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Attitudes Toward Advance Care Planning Among Persons with Dementia and their Caregivers

Corinne Pettigrew, PhD^a, Rostislav Brichko, BA^a, Betty Black, PhD^b, Maureen K. O'Connor, PsyD, ABPP-CN^c, Mary Guerriero Austrom, PhD^d, Maisha T. Robinson, MD^e, Allison Lindauer, PhD, NP^f, Raj C. Shah, MD^g, Guerry M. Peavy, PhD^h, Kayla Meyer, BAⁱ, Frederick A. Schmitt, PhD^j, Jennifer H. Lingler, PhD, CRNP, FAAN^k, Kimiko Domoto-Reilly, MD^l, Dorothy Farrar-Edwards, PhD^m, Marilyn Albert, PhD^a

^aDepartment of Neurology, Johns Hopkins School of Medicine, 1620 McElderry St., Baltimore, MD, 21205, USA

^bDepartment of Psychiatry and Behavioral Sciences, Johns Hopkins School of Medicine, 5300 Alpha Commons Dr., Baltimore, MD 21224, USA

^cDepartment of Neurology, Boston University School of Medicine, 72 East Concord St., B-7800, Boston, MA 02118, USA

Corresponding author: Dr. Corinne Pettigrew, 1620 McElderry St., Reed Hall 1, Baltimore, MD 21205, cpettigrew@jhmi.edu; Phone: 410-614-0363; Fax: 410-502-2189.

Description of Authors' Roles

Dr. Corinne Pettigrew supervised data submission, carried out statistical analyses, and drafted and revised the manuscript for content.

Mr. Rostislav Brichko assisted in data collection and statistical analyses, and drafted and revised the manuscript for content.

Dr. Betty Black formulated the research question, designed the study, and revised the manuscript for content.

Dr. Maureen K. O'Connor supervised data collection.

Dr. Mary Guerriero Austrom supervised data collection and revised the manuscript for content.

Dr. Maisha T. Robinson supervised data collection and revised the manuscript for content.

Dr. Allison Lindauer supervised data collection and revised the manuscript for content.

Dr. Raj C. Shah supervised data collection and revised the manuscript for content.

Dr. Guerry M. Peavy supervised data collection and revised the manuscript for content.

Ms. Kayla Meyer supervised data collection, collected data, and revised the manuscript for content.

Dr. Frederick A. Schmitt supervised data collection and revised the manuscript for content.

Dr. Jennifer H. Lingler supervised data collection and revised the manuscript for content.

Dr. Kimiko Domoto-Reilly supervised data collection and revised the manuscript for content.

Dr. Dorothy Farrar-Edwards supervised data collection and revised the manuscript for content.

Dr. Marilyn Albert formulated the research question, designed and coordinated the study, supervised data collection, and drafted and revised the manuscript for content.

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Dr. Kimiko Domoto-Reilly – none

Dr. Dorothy Farrar-Edwards – none

Dr. Marilyn Albert – none

^dDepartment of Psychiatry, Indiana University School of Medicine, 355 W. 16th St., Goodman Hall, Suite 2800, Indianapolis, IN 46202, USA

^eDepartment of Neurology, Mayo Clinic, 4500 San Pablo Rd., Jacksonville, FL 32224, USA

^fDepartment of Neurology, Layton Aging and Alzheimer's Disease Center, Oregon Health & Science University, 3181 S.W. Sam Jackson Park Rd., Portland, OR 97239, USA

^gDepartment of Family Medicine and the Rush Alzheimer's Disease Center, Rush University Medical Center, 1750 W. Harrison Street., Suite 1000, Chicago, IL 60612, USA

^hDepartment of Neurosciences, University of California, San Diego School of Medicine, 9444 Medical Center Drive, Suite 1-100, La Jolla, CA 92037, USA

ⁱDepartment of Neurology, University of Kansas Medical Center, 4350 Shawnee Mission Parkway, MS 6002, Fairway, KS 66205, USA

^jDepartment of Neurology & Sanders-Brown Center on Aging, University of Kentucky, 800 South Limestone St., Lexington, KY 40536, USA

^kDepartment of Health & Community Systems, University of Pittsburgh School of Nursing, 415 Victoria Hall, 3500 Victoria St., Pittsburgh, PA 15261, USA

^lDepartment of Neurology, University of Washington, 325 9th Ave., 3rd Floor West Clinic, Seattle, WA 98104, USA

^mDepartment of Kinesiology-Occupational Therapy, University of Wisconsin Madison School of Education, 2170 Medical Sciences Center, 1300 University Ave., Madison, WI 53706, USA

Abstract

Objectives.—To examine factors that influence decision-making, preferences, and plans related to advance care planning (ACP) and end-of-life care among persons with dementia and their caregivers, and examine how these may differ by race.

Design.—Cross-sectional survey.

Setting.—13 geographically dispersed Alzheimer's Disease Centers across the United States.

Participants.—431 racially diverse caregivers of persons with dementia.

Measurements.—Survey on 'Care Planning for Individuals with Dementia'.

Results.—Respondents were knowledgeable about dementia and hospice care, indicated the person with dementia would want comfort care at the end stage of illness, and reported high levels of both legal ACP (e.g., living will; 87%) and informal ACP discussions (79%) for the person with dementia. However, notable racial differences were present. Relative to white persons with dementia, African American persons with dementia were reported to have a lower preference for comfort care (81% vs. 58%), and lower rates of completion of legal ACP (89% vs. 73%). Racial differences in ACP and care preferences were also reflected in geographic differences. Additionally, African American study partners had a lower level of knowledge about dementia, and reported a greater influence of religious/spiritual beliefs on the desired types of medical

treatments. Notably, all respondents indicated that more information about the stages of dementia and end-of-life health care options would be helpful.

Conclusions.—Educational programs may be useful in reducing racial differences in attitudes towards ACP. These programs could focus on the clinical course of dementia and issues related to end-of-life care, including the importance of ACP.

Keywords

dementia; Alzheimer's disease; advance care planning; care preferences; race; end-of-life care

Introduction

Advance care planning (ACP) provides an opportunity for individuals to communicate decisions about future health care preferences, under circumstances in which their ability to do so may be compromised. These decisions often include care directives, treatment preferences, and designation of a health care proxy, and help provide guidance for those who may need to make decisions on an individual's behalf. ACP can occur through formal mechanisms, including legal documents such as advance directives, living wills, and health care proxy designations, as well as informal mechanisms, such as verbal conversations with family members or caregivers.

In dementia, ACP poses unique challenges (Jones et al., 2016; Cotter et al., 2018). The protracted course of dementia is characterized by progressive cognitive decline and loss of decision-making capacity, followed by functional dependence and terminal illness. As dementia severity increases, involvement in medical decision-making by the person with dementia (PWD) gradually declines and transitions to a proxy, typically a family member (Hirschman et al., 2004). This poses challenges for the timing at which ACP documents are completed (Ryan et al., 2017). Nonetheless, ACP remains critically important for providing insight into an individual's health care goals. Additionally, there is considerable evidence that aggressive medical treatments at the end of life are associated with a lower quality of life for those with dementia, and reduced care satisfaction among care proxies (Engel et al., 2006; Givens et al., 2010; Mitchell et al., 2012; Teno et al., 2012). There is also evidence that care plans are associated with improved end-of-life outcomes, such as reduced health care utilization, both in persons with dementia (Dixon et al., 2018) and among mixed patient populations (Brinkman-Stoppelenburg et al., 2014).

Although a small number of retrospective studies have suggested that persons with dementia or cognitive impairment may be more likely to engage in some aspects of ACP relative to individuals without memory impairment (Choi et al., 2018; Jeznach et al., 2015), multiple factors may serve as barriers to the initiation of ACP in dementia and challenges to care decision-making (e.g., Denning et al., 2011; Hirschman et al., 2008; Jones et al., 2016; Noh et al., 2018; Van der Steen et al., 2014), including avoidance of the topic, need for education regarding ACP, and racial minority status, among others. Racial disparities in the extent of ACP and preferences for end-of-life care have been well documented in a range of chronic medical conditions. These studies have shown that African Americans are less likely to engage in ACP, and more likely to prefer aggressive rather than comfort care (Hong et al.,

2018; Kwak et al., 2005; Sanders et al., 2016). However, few studies have addressed racial disparities in ACP and care preferences in dementia. Although these studies have tended to echo the broader literature (e.g., Connolly et al., 2012; Lingler et al., 2008; Tjia et al., 2018; Triplett et al., 2008), additional quantitative work is needed. For example, a number of prior studies were conducted in nursing home settings, which may limit their generalizability to individuals living in the community. Additionally, prior well-powered quantitative studies on the extent of ACP in dementia have typically used retrospective designs and focused on formal ACP mechanisms, but have given less consideration to informal ACP approaches (such as verbal plans). Moreover, qualitative studies of smaller sample sizes have suggested informal approaches to care planning may prove important among African Americans (Moss et al., 2018a), and among individuals and families affected by dementia more generally (Dickinson et al., 2013; Givens et al., 2018; Ryan et al., 2017).

To our knowledge, no prior studies have surveyed a large sample of caregivers of persons with dementia living in the community with detailed questions about preferences, plans, and attitudes related to ACP and end-of-life care in the context of dementia, or examined racial differences in these measures. This question is especially important given dementia prevalence is on the rise, with racial and ethnic minority groups being particularly vulnerable. For example, according to an Alzheimer's Association (2019) estimate, African Americans are twice as likely to develop dementia as non-Hispanic whites.

In this study, we surveyed 431 racially and geographically diverse caregivers of persons with dementia who are enrolled in Alzheimer's Disease Centers (ADC) across the United States. The survey included questions about the caregiver's understanding of Alzheimer's disease (AD) and dementia, and hospice care; perceptions about the PWD's primary goals for medical care; the PWD's ACP status; the role of religious/spiritual beliefs in decisions about medical care; and questions about the helpfulness of more information about these topics. The overall goal of this study was to gain a more comprehensive understanding of the factors that influence decision-making regarding ACP among persons with dementia and their caregivers, and to examine differences by race. Based on prior literature, we hypothesized that African American respondents would be less likely than white respondents to complete advance directives, and more likely to endorse a desire for more aggressive treatment at the end of life. We also hypothesized that these racial differences would be reflected in geographic differences in attitudes about ACP.

Methods

Setting and Sample

Participants were part of the National Institute on Aging's ADC program. This program supports research on AD and related disorders, in part through the establishment of longitudinal cohorts of research volunteers that undergo standardized cognitive and clinical evaluations. Most ADCs also acquire biomarker information on their participants (e.g., derived from blood or imaging procedures). The program currently includes >30 Centers located at major medical institutions across the U.S. All ADCs were invited to participate and data were gathered from 431 individuals from 13 ADCs nationwide (almost half of the ADCs funded at the time the study began). Every effort was made to include

ADCs that represented a wide geographic distribution. All participating sites obtained Institutional Review Board (IRB) approval, with documentation of IRB compliance sent to the coordinating center at the Johns Hopkins Alzheimer's Disease Research Center (JHADRC).

Each ADC follows their participants annually with a standardized comprehensive clinical and cognitive battery, known as the Uniform Data Set (UDS; Beekly et al., 2007; Morris et al., 2006; Weintraub et al., 2009). Information from the UDS is the primary source of information on which clinical syndromic diagnoses are based (e.g., normal, mild cognitive impairment, dementia).

A study partner, typically a family member, provides information about how the participant is functioning in daily life. For the present study, each ADC was asked to recruit study partners of persons with dementia enrolled at their center to complete the survey. The study partner was expected to meet the following criteria: 1) not a paid caregiver for the PWD, 2) able to consent to the study, and 3) able to communicate in English. Each study partner was administered a survey (described below), which is the source of the data examined here.

Survey Development, Collection, and Submission

The 'Care Planning for Individuals with Dementia' survey was designed to evaluate preferences and plans related to end-of-life care among individuals across various stages of dementia, and assess factors that might influence care plans and decisions. The survey is included in the online Supplementary Materials (Appendix A1, attached to the electronic version of this paper at <https://www.cambridge.org/core/journals/international-psychogeriatrics>), along with details about the pilot phase of the study during which the survey was designed and tested (Appendix A2). This survey is not part of the UDS.

The survey was composed of a series of multiple choice questions on the following topics: 1) knowledge and perceptions about AD and dementia, including changes that occur throughout the clinical course of dementia and when information about the clinical course of dementia should be provided; 2) extent to which the PWD is capable of participating in medical decisions currently and over time; 3) whether the PWD has completed different types of ACP, including medical power of attorney, living will, and discussions about medical care preferences; 4) perceptions about the PWD's primary goals for medical care (intensive, basic, comfort), whether further discussion about goals for medical care is needed, and the extent to which religious/spiritual beliefs influence medical care decisions; 5) perceptions about hospice care; 6) level of comfort with survey topics; and 7) the helpfulness of more information about the survey topics (e.g., stages of dementia, end-of-life care), and how this information should be provided. Where necessary, the survey included in-line definitions of key terms/concepts. For example, basic medical care was defined as the use of some medical treatments, such as treatment with antibiotics and fluids, and hospitalization for sudden illnesses, but not intensive care (e.g., cardiopulmonary resuscitation, feeding tubes). By comparison, comfort care was defined as the use of treatments to relieve uncomfortable symptoms (e.g., medications for pain relief, oxygen for breathing assistance) (see the survey for more details).

ADC staff at participating sites were asked to administer the survey to study partners of persons with dementia who agreed to participate, either over the phone or during an in-person visit to the ADC. The survey questions were answered by the study partner after completing the informed consent process. General background information on the study partner and PWD was completed using information obtained as part of the UDS, including: demographics (age, sex, years of education, race, ethnicity), Clinical Dementia Rating (CDR; Morris, 1993), dementia etiology, and information about the frequency of contact between the study partner and the PWD. Completed surveys were electronically submitted to the JHADRC coordinating center via a password-protected site. Sites received \$25 per survey completed to offset the effort associated with data collection. Data were collected from 09/2015-09/2017.

Statistical Analyses

Item-level data and summary variables were quantified using proportions for categorical variables and means with standard deviations for continuous variables. In addition, four summary variables were created. The ‘knowledge about dementia’ score summarized mean accuracy on 10 true/false questions assessing knowledge about AD and dementia. Questions about the extent of ACP that had occurred were summarized in three dichotomous variables. The ‘Legal ACP’ variable reflected the presence of formal ACP for the PWD (1 if medical power of attorney *or* living will completion was reported; otherwise 0). The ‘ACP discussions only’ variable reflected the completion of informal ACP only (1 if the study partner reported engaging in discussions with the PWD about medical treatments wanted in the *absence of* completing formal ACP, otherwise 0). Lastly, the ‘Any ACP’ variable reflected engagement in any type of ACP (1 if formal or informal ACP was reported, otherwise 0).

Analyses by race were run by either the race of the study partner, or race of the PWD, as specified in the Results. The race variables were based on self-report, as documented in the UDS. The small number of individuals who did not identify as white or African American race were excluded from these analyses. Racial differences in demographic variables were compared with t-tests and chi-square tests, as appropriate. To evaluate the specific hypotheses mentioned above, selected outcomes were defined a priori, and racial differences were examined with linear regression models for continuous variables and logistic regression models for binary variables, with a significance level set at $p < 0.05$. Due to missingness in some demographic variables, the effect of race on the outcomes of interest were first evaluated in unadjusted univariate models, followed by multivariate models adjusted for the following study partner or PWD characteristics: age (continuous), sex (dichotomous), education (dichotomous, ≤ 12 vs. >12 years of education), and Hispanic/Latino ethnicity (dichotomous). There were few differences in the patterns of results between unadjusted and adjusted models; model results therefore reflect adjusted analyses, unless otherwise indicated. Analyses were run in SPSS (version 22.0).

Results

Demographics

Demographic characteristics of the study partners (survey respondents) and persons with dementia are shown in Table 1. Study partners had a mean age of 68.4 years, 69% were female, and 85% had >12 years of education. A total of 375 of the study partners were white (87%) and 42 were African American (10%). Study partner demographics did not differ by race (all $p > .05$). Study partners tended to be a relative (spouse, $n = 319$, 74%; child, $n = 98$, 21%) of the PWD, and living with the PWD at the time of survey completion ($n = 331$, 77%). Of those not living together, in-person visits tended to occur at least weekly ($n = 82/100$, 82%).

The persons with dementia had a mean age of 76.3 years, 46% were female, 76% had >12 years of education, and were primarily white ($n = 380$, 88%) or African American ($n = 44$, 10%). Varying dementia disease stages were represented. Approximately half ($n = 201$, 48%) were moderate-to-severely impaired at the time of survey completion (as indicated by a CDR score ≥ 2), and 216 individuals had mild dementia, as reflected by a CDR of 1 or 0.5 (note that individuals with CDR = 0.5 span a wide range of severity, and the upper end can be consistent with mild dementia). The majority had a primary diagnosis of dementia due to AD ($n = 341$, 80%). As shown in Table 1, the African American persons with dementia were older ($t(420) = -3.31$, $p < .001$), more likely to be female ($\chi^2(1, N = 424) = 4.53$, $p = .03$), had fewer years of education ($\chi^2(1, N = 419) = 7.98$, $p = .005$), and more likely to be moderately-to-severely impaired (CDR 0-1 vs. 2+; $\chi^2(1, N = 412) = 6.12$, $p = .01$).

Knowledge About Dementia, Hospice Care, and the Desire for More Information

Knowledge about dementia.—Responses to questions related to knowledge about dementia, hospice care, and the desire for more information are shown in Table 2. Overall, survey respondents had a high level of basic knowledge about dementia and AD, as indicated by a mean score of 8.4/10 on the true/false questions. However, knowledge scores were significantly lower for African American relative to white respondents (Table 4; $\beta = -0.30$, $p < .001$). Across all respondents, accuracy was >80% on all but three questions (see Table 2), two of which concerned knowledge about later disease stages. Similarly, respondents reported having the highest degree of understanding about the mild (96%) and moderate (93%) stages of dementia, but knew less about the severe/late stage (78%). Nonetheless, respondents understood that the PWD's ability to participate in medical decisions declines with disease progression (98%), and that knowing what to expect as dementia progresses would help in planning for future medical decisions (99%). Respondents also reported that the *family* of the PWD should be informed about what happens in the late stage of the disease within about a year after a diagnosis is received (74%). However, a much smaller proportion believed that the PWD should be informed about what happens in the late stage of the disease in this same time frame (53%). The majority of respondents also reported they would trust and accept a health care provider's opinion that a PWD was in the end stage of disease (91% 'completely' or 'somewhat').

Knowledge about hospice care.—The majority of respondents reported having at least some knowledge about hospice care (85%) and their answers to specific questions about hospice reflected this. For example, 91% knew that hospice includes pain and symptom management, and the majority believed that hospice relieves suffering (89%), rather than believing that a decision to use hospice care means giving up (10%).

Desire for more information.—Despite reporting a good degree of knowledge about dementia and hospice care, the majority of respondents indicated it would be helpful to have more information about the stages of dementia, health care decision-making, treatment options, and end-of-life care (74%). This desire for more information did not differ by respondent race (Table 4; OR = 2.86, 95% CI (0.98, 8.34), $p = .06$). Of those who indicated that more information would be helpful, more information about the stages of dementia, end-of-life care, and treatment options were most commonly endorsed, of the options available. Respondents indicated that it would be most helpful for this information to be provided through conversations with health care providers, brochures, and educational seminars.

Perceptions About Primary Goals for Medical Care

Findings regarding discussions about care plans, primary goals for medical care, and extent of ACP are shown in Table 3. On average, study partners indicated that family members would be able to openly discuss end-of-life care decisions, and would be supportive of the decisions made by each individual. Approximately 40% of respondents indicated that religious/spiritual beliefs would have at least some influence ('somewhat' or 'a great deal') on the type of medical treatments that might be wanted (beliefs of PWD, $n = 161$, 37%; beliefs of study partner, $n = 179$, 42%). Defined in this way, the influence of religious/spiritual beliefs on the type of medical treatments wanted differed by race (see Table 4), as there was a greater influence of religious/spiritual beliefs among African American relative to white respondents (beliefs of PWD, by race of PWD, OR = 2.03, 95% CI (1.05, 3.90), $p = .04$; beliefs of study partner, by race of study partner, unadjusted OR = 2.16, 95% CI (1.13, 4.14), $p = .02$; adjusted OR = 1.97, 95% CI (0.97, 4.01), $p = .06$).

Study partners were asked about their beliefs about the level of care the PWD would want at two different time frames. Study partners most commonly indicated that basic care would be wanted *at present* (45%), but that comfort care would be wanted *at the end stage of illness near the end of life* (78%). Preference for comfort care (relative to other types of care) differed by the race of the PWD (Table 4). A lower preference for comfort care at the end stage of illness was reported for African American persons with dementia (OR = 0.32, 95% CI (0.16, 0.64), $p = .001$). This effect was not significant for care preferences at present (OR = 0.38, 95% CI (0.14, 1.02), $p = .06$).

Extent of Advance Care Planning Related to Future Medical Decisions

Variables reflecting ACP related to future medical decisions for the PWD are shown in Table 3, including responses to questions about medical power of attorney, living will, and informal discussions, as well as the ACP summary variables. The majority of study partners reported being the health care proxy for the PWD ($n = 402$, 94%). The majority

of respondents also reported that at least some form of ACP had occurred ('any ACP', 94%), reflecting the combination of both formal ACP mechanisms ('legal ACP', 87%) and informal discussions about medical treatments ('informal ACP', 79%; i.e., engagement in discussions about medical treatments irrespective of formal ACP completion). Only a small number of respondents reported that *only* discussions about medical treatments at the end of life had occurred in the absence of legal action ('ACP discussions only', 7%). Despite high rates of ACP, respondents tended to indicate a need for further discussions about the types of medical care wanted by the PWD.

There were, however, notable racial differences in the types of ACP that had taken place (Table 4). Relative to white persons with dementia, a lower proportion of African American persons with dementia had completed 'legal ACP' (89% vs. 73%; OR = 0.32, 95% CI (0.15, 0.71), $p = .005$). However, these differences were not significant when formal and informal forms of ACP were considered together ('any ACP', 95% vs. 88%; OR = 0.37, 95% CI (0.13, 1.11), $p = .08$), or when considering informal ACP ('Informal ACP' (Q24), 80% vs. 70%; OR = 0.57, 95% CI (0.28, 1.17), $p = .13$; 'ACP discussions only', 6% vs. 14%; OR = 2.56, 95% CI (0.88, 7.46), $p = .08$).

Differences in Goals for Medical Care and ACP Across Geographic Regions

Prior studies have shown geographic differences in the preponderance of intensive medical treatments at the end of life (e.g., Gozalo et al., 2011; Mitchell et al., 2003; Teno et al., 2002). We therefore examined regional differences in race and attitudes related to ACP. ADC sites were categorized into four regions: Southeast (3 sites in FL, KY, MD), Northeast (3 sites in MA and PA), Midwest (5 sites in IL, IN, KS, MN, WI), and West (3 sites in CA, OR, WA). The percentage of African American persons with dementia was highest in the Southeast ($n = 11/66$, 17%) and Midwest ($n = 18/125$, 14%) relative to the Northeast ($n = 11/137$, 8%) and West ($n = 4/103$, 4%). The differential geographic distribution of individuals by race reflected regional differences in attitudes toward ACP and medical care at the end of life. On average, preference for comfort care at the end stage of illness was lowest among persons with dementia living in the Southeast (71%) and Midwest (73%; vs. Northeast, 83%; West, 83%). Similarly, persons with dementia living in the Southeast were reported to have the lowest completion of 'legal ACP' (70%; vs. Midwest, 86%; Northeast, 95%; West, 88%), and the highest completion of ACP discussions in the absence of legal action ('ACP discussions only': Southeast, 26%; Midwest, 6%; Northeast, 2%; West, 3%).

Level of Comfort with Survey Topics

The majority of respondents indicated that they were comfortable with the survey topics ($n = 391$, 91% 'somewhat comfortable' or 'very comfortable'; 1% 'very uncomfortable').

Discussion

The present study examined the extent of advance care planning among a well-characterized, racially and geographically diverse sample of 431 study partners of persons with dementia, and explored factors that affect decisions about ACP, attitudes towards end-of-life care in dementia, and racial differences in these measures. Overall, high rates of ACP were

reported, consistent with recent reports (Choi et al., 2018; Jeznach et al., 2015). There were, however, notable racial differences in attitudes toward ACP between African American and white respondents. African American persons with dementia, as reported by their study partners, were less likely than white persons with dementia to have completed formal documents reflecting ACP at the end of life. Additionally, African Americans were less likely to prefer comfort care as the primary goal of care and thus more likely to indicate a preference for more intensive forms of medical care at the end of life.

The lower rates of legal ACP completion among African Americans, as assessed by a medical power of attorney or living will, were in line with our hypothesis, and with a number of prior studies among persons with dementia (Lingler et al., 2008; Tjia et al., 2018; Triplett et al., 2008) and in the broader ACP literature (Hong et al., 2018; Sanders et al., 2016). However, when both formal and informal approaches were considered together, racial differences in the extent of ACP were attenuated to non-significant levels. While there has been a recent emphasis on the importance of informal approaches to ACP, both among persons with dementia generally (Dickinson et al., 2013; Ryan et al., 2017), as well as among African Americans with dementia (Moss et al., 2018a), only formal documents are recognized by the health care system. It is therefore difficult for those without formal documents to have their wishes recognized at the end of the life. Nonetheless, in the absence of formal documents, informal approaches may enable caregivers or family members to provide the default decision-maker with at least some guidance, for making care decisions that are in-line with an individual's wishes (Givens et al., 2018).

When considering type of medical care wanted at end stage illness, a preference for comfort care was less likely to be reported for African American compared to white persons with dementia (58% vs. 81%, respectively). This finding was in line with our hypothesis, and prior literature, which has reported similar preferences among African Americans in other disease conditions (e.g., Hopp and Duffy, 2000; Kwak and Haley, 2005; Sanders et al., 2016).

Reasons for these racial differences in legal ACP and care preferences are not well understood, though two recent reviews suggest a complex interplay of factors may be involved (Hong et al., 2018; Sanders et al., 2016). For example, Sanders et al. (2016) proposed that care planning and preferences among African Americans are influenced by historical factors that operate at personal, interpersonal, and structural levels. In their model, social factors (e.g., sociodemographic disadvantage, mistrust, health care access and literacy), together with personal factors (e.g., religion and spirituality, family and community, beliefs about death) converge to impact ACP, and may result in a preference for informal approaches to ACP and more aggressive end of life care. Supporting this type of multi-factorial model, we found that African Americans and white respondents differed in their knowledge about dementia and AD, and in the influence of religious/spiritual beliefs on medical treatment preferences.

The present study has several limitations. Only 10% of participants were African American. Although modest, this proportion is in line with the proportion of black/African American individuals in the U.S. population (~13%), as per the 2010 U.S. Census. There are

several factors that limit the generalizability of this study to the U.S. population at large. For example, individuals followed through the ADC programs are research study volunteers, typically required to have a study partner, who agree to be followed with annual assessments. Likely due to these requirements, they tend to be well educated, and more knowledgeable about dementia than would be found outside the ADC setting. Additionally, ADCs are located in major medical centers, primarily in urban settings. These characteristics may differentiate our participants from persons with dementia who are not followed by ADC programs. ADC study partners are not required to be caregivers or decisional proxies for the PWD, though in most cases both are true, as reflected by the fact that 95% of study partners in this study were either a spouse or child. Additionally, the survey topic may have deterred some from participating in the study, and this might be especially true for individuals who have not engaged in ACP. Lastly, due to funding limitations, it was not possible to prepare a survey in Spanish; we therefore have little information about attitudes toward ACP by individuals with a Hispanic background, who represent a significant portion of the U.S. population.

This study also has a number of strengths. To our knowledge, it is the largest in-depth, community-based assessment of attitudes towards ACP and end-of-life care among study partners of persons with dementia. While a number of prior studies have examined ACP in the context of dementia, studies with larger sample sizes have tended to be retrospective reviews of existing records or study variables (e.g., Choi et al., 2018; Jeznach et al., 2015; Lingler et al., 2008; Tjia et al., 2018), placing limits on the amount of information that can be extracted, whereas studies collecting more detailed information about attitudes towards ACP have tended to be qualitative, with smaller sample sizes (e.g., Hirschman et al., 2008; Moss et al., 2018a; Ryan et al., 2017). Moreover, even fewer studies have explicitly addressed racial differences related to these issues, in the context of dementia (Bonner et al., 2014; Connolly et al., 2012; Moss et al., 2018a, 2018b).

Given the evidence noted above that intensive medical treatments at the end of life are associated with a lower quality of life for persons with dementia, and reduced care satisfaction among care proxies, the question arises of whether it would be valuable to develop educational programs that provide information about end-of-life care planning, options, and outcomes for minority populations. The results of the present study suggest that these programs might first focus on the clinical course of dementia, given that African American respondents scored lower on questions related to knowledge about dementia and AD, and were more likely to indicate that information about the stages of disease progression would be helpful (relative to white respondents). Such knowledge about disease trajectory may be important to understanding the utility of ACP in the context of dementia (Lai et al., in press). Survey respondents also provided several preferred avenues by which educational content might be provided, and attitudes changed. When asked which sources of information about end-of-life care would be most helpful, the overwhelming majority of respondents said a conversation with a health care provider would be most beneficial, though brochures and educational seminars were also cited as valuable methods of distributing information. This might provide an opening for addressing the role of ACP in ensuring that end-of-life care is concordant with an individual's wishes and based on an understanding of what the alternatives entail, though the timing of these programs, relative to when a

PWD receives their diagnosis, would have to be carefully considered (Lai et al., in press). If resources for educational programs are limited, the present findings suggest that it might be possible to have a meaningful impact on the use of intensive medical care at the end of life by focusing on selected racial/ethnic minority groups and/or geographic regions. However, since we found no racial differences in the desire for more information about the course of dementia and treatment options (as hypothesized), educational resources should ideally be made available to anyone impacted by dementia, early in the clinical disease course.

Educational programs could be targeted to caregivers, family members (Desin et al., 2016), and individuals in early disease stages alike, and primarily focus on the clinical course of dementia and issues related to end-of-life care, including health care decision-making and treatment options. To date, evidence for the efficacy of interventions to increase participation in care planning among persons with dementia is limited (Bryant et al., 2018), although discussions related to goals of care may be associated with an increased acceptance of dementia diagnosis among health care proxies (Givens et al., 2018). Additionally, prior studies in other health conditions have found that knowledge about ACP facilitates its completion (Hong et al., 2018; Morrison et al., 2004), and ACP interventions may be effective in increasing ACP and receipt of care that is concordant with a patient's wishes (Houben et al., 2014). Additional studies are therefore needed to systematically evaluate the efficacy of these types of educational approaches for increasing knowledge, changing attitudes related to end-of-life care and ACP, and improving earlier engagement in ACP, especially among racial/ethnic minority populations.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1.

Demographics of study partners and persons with dementia.

Variable	All Participants			By Race	
	All Participants	N missing	White	African American	
<i>Study partners</i>					
N	431	0	375	42	
Age, mean (SD)	68.4 (11.6)	25	68.8 (11.4)	65.2 (13.6)	
	N (%)	N missing	N (%)	N (%)	
Sex, female	296 (68.7)	0	252 (67.2)	33 (78.6)	
Education 12 years	352 (84.8)	16	306 (84.5)	34 (85.0)	
Race	375 (87.2)	1	-	-	
	African American	-	-	-	
	Other	-	-	-	
Ethnicity	16 (3.7)	1	10 (2.7)	2 (4.8)	
	Unknown	-	2 (0.5)	1 (2.4)	
<i>Persons with dementia</i>					
N	431	0	380	44	
Age, mean (SD)	76.3 (10.2)	2	75.7 (10.2)	81.0 (8.7) *	
	N (%)	N missing	N (%)	N (%)	
Sex, female	198 (45.9)	0	169 (44.5)	27 (61.4) *	
Education 12 years	324 (76.1)	5	292 (77.7)	25 (58.1) *	
Race	380 (88.2)	0	-	-	
	African American	-	-	-	
	Other	-	-	-	
Ethnicity	14 (3.2)	0	11 (2.9)	3 (6.8)	
	Unknown	-	1 (0.3)	0 (0.0)	
CDR 0	2 (0.5)	12	2 (0.5)	0 (0.0)	
0.5	63 (15.0)	-	57 (15.5)	4 (9.1)	
1	153 (36.5)	-	139 (37.8)	11 (25.0)	

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Variable	All Participants		By Race	
	All Participants	N missing	White	African American
2-3	201 (48.0)	-	170 (46.2)	29 (65.9) *

* Asterisks indicate significant differences by race of the person with dementia ($p < .05$).

Note, the demographics of the study participants are comparable to the demographics of individuals aged 65+ in the U.S. population as a whole, based on U.S. Census estimates.

Table 2.

Knowledge about dementia, hospice care, and the desire for more information.

Variable	Accuracy (%)	N missing
Basic knowledge about Alzheimer's disease and dementia		
Alzheimer's disease is one type of dementia. (Q1)	94.2	0
If trouble with memory and confused thinking appears suddenly, it is likely due to Alzheimer's disease. (Q2)	90.7	2
Trouble handling money or paying bills is a common early symptom of Alzheimer's disease. (Q3)	81.9	1
When a person with dementia becomes agitated, a medical examination might reveal other health problems that caused the agitation. (Q4)	90.9	1
In rare cases, people have recovered from Alzheimer's disease. (Q5)	93.0	1
Once people have dementia due to Alzheimer's disease, they are no longer capable of making informed decisions about their own care. (Q6)	72.1	1
When people with dementia begin to have difficulty taking care of themselves, caregivers should take over right away. (Q7)	69.9	2
Alzheimer's disease cannot be cured. (Q8)	94.9	2
Eventually, a person with dementia due to Alzheimer's disease will need 24-hour supervision. (Q9)	90.4	3
After symptoms of dementia due to Alzheimer's disease appear, the average life expectancy is 6 to 12 years. (Q10)	66.2	8
Mean (SD) knowledge about dementia score (for above questions; /10)	8.4 (1.3)	0
Knowledge about what happens in each stage of dementia		
Mild stage when memory problems, like forgetting conversations, are noticeable to family or friends. (Q13a)	96.3	0
Moderate stage when help is needed with some day-to-day activities, like preparing sandwiches. (Q13b)	92.6	0
Severe or late stage when extensive help is needed with daily activities, like bathing or eating. (Q13c)	78.3	0
Agreement with statements about dementia		
Individuals with dementia will have more difficulty making medical decisions for themselves as their disease progresses. (Q11)	97.7	0
Knowing what to expect as dementia progresses can help patients and families plan for medical decisions in the future. (Q12)	98.6	1
Opinions regarding when health care providers should provide information about the late stage of disease		
When is the best time for health care providers to inform patients about what happens in the late stage of the disease? (Q14)		
When the patient first gets the diagnosis	43.4	0
About a year after the patient has had the diagnosis	9.5	-
After the patient has had the disease for a few years	12.8	-
When the patient enters the end-stage of the disease	2.6	-
Never	12.8	-
Don't know	19.0	-
% 'strongly agree' or 'agree'		
% endorsed		

When is the best time for health care providers to inform family members about what happens in the late stage of the disease? (Q15)	% endorsed	N missing
When the patient first gets the diagnosis	61.5	0
About a year after the patient has had the diagnosis	12.3	-
After the patient has had the disease for a few years	14.6	-
When the patient enters the end-stage of the disease	3.9	-
Never	0.2	-
Don't know	7.4	-
Statements about hospice care		
Level of knowledge about hospice care. (Q36)	85.3	N missing 4
Hospice care focuses on caring, not curing. (Q37)	93.9	N missing 3
Hospice care can be provided at home, in a hospice center or in a nursing home. (Q37)	95.1	-
Hospice care includes managing the patient's pain and symptoms. (Q37)	90.7	-
Hospice care provides bereavement care and counseling to family and friends. (Q37)	79.4	-
Don't know. (Q37)	0.7	-
% 'strongly agree' or 'somewhat agree'		N missing
Hospice care relieves suffering. (Q38a)	89.0	4
Hospice care speeds up or quickens the dying process. (Q38b)	9.7	8
A decision to use hospice care is giving up. (Q38c)	9.8	11
Helpfulness of more information about the course of dementia and treatment options		
More information about the stages of dementia, health care decision making, treatment options or end-of-life care would be helpful. (Q41)	73.8	N missing 3
Stages of dementia and what usually happens as dementia progresses. (Q41a)	77.8	-
Health care decision-making and treatment options. (Q41a)	68.7	-
End-of-life care for persons with dementia. (Q41a)	74.1	-
Financial issues related to caring for someone with dementia. (Q41a)	57.9	-
Legal issues related to caring for someone with dementia. (Q41a)	52.5	-
Means of providing more information about the course of dementia and treatment options (41b)		
Brochures (Q41b)	66.5	N missing -
Videos (Q41b)	40.2	-
Educational seminars (Q41b)	59.5	-

-	20.9	
-	75.3	
-	14.9	
-	16.8	

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Table 3. Discussions about care plans, primary goals for medical care, and extent of advanced care planning.

Variable	% 'strongly agree' or 'somewhat agree'	N missing
Discussing end-of-life care and treatment options with family members		
My family members would support the level of treatment that he/she would or would not want at the end of life. (Q30a)	93.7	2
My family is able to openly discuss issues about end-of-life care. (Q30b)	86.7	1
In my family, we feel each member should make his/her own end-of- life care decisions. (Q30c)	84.1	3
Members of my family would be better able to discuss end-of-life care and treatment options if they had more information. (Q30d)	66.7	1
My family strives to agree on important decisions. (Q30e)	83.1	0
Influence of religious or spiritual beliefs in medical treatments wanted		
Influence of patient's beliefs (Q32)		
A great deal	% endorsed 20.2	N missing 1
Somewhat	17.2	-
A little bit	10.7	-
Not at all	42.8	-
Don't know	9.1	-
Influence of study partner's beliefs (Q34)		
A great deal	% endorsed 21.7	N missing 2
Somewhat	20.0	-
A little bit	13.5	-
Not at all	42.0	-
Don't know	2.8	-
Primary goals for medical care: Type of care wanted		
Level of medical care study partner believes is wanted at the present time (Q25)		
Intensive	% endorsed 28.8	N missing 1
Basic	44.9	-
Comfort	22.1	-
Don't know	4.2	-
Level of medical care study partner believes is wanted at the end stage of illness near the end of life (Q26)		
	% endorsed	N missing

	Intensive		3.3	1
	Basic		11.9	-
	Comfort		78.4	-
	Don't know		6.5	-
	Extent of advanced care planning		% endorsed	N missing
	Study partner is health care proxy for individual with dementia (Q21)		93.5	1
	Don't know		2.1	
	Formal ACP - Medical power of attorney naming a health care proxy has been completed (Q22)		81.8	2
	Don't know		6.8	-
	Formal ACP - Living will describing medical treatments wanted has been completed (Q23)		74.9	0
	Don't know		6.0	-
	Informal ACP - Study partner and individual with dementia have had discussions about medical treatments wanted (Q24)		79.0	3
	Don't know		0.5	-
	ACP summary variables		% completed	N missing
	Any ACP - some form of formal or informal ACP has occurred		94.2	1
	Legal ACP - some form of formal ACP has occurred		87.0	0
	ACP discussions only - informal discussions have occurred, without legal action		7.0	3
	Need for additional discussions about types of medical treatment wanted			
	Further discussion between individual with dementia and study partner is needed (Q27)		% endorsed	N missing
	Yes		38.8	1
	No		26.7	-
	No because no longer capable to have discussion		30.5	-
	Don't know		4.0	-
	Health care provider and individual with dementia have discussed type of medical treatments wanted (Q28)		% endorsed	N missing
	Yes		30.9	1
	No		50.0	-
	Don't know		19.1	-
	Further discussion between individual with dementia and health care provider is needed (Q29)		% endorsed	N missing
	Yes		36.5	1
	No		25.3	-

-	7.9			
-	30.2	No because no longer capable to have discussion		
		Don't know		

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Table 4.

Differences in outcome variables by race of respondent or person with dementia.

Variable	White		African American	
	Mean (SD) accuracy	N (%) endorsed	Mean (SD) accuracy	N (%) endorsed
Basic knowledge about Alzheimer's disease and dementia by respondent race				
Knowledge about AD and dementia (score; /10)	8.5 (1.2)		7.4 (1.4)	
Helpfulness of more information about the course of dementia and treatment options by respondent race				
More information about the stages of dementia, health care decision-making, treatment options or end-of-life care would be helpful. (Q41)	271/373 (72.7)		34/41 (82.9)	
Stages of dementia and what usually happens as dementia progresses. (Q41a)	208/271 (76.8)		28/34 (82.4)	
Health care decision-making and treatment options. (Q41a)	186/271 (68.6)		22/34 (64.7)	
End-of-life care for persons with dementia. (Q41a)	204/271 (75.3)		21/34 (61.8)	
Financial issues related to caring for someone with dementia. (Q41a)	154/271 (56.8)		20/34 (58.8)	
Legal issues related to caring for someone with dementia. (Q41a)	136/271 (50.2)		20/34 (58.8)	
Means of providing more information about the course of dementia and treatment options by respondent race				
Brochures (Q41b)	173/271 (63.8)		28/34 (82.4)	
Videos (Q41b)	102/271 (37.6)		18/34 (52.9)	
Educational seminars (Q41b)	158/271 (58.3)		24/34 (70.6)	
Social media (Q41b)	43/271 (15.9)		8/34 (23.5)	
Conversation with clergy (Q41b)	38/271 (14.0)		8/34 (23.5)	
Conversation with health care provider (Q41b)	205/271 (75.6)		26/34 (76.5)	
Influence of religious or spiritual beliefs in medical treatments wanted				
Influence of patient's beliefs by race of the person with dementia (Q32)				
A great deal	78/379 (20.6)		9/44 (20.5)	
Somewhat	57/379 (15.0)		15/44 (34.1)	
A little bit	42/379 (11.1)		4/44 (9.1)	
Not at all	169/379 (44.6)		10/44 (22.7)	
Don't know	33/379 (8.7)		6/44 (13.6)	
Influence of study partner's beliefs by respondent race (Q34)				
A great deal	83/373 (22.3)		9/42 (21.4)	

Somewhat	68/373 (18.2)	16/42 (38.1)
A little bit	53/373 (14.2)	3/42 (7.1)
Not at all	158/373 (42.4)	13/42 (31.0)
Don't know	11/373 (2.9)	1/42 (2.4)
Primary goals for medical care: type of care wanted by race of the person with dementia		
Level of medical care study partner believes is wanted at the present time (Q25)		
Intensive	104/380 (27.4)	18/43 (41.9)
Basic	171/380 (45.0)	17/43 (39.5)
Comfort	89/380 (23.4)	6/43 (14.0)
Don't know	16/380 (4.2)	2/43 (4.7)
Level of medical care study partner believes is wanted at the end stage of illness near the end of life (Q26)		
Intensive	10/380 (2.6)	4/43 (9.3)
Basic	43/380 (11.3)	7/43 (16.3)
Comfort	307/380 (80.8)	25/43 (58.1)
Don't know	20/380 (5.3)	7/43 (16.3)
Extent of advanced care planning by race of the person with dementia		
Formal ACP - Medical power of attorney naming a health care proxy has been completed (Q22)		
Don't know	314/378 (83.1)	31/44 (70.5)
Don't know	24/378 (6.3)	5/44 (11.4)
Formal ACP - Living will describing medical treatments wanted has been completed (Q23)		
Don't know	296/380 (77.9)	21/44 (47.7)
Don't know	25/380 (6.6)	1/44 (2.3)
Informal ACP - Study partner and individual with dementia have had discussions about medical treatments wanted (Q24)		
Don't know	303/378 (80.2)	30/43 (69.8)
Don't know	1/378 (0.3)	1/43 (2.3)
ACP summary variables		
Any ACP - some form of formal or informal ACP has occurred		
	361/380 (95.0)	38/43 (88.4)
Legal ACP - some form of formal ACP has occurred		
	337/380 (88.7)	32/44 (72.7)
ACP discussions only - informal discussions have occurred, without legal action		
	24/378 (6.3)	6/43 (14.0)