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Relationship among Trust in Physicians, Demographics, and End-of-life Treatment Decisions Made by African American Dementia Caregivers

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Abstract

Purpose—A pilot study was conducted in an urban African American community to explore the relationship between trust in physicians, demographics and end-of-life treatment decisions made by African American caregivers of family members with dementia: namely, cardiopulmonary resuscitation, mechanical ventilation and tube feeding.

Methods—In a cross-sectional design, standard measures were administered to a convenience sample of 68 African American caregivers of family members with dementia. Univariate and multivariate analyses were used to explore associations among the variables.

Results—Those with more education exhibited higher ($p = 0.035$) trust in physicians than less educated individuals. Caregivers who were more trusting of their physicians were more likely to use mechanical ventilation ($p = 0.0005$) than were less trusting caregivers. Conversely, more trusting caregivers were less likely to use tube feeding ($p = 0.022$).

Conclusions—Our findings suggest relationships exist among trust in physicians, demographics and end-of-life treatment decisions. Thus, health care providers should consider African American

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.

caregivers' perceived trust in physicians when counseling about dementia and end-of-life treatment choices.

Keywords

Trust in physicians; African American; dementia; cardiopulmonary resuscitation; mechanical ventilation; tube feeding

The number of elderly African Americans (AA) is growing, and will increase from 2.7 million in 1995 to a projected 8.6 million by 2050.¹ AAs are two times more likely to be diagnosed with dementia than White Americans (WAs).² The extensive debilitating sequelae of dementia compromise quality of life and often require decisions about end-of-life (EOL) treatments, such as cardiopulmonary resuscitation, mechanical ventilation, or tube feeding.³⁻⁵ Trust in physicians, defined as a reassuring feeling of confidence or reliance in the physicians and their intent, is an important factor in AAs' medical decision making.⁶ However, it is unknown if trust in physicians influences EOL treatment decisions made by AA caregivers of family members with dementia.

Trust is widely acknowledged to be essential for effective communication and compliance with health care. Some researchers found that AAs may be more mistrustful of the health care system than non-AAs and this mistrust affects their health care choices.⁷⁻⁹ More specifically, trust is commonly cited as an issue when discussing barriers to improving EOL care for AAs. For example, AAs were suspicious of the health care system and felt that powerlessness negatively influenced their attitudes about EOL decision making and advance directives.¹⁰ Additionally, trust was found to be a significant factor that influenced AA caregivers of family members with dementia choices for cardiopulmonary resuscitation and mechanical ventilation. Mistrust caused AAs to stipulate in living wills that every effort should be made to sustain life regardless of illness status and was found to be a barrier for clinical trial recruitment.^{11,12} AA patients also sometimes suspected that they may be experimented upon surreptitiously or that physicians may wish to save money or effort by withholding treatment from them.^{13,14}

Empirical data support the premise that family members serve as agents for relatives with dementia by making EOL treatment decisions for cardiopulmonary resuscitation, mechanical ventilation, and tube feeding.¹⁵ However, it has not been established how trust in physicians relates to demographics and EOL treatment decisions (cardiopulmonary resuscitation, mechanical ventilation, and tube feeding) made by AA caregivers of family members with dementia. Given this gap, the pilot study was conducted.

The pilot study was implemented within the framework of a larger study examining the feasibility of implementing an advance care treatment plan (ACT-Plan) with African American caregivers of family members with dementia. The larger study was a group-based education theoretically based intervention that included strategies to enhance knowledge, self-efficacy, and behavioral skills to make EOL treatment plans in advance: specifically, cardiopulmonary resuscitation, mechanical ventilation, and tube feeding. The findings reported herein are abstracted from the larger data set and describe the relationship among trust in physicians, demographics, and EOL treatment decisions made by AA caregivers of family members with dementia. The information gathered could point toward ways in which trust in physicians might be used to influence AA caregivers' EOL treatment decisions for family members with dementia.

Methods

Design

All participants from the larger trial were recruited from adult day care centers located in an urban Midwestern AA community and used for this pilot study. Study approval was obtained from the Institutional Review Board (IRB) at the authors' University and from administrators of the adult day care centers where the study was conducted.

Sample, Setting and Recruitment

Sample—The sample, setting, and recruitment procedures, as described in the next several paragraphs of this subsection, were performed in the larger intervention study and consequently utilized in this pilot. The convenience sample consisted of 68 AA caregivers with relatives (care recipients) enrolled in adult day care centers. The care recipients were AAs over the age of 65, with very high participation in center-approved activities. They had physician-generated diagnoses of dementia caused by Alzheimer disease or other related neurological disorders and were reported to be in varying stages of the disease.

Caregivers were eligible for participation if they self-reported being: (a) AAs; (b) relatives of care recipients; (c) the designated decision maker for the care recipient; and (d) knowledgeable about the care recipient's recent and past medical history. Inclusion criteria for the care recipients were: (a) AAs, (b) with physician-generated diagnoses of dementia; and (c) no written advance care plan.

Setting—The settings were five adult day care centers located in neighboring communities that were geographically comparable and similar in demographic and socioeconomic characteristics. Client enrollment varied by site due to physical capacity of the buildings that housed the programs, availability of staff, and length of time that programs were in operation. Overall, the centers maintained an average enrollment of ($n = 56$, 83%) eligible dementia clients at any given time throughout the year. Clients were similar demographically across sites as most ($n = 63$, 92%) were females and all were elderly (mean age = 80 years). They were comparable socioeconomically across sites; the majority ($n = 61$, 90%) paid for services via State Department of Aging funding.

All clients enrolled in the centers were AAs. The directors at each site reported having similar philosophies regarding EOL care for clients and family caregivers. No difference among the day care centers was observed during site visits regarding administration of services and education programs offered.

Recruitment—Recruitment of study participants was initiated after Institutional Review Board (IRB) authorization. The principal source of participant recruitment was referrals from the directors of the adult day care centers. The PI and project director met with caregivers at the monthly caregiver meetings at each site to introduce the study and solicit eligible participants. Monthly meetings were conducted as needed until all 68 participants were recruited.

Within two weeks of recruitment, eligible participants received information by telephone and in the form of a letter with the details for participation. The IRB-approved consent form was signed by all participants prior to acceptance into the study. The study instruments were distributed to participants by the trained research assistant (RA) who remained in the room to answer questions and offer help if needed for the study participants to complete the questionnaires. For example, for those participants who stated they were having difficulty in understanding the questionnaire or who appeared so (e.g., not reading or completing the

questionnaire, demonstrating a confused or blank facial expression), the RA would assist them by reading questions aloud. All instruments were collected, counted, and checked immediately for missing items. Participants were asked to complete items if they were missed in error or because of misunderstanding.

Measures

Demographic characteristics were measured using a demographic survey. Caregiver characteristics included age, gender, education, income, employment, religious affiliation, years of caregiving, and relationship to care recipient. Care recipient characteristics measured included age, gender, length (stage) of dementia, type of dementia, and if care recipients lived with their caregiver.

Decisions made for cardiopulmonary resuscitation, mechanical ventilation, and tube feeding were assessed using the 5-item End-of-Life Treatment Decisions questionnaire.⁹ This scale contains dichotomous (yes/no) and open-ended items on treatment decisions made. There was concordance between the open-ended responses and the response choice selected, as demonstrated in a previous feasibility study with good validity.⁹

Trust in physicians was assessed with a previously developed AA Trust in Physicians Scale used in two studies conducted with AAs ($n = 156$; $n = 68$).^{15,16} This 38-item, Likert scale consisted of three subscales: perceived medical knowledge of physicians, concern for patients, and accessibility to patients (Cronbach's $\alpha = 0.73, 0.76$, and 0.84 , respectively). The overall reliability for the scale is 0.92 .¹⁶ The scoring for the scale is summative, with higher scores indicating greater trust.

Statistical Analysis

Descriptive statistics including means, frequencies, and standard deviations were employed to describe sample demographics and trust in physicians. Univariate and multivariate analyses were used to explore associations among the variables. Specifically, t tests and ANOVA were used to examine the association of trust in physicians by demographic characteristics. t tests were used to investigate trust in physicians by the three EOL treatment decisions: cardiopulmonary resuscitation, mechanical ventilation, and tube feeding.

Results

Demographics

The mean age of the caregivers was 59.0 years; most were female ($n = 54, 79.4\%$); and the majority had some college education or higher ($n = 50, 73.5\%$) (Table 1). Half were employed ($n = 32$) and half were retired ($n = 34$). Twenty-five participants reported an income of less than \$40,000, whereas 28 participants reported an income of \$40,000 or greater. Religious affiliation included 25 participants who reported being Baptist, 22 "Other" and 12 Catholic. Nearly half of participants had been caregivers from a period of one to three years ($n = 32, 47.1\%$), and half were daughters of care recipients ($n = 35, 51.5\%$).

Care recipients mean age was 80.1 years and most were female ($n = 57$) (Table 1). Majority of care recipients lived with their caregivers ($n = 51, 75\%$). Nearly half had dementia for 1–3 years ($n = 32, 47.1\%$); 14 had it for 4–6 years; and 16 had it for 7–10 years. Length of known dementia was relatively consistent with length of time that caregivers had provided care. Nearly half of the care recipients had Alzheimer's ($n = 33, 48.5\%$), and 16 had dementia caused by stroke.

Trust in Physicians by Demographic Characteristics

Trust in physicians by gender demonstrated a trend towards significance ($p = 0.06$), with the mean values indicating that males were more trusting of physicians than females (Table 2). Trust in physicians by education was significant ($p = 0.04$). College graduates were more trusting of physicians than were those with less than college education.

Trust in Physicians by EOL Treatment Decisions

Trust in physicians by cardiopulmonary resuscitation decision yielded no significance. For trust in physicians by mechanical ventilation decision, more trusting caregivers were more likely to use mechanical ventilation ($p = 0.0005$) (Table 3). Trust in physicians by tube feeding decision was also significant ($p = 0.02$) and suggests that more trusting caregivers would not use tube feeding.

Discussion

African Americans are often mistrustful of the overall health care system due to several disparities: they are often underserved with dementia care and education, they receive services late in the course of the disease, they have little to no familiarity with Advance Care Planning (ACP) and they seldom engage in substantive ACP discussions with primary caregivers.¹⁷ Additionally, they may receive little informed knowledge regarding the disease trajectory and options for EOL care.^{5,11,18} If information is given, it is often inconsistent and incorrect.¹⁷ Mistrust in physicians is an important concept that impacts EOL treatment decisions made by AAs given the care and education inequities in relation to dementia.

The findings from this study indicate a trend that males were more trusting of physicians than females ($p = 0.06$). There was a significant positive relationship between caregivers with college education or above and trust of physicians. This relationship is possibly because, with increased education, caregivers are more likely to have more knowledge about the health care system, advocate for the care recipient, and have insurance or other financial resources to choose physicians they trust.

Our aim was to examine the relationship between trust in physicians on cardiopulmonary resuscitation, mechanical ventilation, and tube feeding treatment decisions made by AA caregivers of family members with dementia. Findings indicate that there were no significant differences for trust by cardiopulmonary resuscitation decision. However, there were significant differences for trust by mechanical ventilation and tube feeding decisions. More trusting caregivers reported they would use mechanical ventilation and not use tube feeding. These findings are consistent with results from the larger study, which found that caregivers were more inclined to request mechanical ventilation treatments when physicians discussed options to initiate treatment temporarily.¹⁵ Having trust in physicians promoted caregivers' receptivity to education and knowledge provided via EOL discussions and ultimately in informed EOL choices.¹⁵ Considering this, one possible explanation for our finding is that more trusting caregivers may have had conversations with physicians about EOL treatments and learned that mechanical ventilation is easier to initiate¹⁹ and that tube feeding is less effective at EOL.²⁰ These findings reflect our current best thinking in terms of mechanical ventilation and tube feeding for patients who are more trusting of physicians.

Limitations

As previously mentioned, the principal source of participant recruitment was referrals from the directors of the adult day care centers. Selecting more trusting caregivers may have introduced a selection bias; namely, their referral may indicate that they had a good relationship with the referring directors and by inference are more trusting than a random

sample might have been. Thus, the full range of trust may have not been captured. This study was cross-sectional and only focused on AAs, which limited application to causality and other racial groups. Lastly, no data were collected regarding the demographics of the physicians.

Conclusion

Although preliminary in nature, our findings suggest that there are relationships among trust in physicians demographics and certain end-of-life treatment decisions made by AA caregivers of family members with dementia. Given these relationships, all health care providers should be attentive to the importance of trust in physicians when working with AAs. In particular, advanced practice nurses (APNs) should be aware that mistrust in physicians may exist and might impede effective teaching when working with AA patients and their families. Therefore, nurses should first assess whether trust factors exist prior to approaching sensitive subjects such as EOL treatment options; if so, trust-building strategies should be included in the overall care plan. Effective dialogue can then begin that assists the caregivers with making the best informed and most unbiased EOL treatment choices for critically ill relatives. APNs will then be able to support the families with plans for cardiopulmonary resuscitation, mechanical ventilation, and/or tube feeding. It is quite possible that similar relationships exist among demographics, EOL decisions, and trust in health care providers *other* than physicians. Future research should include a replication of this study conducted with a larger sample size to validate the findings obtained in this study and should include other types of health care providers.

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Table 1

Caregiver and Care Recipient Demographics

Caregiver Characteristics (N = 68)	Mean/n	SD/%	Care Recipient Characteristics (N = 68)	Mean/n	SD/%
Age	59.0	10.2	Age	80.1	8.4
Gender			Gender		
Female	54	79.4	Female	57	83.8
Length of Caregiving			Length of Dementia		
1–3yr	32	47.1	1–3yr	32	47.1
4–6yr	15	22.1	4–6yr	14	20.5
7–10yr	13	19.1	7–10yr	16	23.6
11 or more yr	8	11.7	11 or more	6	8.8
Relationship to Care Recipient			Type of Dementia		
Spouse	11	16.2	Alzheimer	33	48.5
Sibling	7	10.3	Dementia caused by stroke	16	23.6
Daughter	35	51.5	Other	2	2.9
Son	8	11.7	D/K	17	25
Other relative	7	10.3			
Education					
Less than HS	3	4.4			
HS graduate	15	22.1			
Some college or higher	50	73.5			

Table 2Trust in Physicians by Demographic Characteristics^a

AA Trust in Physicians Scale score			
	Mean	SD	<i>p</i>
Gender			
Male	159.2	18.1	0.06
Female	147.7	25.1	
Education			
Less than college	147.5	30.6	0.04
College graduate or above	151.06	21.7	

^aScale Score Range = 38 to 190; 190 = greatest trust; 38 = lowest trust.

Table 3Trust in Physicians by End of Life Decision^a

AA Trust in Physicians Scale score			
Decision	Mean	SD	<i>p</i>
Cardiopulmonary Resuscitation			
will use	149	22.7	0.77
will not use	151.7	28.8	
Mechanical Ventilation			
will use	150	15.5	0.00
will not use	146.4	30.2	
Tube Feeding			
will use	146.9	20.7	0.02
will not use	150.4	32	

^aScale Score Range = 38 to 190; 190 = greatest trust; 38 = lowest trust.