70.6%)	7 (50.0%)	
Don't know	2 (3.1%)	1 (2.0%)	1 (7.1%)	
Employment status				1.000 ^a
Employed	36 (55.5%)	28 (54.9%)	8 (57.1%)	
Not employed	29 (44.7%)	23 (45.1%)	6 (42.9%)	
Years of school completed				.289 ^a
Grades 8-11	3 (4.6%)	2 (3.9%)	1 (7.1%)	
Grade 12	16 (24.6%)	10 (19.6%)	6 (42.9%)	
1-3 years college	21 (32.3%)	18 (35.3%)	3 (21.4%)	
4 years college	7 (10.8%)	7 (13.7%)	0 (0.0%)	
Some graduate school	2 (3.1%)	1 (2.0%)	1 (7.1%)	
Graduate degree	11 (16.9%)	10 (19.6%)	1 (7.1%)	
Some doctoral work	2 (3.1%)	1 (2.0%)	1 (7.1%)	
Doctorate degree	3 (4.6%)	2 (3.9%)	1 (7.1%)	
Insurance coverage ^c				.764 ^a
Public	29 (44.6%)	22 (43.1%)	7 (50.0%)	
Private	46 (70.8%)	37 (72.5%)	9 (64.3%)	.741 ^a

Care Recipient Formal or Informal End-of-Life Care Plan, N = 65				
Family Caregiver Characteristic	N = 65 n (%)	Yes n = 51 n (%)	No, n = 14 n (%)	P Value
Military	3 (4.6%)	3 (5.9%)	0 (0.0%)	.591 ^a
None	3 (4.6%)	2 (3.9%)	1 (7.1%)	1.000 ^a
Residence location (self-described)				.690 ^a
Rural	17 (26.2%)	12 (23.5%)	5 (35.7%)	
Urban	24 (36.9%)	19 (37.3%)	5 (35.7%)	
Suburban	24 (36.9%)	20 (39.2%)	4 (28.6%)	
Difficulty paying for “basics”				.073 ^a
Not difficult at all	32 (49.2%)	28 (54.9%)	4 (28.6%)	
Not very difficult	9 (13.8%)	5 (9.8%)	4 (28.6%)	
Somewhat difficult	19 (29.2%)	13 (25.5%)	6 (42.9%)	
Very difficult	5 (7.7%)	5 (9.8%)	0 (0.0%)	
Relationship with care recipient				.019 ^a
Spouse	9 (13.8%)	6 (11.8%)	3 (21.4%)	
Daughter	32 (49.2%)	29 (56.9%)	3 (21.4%)	
Son	6 (9.2%)	5 (9.8%)	1 (7.1%)	
Sister	4 (6.2%)	4 (7.8%)	0 (0.0%)	
Niece	6 (9.2%)	2 (3.9%)	4 (28.6%)	
Other relative	8 (12.3%)	5 (9.8%)	3 (21.4%)	
Length of time in caregiving role, years				.619 ^d
Median (IQR)	4 (4)	4 (5)	4.5 (2.25)	
Range	.17 – 18	.17 – 18	1 – 16	
Gender				.493 ^a
Male	17 (26.2%)	12 (23.5%)	5 (35.7%)	
Female	48 (73.8%)	39 (76.5%)	9 (64.3%)	
Age				.822 ^a
60-69 years	5 (7.7%)	3 (5.9%)	2 (14.3%)	
70-79 years	18 (27.7%)	14 (27.5%)	4 (28.6%)	
80-89 years	27 (41.5%)	21 (41.2%)	6 (42.9%)	
90-99 years	14 (21.5%)	12 (23.5%)	2 (14.3%)	
100-109 years	1 (1.5%)	1 (2.0%)	0 (0.0%)	
Age, years, Mean (SD) <i>P</i>	82.8 (8.5)	83.5 (8.2)	80.1 (9.4)	.186 ^b
Institutionalization Status				.432 ^a
Institutionalized	11 (16.9%)	10 (19.6%)	1 (7.1%)	
Noninstitutionalized	54 (83.1%)	41 (80.4%)	13 (92.9%)	
Type of memory loss (caregiver self-report)				
Alzheimer disease	23 (35.4%)	13 (25.5%)	10 (71.4%)	
Vascular dementia	10 (15.5%)	10 (19.6%)	0 (0.0%)	
Unknown/unclassified	26 (40.0%)	22 (43.1%)	4 (28.6%)	

Care Recipient Formal or Informal End-of-Life Care Plan, N = 65				
Family Caregiver Characteristic	N = 65 n (%)	Yes n = 51 n (%)	No, n = 14 n (%)	P Value
Other dementias	6 (9.2%)	6 (11.8%)	0 (0.0%)	.009 ^a
PACE enrolled				.487 ^a
Enrolled	16 (24.6%)	14 (27.5%)	2 (14.3%)	
Not enrolled	49 (75.4%)	37 (72.5%)	12 (85.7%)	
Length of time since diagnosis, years				.277 ^d
Median (IQR)	4 (3)	4 (3)	4 (2)	
Range	0-16	0-13	1-16	
Number of comorbidities Mean (SD)	2.8 (2.0)	3.1 (2.0)	1.4 (1.3)	.005 ^b

Abbreviations: IQR, interquartile range; PACE, Program of All-Inclusive Care for the Elderly; SD, standard deviation;

^aExact 2-sided χ^2 test.

^bIndependent samples 2-sided *t* test.

^cSome caregivers had more than one type of insurance coverage.

^dMann-Whitney *U* test.