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Cultural Diversity and Views on Alzheimer's Disease in Older African Americans

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Running Head: Culture and Views on Alzheimer's Disease in African Americans

Abstract

Cultural constructs prevalent in older African Americans may influence their risk perceptions and knowledge of Alzheimer's disease (AD). To examine this issue, we administered 3 sociocultural scales, the Alzheimer's Disease Knowledge Scale, and a Risk Perception questionnaire to 271 older African Americans who were recruited from a large community senior center and local churches. Higher Present Time Orientation was significantly related to perceptions of having little control over risks to health ($p = .004$), God's Will in determining AD ($p = .001$), and lower AD knowledge ($p < .0001$), and marginally related to having little control over developing AD ($p = .052$). Religiosity was marginally related to having little control over risks to health ($p = .055$) and getting AD" ($p = .057$). Post hoc inter-group comparisons found significant differences in the highest vs. lowest scoring Religiosity groups. There were no significant differences by Future Time Orientation. Most subjects (57.6%) were unaware that African Americans were at higher risk for AD than whites. These data indicate that cultural diversity within older African Americans may shape health perceptions and knowledge of AD. This diversity may contribute to disparities in the detection and treatment of AD in this high risk population.

Key Words: Cultural Diversity, Alzheimer's Disease, African Americans

Introduction

The population is aging, the prevalence of Alzheimer's disease (AD) is increasing, and our society is becoming more diverse racially.¹ For older African Americans, who comprise one of the fastest growing minorities in the United States, the risk of AD is higher than in whites and the diagnosis of AD comes at more advanced stages when outcomes are less promising, care is costlier, caregiver burden is heavier, and institutionalization is more likely.¹⁻⁵ Given these disparities, increasing older African Americans' access to early diagnosis and treatment of AD is important.

One of the determinants of access to care is health beliefs about AD, which vary between racial and ethnic groups. Differences between racial groups reflect differing values, beliefs, and practices, which shape familial roles, community involvement, and sense of self-efficacy, and different experiences with and trust in the medical system, including experiences of discrimination and the cultural relevance of doctor-patient communications. African Americans perceive less threat from AD than whites and tend to attribute memory loss to normal aging, stress, exposure to toxins, mental illness, or God's will.⁶⁻⁹ Less is known about variation within racial groups, especially concerning cultural factors that shape health beliefs. Differences in education, income, region of origin, neighborhood residence, degree of assimilation, and the extent to which individuals value personal control and spirituality, may directly or indirectly influence the expression of various cultural constructs. Differences in religiosity and time orientation, for example, are known to influence health behaviors and health outcomes.¹⁰⁻¹² Religiosity, or spiritual beliefs and practices, is closely linked to beliefs about health and disease in older African Americans.^{10,13} Emphases on healthy lifestyles and social support, experiences of positive affect, and prohibitions against drug and alcohol use may account for positive associations between religiosity and better health.

Time orientation refers to the salience of present and future time considerations, where the former focuses on immediate or short-term consequences and the latter on planning for the future.¹⁰ People oriented to the future are more likely to engage in health-promoting behaviors whereas those who are more present-oriented are less able or inclined to connect present behaviors with future outcomes.^{10,13} To explore these issues further, we surveyed a community sample of older African Americans and herein report associations between these cultural constructs with perceptions of control over health risks and knowledge of and willingness to seek treatment for AD.

Methods

Staff members of an urban senior community center serving over 2,500 older adults annually (Center in the Park, Philadelphia, PA) recruited subjects from the senior center, senior housing facilities, other senior centers and local churches that predominantly serve older African Americans from July to September, 2011. Because we collected only de-identified data (i.e., age, gender, and race), Thomas Jefferson University's Institutional Review Board approved a verbal consent process. Subjects were asked to complete a survey comprised of the following instruments and questions:

Cultural Characteristics: Lukwago *et al* (2001) developed brief scales to measure cultural constructs that are prevalent in urban African Americans and are associated with health-related beliefs or practices. We administered the Present Time Orientation, Future Time Orientation, and Religiosity scales (Table 1). Responses range on a 4 point scale from “strongly agree” (3) to “strongly disagree” (0), with higher scores indicating higher levels of the characteristic. In the initial psychometric testing in African American women from low income urban housing communities, Cronbach's alpha coefficients were: Religiosity (9 items; $\alpha=.88$); Present Time Orientation (5 items; $\alpha=.73$), and Future Time Orientation (5 items; $\alpha=.72$).¹¹ In our sample, the respective alpha coefficients were: .90, .72, and .67]. The time orientation scales represent 2 distinct unidimensional scales with low inter-correlation ($r = - 0.09$; $p = 0.15$). Thus, some individuals may be future-oriented in some areas of their lives and present-oriented in others.

Alzheimer's Disease Knowledge Scale (ADKS): The ADKS consists of 30 true/false items that cover risk factors, assessment and diagnosis, symptoms, course, life impact, caregiving, and treatment and management of AD and has high internal consistency (.71).¹⁵ Carpenter *et al* (2009) designed the ADKS to assess AD knowledge among health care professionals and the

general public.¹⁵ Score range from 0 to 30, with higher scores indicating greater knowledge of AD. In our sample, the alpha coefficient was .52.

Risk Perceptions: We adapted questions from the Risk Perceptions Survey for Diabetes to apply to AD.¹⁶ The 6 questions assessed perceptions of control over general health and developing AD, concern about developing AD, willingness to seek medical care for memory loss, the role of God's Will in developing AD, and African Americans' risk of AD relative to whites. Table 2 lists the full wording of each item. Subjects' responses were "agree" or "not agree" with each item.

Statistical Analyses:

The primary analysis examined the relationships between the 3 cultural characteristics and the ADKS and Risk Perceptions. The primary research question of how these relationships differ among unique individuals led us to classify participants categorically on the cultural constructs. Although we recognize that cultural phenomena are not easily fitted to categories, the categorical approach seems best suited to describe explicit rather than relative relationships and yields results with more discernable clinical implications. Because subjects' scores on the cultural characteristics were normally distributed, we grouped subjects into high (upper 25% of the distribution), medium (middle 50%), and low (bottom 25%) scoring categories. To evaluate relationships between the cultural characteristics and ADKS and Risk Perceptions, we conducted a series of chi-square analyses for categorical data and one way ANOVAs for continuous data. Regression analyses with each cultural construct considered as a continuous score were conducted to examine the independent relationships of each risk perception with each construct.

Results

The sample was comprised of 271 African Americans (81% women) whose average age (standard deviation) was 71.6 years (9.1). Overall, 70.5% of the sample believed they could control risks to their health; 68.0% believed they could take steps to prevent AD; 59.4% were concerned about developing AD; 94.2% would ask their primary care physician about memory loss; and 49.3% believed it was “God’s Will” whether or not they developed AD. Most subjects (57.6%) were unaware that African Americans were at higher risk for AD than whites. The average (standard deviation) ADKS score in this sample was 18.7 (3.7). The 4 most common errors on the test (and the proportion of subjects who made them) were: caregivers should take over right away when someone with AD can’t care for themselves (85%); it’s helpful to remind someone with AD when they repeat themselves (69%); scientific evidence proves that mental exercise prevents AD (67%); and people with AD are unable to make informed decisions about their own care (67%).

The mean Present Time Orientation score in the sample was 11.2 (2.3); the median score (range) was 11 (4 – 20). There were 97 subjects (35.8%) in the bottom 25th percentile of Present Time Orientation scores, 94 (34.7%) in the 25th to 75th percentile, and 80 (29.5%) in the upper 75th percentile. Table 2 shows the Risk Perceptions by the 3 Present Time Orientation groups. Present Time Orientation was related to having “Little control over risks to my health” ($X^2 = 11.0$, $df 2$; $p = .004$). Compared to subjects in the highest-scoring and middle-scoring Present Time Orientation groups (41% and 31% of who endorsed this item, respectively), subjects in the lowest-scoring group (19% of whom endorsed the item) were less likely to report having little control over their health (lowest vs. middle group: $X^2 = 3.9$, $df 1$, $p = .049$; and lowest vs. highest group: $X^2 = 11.0$, $df 1$, $p = .001$). The same pattern was evident regarding “Not much I can do about getting AD” ($X^2 = 5.9$, $df 2$; $p = .052$) and “It’s God’s Will if I get AD”

($X^2 = 14.1$, $df 2$; $p = .001$). For “Not much I can do about getting AD”, subjects in the highest Present Time Orientation group were more likely to endorse this item (43% endorsed it) compared to subjects in the lowest Present Time Orientation group (26% endorsed it) [$X^2 = 5.8$, $df 1$, $p = .016$]. For “It’s God’s Will if I get AD”, subjects in the highest and middle Present Time Orientation groups (63% and 55%, respectively) were more likely than subjects low in Present Time Orientation (36%) to hold this belief ($X^2 = 12.9$, $df 1$, $p < .001$, and $X^2 = 7.1$, $df 1$, $p = .008$, respectively). A regression analysis with Present Time Orientation as the dependent variable (and considered as a continuous score) revealed that “Little control over risks to my health” (0.009) and “It’s God’s Will if I get AD” (0.0001) were independently associated with Present Time Orientation. There were no significant differences in concern about developing AD (range across groups 60% to 61%), willingness to seek treatment (93% to 100%), or awareness that African Americans have a higher AD risk than whites (40% to 53%). Table 2 also shows that subjects who scored high in Present Time Orientation had significantly lower ADKS scores than less present-time oriented subjects [$f(2, 268) = 15.2$; $p < .0001$].

The mean Religiosity score in the sample was 29.7 (4.3); the median score (range) was 29 (9 - 36). There were 101 subjects (37.3%) in the bottom 25th percentile of Religiosity scores, 107 (39.5%) in the 25th to 75th percentile, and 63 (23.2%) in the upper 75th percentile. Table 2 shows the Risk Perceptions by the 3 Religiosity groups. Religiosity scores were marginally related to having “Little control over risks to my health” ($X^2 = 5.8$, $df 2$; $p = .055$). Fewer subjects with high vs. low Religiosity held this belief (19% vs. 37%, respectively; $X^2 = 5.73$, $df 1$; $p = .017$). Similarly, Religiosity scores were marginally related to “Not much I can do about getting AD” ($X^2 = 5.7$, $df 2$; $p = .057$). Fewer subjects with high vs. low Religiosity tended to hold this belief (27% vs. 42%, respectively; $X^2 = 3.5$, $df 1$, $p = .061$). Regression analyses did not show independent effects of these two risk perceptions. There were no significant differences between Religiosity level and “concern about developing AD” (range across groups 59% to

62%), the “role of God’s Will” (47% to 55%), “willingness to seek treatment” (68% vs. 78%), or awareness that “African Americans have a higher AD risk than whites” (41% to 51%). Table 2 also shows that ADKS scores did not differ by level of Religiosity.

The mean Future Time Orientation score was 14.2 (2.1); the median was 14 (7 – 20). There were 89 subjects (33.1%) in the bottom 25th percentile of Present time Orientation scores, 70 subjects (26.0%) in the 25th to 75th percentile, and 110 (40.9%) in the upper 75th percentile. There were no significant differences in Risk Perceptions or ADKS scores between subjects in these 3 Future Time Orientation groups although there was a trend for future-oriented participants to have greater AD knowledge ($p = .056$). Inter-correlations among Religiosity, Present Time Orientation, and Future Time Orientation were low. The only significant correlation was between Future Time Orientation and Religiosity ($r = .33, p < .001$).

Discussion

Race is sometimes taken as a proxy for culture but our data indicate that not all African Americans share the same cultural beliefs to the same extent. This finding is not surprising given that variability in acculturation, family values, developmental experiences, level and quality of education, occupational accomplishments, and sense of self-efficacy may influence the expression of different cultural constructs. We found a substantial degree of variability in Religiosity and Present- and Future-time Orientation; variations in Present Time Orientation and Religiosity were associated with differences in risk perceptions and/or knowledge of AD. This finding must be viewed in light of the study's limitations, however. First, the sample is not representative of older African Americans in general given the recruitment strategies we used (i.e., convenience sampling, and senior center and church recruitment sites) and that majority of participants were women. Our results, therefore, require replication in more representative population-based samples. Second, we had no data on education of subjects. A recent survey of Center in the Park members, however, found that 13.3% had less than a high school education; 31.1% had graduated high school; 33.1% had some college or an associate's degree; and 13.3% had graduated college.¹⁷ Lacking data on education in our sample prevents us from investigating associations of education with risk perceptions, AD knowledge, or the cultural constructs. Third, the cultural construct scales were initially validated only in women; although women represented 81% of our sample, the validity of these scales is uncertain in men. Fourth, some associations reached only marginal statistical significance and warrant further investigation. These limitations notwithstanding, the study has a number of strengths, including the large sample size, systematic subject assessment using standardized instruments, and the new associations we found between common cultural constructs and health beliefs about AD.

We found that that most subjects believed that they could control risks to their health in general and AD in particular and would consult their primary care physicians if they had signs of memory loss. Half the subjects believed that “God’s Will” determines whether they will develop AD but those who held this belief were just as likely as others to believe they can influence their health outcomes. Although many participants believe that God ultimately determines their health outcomes, they also believe that maintaining their health adheres to “God’s Will”. We also found that the majority of African American subjects were unaware of their higher risk for AD relative to whites. This difference likely contributes to the under-detection and treatment of cognitive disorders in older African Americans. The most common misperceptions about AD (evident on the ADKS) suggest the need to improve caregivers’ understanding of the balance between respecting autonomy and promoting independence with providing help when needed. The average ADKS score of 18.7 (3.7) in this sample was somewhat lower than the 21.4 (3.5) reported in another study that included African Americans.¹⁵ Different recruitment methods and subject characteristics likely account for the difference. Some but not all studies report an association between low education and low AD knowledge.¹⁸ Ayalon *et al* (2004) found that differences in education did not account for African Americans’ lower AD knowledge compared to whites and speculated that other factors (i.e., economic status) may be responsible.¹⁹ Connell *et al* (2009) found that African Americans had less accurate knowledge of AD (after controlling for education) and were more likely to cite “God’s Will” as a determinant of AD than whites.⁷ They attributed the latter difference to the importance of religion in the lives of many older African Americans and how religion can influence the meaning of disease.

Our data demonstrate that older African Americans’ perceptions of AD vary in the degree to which they endorse two common cultural characteristics, Present Time Orientation and Religiosity. Present Time Orientation reflects the importance of short-term consequences and is often associated with low income and difficult social circumstances, where concern for the

immediate realities of daily life supersede future considerations.¹¹ Such perceptions may negatively influence adherence to medications, use of preventive health care, and health service utilization. We found that people who scored highly on Present Time Orientation were less likely to believe that they could control risks to their health or of AD, and were more likely to believe that “God’s Will” determines whether or not they develop AD. These risk perceptions reveal a passive acceptance of negative health outcomes or a reliance on prayer rather than active involvement in one’s health care. Similarly, Brown and Segal (1996) found that African Americans with hypertension were more present-oriented than whites and were more likely to state, “As long as I’m feeling good now, it’s not important for me to use any kind of medicine for my high blood pressure”.²⁰ We also found that Present Time Orientation was associated with lower knowledge of AD. Lukwago *et al* (2003) similarly found that Present Time Orientation was negatively associated with breast cancer–related knowledge in African American women.¹¹ These data suggest that Present Time Orientation may be a useful predictor of inadequate disease knowledge and may identify subgroups of African Americans who might benefit most from preventive health interventions. By contrast, we found no significant differences in risk perception or AD knowledge by Future Time Orientation. Although future-oriented participants tended to have greater AD knowledge ($p = .056$) and were somewhat less likely to believe they had “little control over their health” or that “there is not much to do about getting AD” compared to other participants, the study was not powered sufficiently for the observed differences to reach traditional level of statistical significance.

Religiosity reflects activities and beliefs about religion and health. Subjects who scored highly on Religiosity had an opposite pattern of responses as subjects who scored highly on Present Time Orientation (although the two cultural characteristics were unrelated). Although not statistically significant at a .05 level, we found that more highly religious subjects tended to endorse having a greater sense of control over their health. It is reasonable to assume that

their greater faith and religious practice reinforce a sense of empowerment or self-efficacy. Others studies suggest, however, that linking “God’s Will” to the development of AD may oppose a biomedical approach to disease and lead to the devaluation of the role of health behaviors in disease genesis and course.²¹⁻²⁴ This may lead to higher disease incidence rates, delays in diagnosis and treatment, and worse health outcomes.²¹ For example, Ark et al (2006) found that subjective religiosity (e.g., perceived closeness with God) was associated with lower hospital utilization and that non-organizational religious behavior (e.g., praying, listening to gospel music) was associated with fewer physician visits in African American women.²⁴ These relationships suggest either that religiosity leads to better health status and less need for health service use or, conversely, a reluctance to seek medical care when it is needed. Congruent with these findings, Cooper et al (2010) found that African Americans accessed AD diagnostic services at more advanced disease stages than whites and were less often prescribed medications for AD.²⁵ We recently reported that informants’ (usually family members) of older African Americans with mild memory impairment underestimated their relatives’ cognitive decline relative to the informants of similarly impaired white participants.²⁶ Differences in education, culture, and socioeconomic status of African American versus white informants may have accounted for their difference perceptions.

Taken together, these data highlight the potential impact of culturally-determined views on health behaviors and the need to appreciate the cultural diversity among older African Americans concerning memory loss. African Americans are at increased risk for AD and worse health outcomes compared with whites.¹ These disparities reflect differences in predisposing medical, genetic, environmental, and perhaps, as our data suggest, cultural factors.^{1-9, 27} Cultural factors related to views of aging and health must be addressed to ensure that individual needs, rather than these factors, determine health outcomes in this high-risk population.²⁸

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