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M E D I C I N E

Attitudes towards advance care planning among persons with dementia and their caregivers

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Background

Advance care planning (ACP) – opportunity to communicate decisions about health care preferences under circumstances in which ability to do so may be compromised (e.g., care directives, treatment preferences, designation of health care proxy)

In the context of dementia, ACP poses unique challenges¹

- With ↑ dementia severity, PWD's medical decision making gradually declines and transitions to proxy, posing challenges for timing at which ACP is completed²
- Aggressive medical treatments (at end of life) associated with lower quality of life for PWD and reduced satisfaction among care proxies³
- Care plans are associated with improved end-of-life outcomes⁴ (e.g., reduced health care utilization)

Multiple factors may serve as barriers to the initiation of ACP and challenges to care decision making⁵

- Avoidance of topic; need for education regarding ACP; racial minority status; among others

¹Cotter et al., 2018; Jones et al., 2016; ²Hirschman et al., 2004; Ryan et al., 2017; ³Engel et al., 2006; Givens et al., 2010; Mitchell et al., 2012; Teno et al., 2012;

⁴Dixon et al., 2018; see also Brinkman-Stoppelenburg et al., 2014; ⁵Dening et al., 2011; Hirschman et al., 2008; Jones et al., 2016; Noh & Kwak, 2018

Goals of Study

Goal 1: Survey a large sample of caregivers of PWD living in the community with detailed questions about preferences, plans, and attitudes related to ACP and end-of-life care

- Gain a more comprehensive understanding of the factors that influence decision-making on these topics

Goal 2: Examine differences in these measures by race

- In a range of chronic medical conditions, racial disparities in the extent of ACP and preferences for end-of-life care have been well documented
 - African American individuals less likely to engage in ACP, and more likely to prefer aggressive rather than comfort care¹
 - In dementia, few studies have addressed racial differences in ACP and care preferences²

Participants and Methods

Surveyed 431 racially and geographically diverse caregivers (study partners) of PWD from 13 ADCs nationwide

‘Care Planning for Individuals with Dementia’ survey

- Topics addressed (via multiple choice questions):
 - **Knowledge and perceptions about AD and dementia**, and hospice care
 - Extent to which PWD is capable of participating in medical decisions (currently; over time)
 - **Whether the PWD has completed different types of ACP**
 - **Perceptions about PWD’s primary goals for medical care**, whether further discussions are needed
 - **Extent to which religious/spiritual beliefs influence medical care decisions**
 - Level of comfort with survey topics
 - **Helpfulness of more information about survey topics**, and how this information should be provided

Demographics

Study partners

	All Participants	By Race	
		<u>White</u>	<u>African American</u>
N	431	375	42
Age, mean (SD)	68.4 (11.6)	68.8 (11.4)	65.2 (13.6)
Female sex, N (%)	296 (68.7)	252 (67.2)	33 (78.6)
Education ≥ 12 years, N (%)	352 (84.8)	306 (84.5)	34 (85.0)

Persons with dementia

	All Participants	By Race	
		<u>White</u>	<u>African American</u>
N	431	380	44
Age, mean (SD)	76.3 (10.2)	75.7 (10.2)	81.0 (8.7) *
Female sex, N (%)	198 (45.9)	169 (44.5)	27 (61.4) *
Education ≥ 12 years, N (%)	324 (76.1)	292 (77.7)	25 (58.1) *
CDR, N (%)	0	2 (0.5)	0 (0.0)
	0.5	63 (15.0)	4 (9.1)
	1	153 (36.5)	11 (25.0)
	2-3	201 (48.0)	29 (65.9) *

Results-1: Knowledge about dementia

High level of basic knowledge about dementia and AD (T/F; $M = 8.4/10$, $SD = 1.3$)

- On average, lower scores for African American vs. white respondents (7.4 vs. 8.5, $p < .001$)

Tended to know less about later disease stages

- 3 T/F questions had accuracy $< 80\%$, all concerned knowledge about *later* disease stages
- Know 'some' or 'a lot' : Mild stage, 96%; Moderate stage, 93%; **Severe/late stage, 78%**

74% - helpful to have more information “about stages of dementia, health care decision making, treatment options or end-of-life care”

- No difference by respondent race ($p = .06$)

Results-2: Perceptions about medical care



Study partner beliefs about level of care the PWD would want

- *At end stage of illness* – **comfort, 78%**; basic, 12%; intensive, 3%
- Lower preference for comfort care (vs. other) among African American vs. white PWD (58% vs. 81%, $p = .001$ by race of PWD)

~40% - Religious/spiritual beliefs would have ‘somewhat’ or ‘a great deal’ of influence on type of medical treatments wanted

- Greater influence of religious/spiritual beliefs among African American vs. white PWD (55% vs. 36%, $p = .04$ by race of PWD)

Results-3: Extent of ACP related to future medical decisions

ACP summary variables across all participants and by race (% completed)

- High rates of ACP but notable racial differences

	All participants	By race		Effect of race
		White	African American	p-value
'Formal ACP' has occurred (Medical power of attorney or living will)	87%	89%	73%	.005 *
'Informal ACP' has occurred (SP & PWD had discussions about medical tx wanted)	79%	80%	70%	.13
'Any ACP' has occurred (‘Formal’ or ‘Informal’)	94%	95%	88%	.08

Summary

Generally knowledgeable about dementia and high rates of ACP were reported

- Lowest level of knowledge about later disease stages

Notable racial differences between African American and white respondents

- Although they echo the broader literature, reasons for racial differences not well understood¹
- Complex interplay of social and personal factors
 - Social: e.g., sociodemographic disadvantage, mistrust, health care access and literacy
 - Personal: e.g., religion/spirituality, family and community, beliefs about death

¹e.g., Hong et al., 2018; Sanders et al., 2016

Study Limitations

- Limited generalizability to population at large
 - Research volunteers; have study partners; agree to annual assessments; well educated
 - Perhaps more knowledgeable about dementia than outside ADC setting
- Proportion of African American respondents was modest (10%)
- Funding limitations prohibited preparation of survey in Spanish
 - Possible future direction, given representation of Hispanic/Latino ethnicity in US

Educational Implications

Desire for more information “about stages of dementia, health care decision making, treatment options or end-of-life care”

Possible benefit of educational programs

- Clinical course of dementia, including trajectories in later disease stages
- Issues related to end-of-life care in dementia (e.g., health care decision-making, treatment options, utility of ACP)

Preferred avenues for providing educational content

- Conversations with health care provider, brochures, educational seminars
- Target family members, caregivers, and PWD in early disease stages

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