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African Americans with Memory Loss: Findings from a Community Clinic in Lexington, Kentucky

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Introduction

The clinical outreach program described in this report was created to address the lack of use of dementia care services by African Americans in central Kentucky. Although not a problem unique to Kentucky, African Americans did not take advantage of dementia services offered through the University of Kentucky's (UK) Alzheimer's Disease Center (ADC), while the same services were in high demand by white members of our region.

African Americans have an increased risk for the development of Alzheimer's disease [1-5], yet they underutilize existing dementia services and are underrepresented in dementia research creating an alarming national trend [6-7]. Without their participation, the medical community is left without the necessary knowledge for developing effective prevention and treatment programs specific and appropriate for them. Furthermore, African American patients with dementia and their families struggle unnecessarily without the care and support that they need.

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Background

Alzheimer's disease (AD), the most common form of dementia, has assumed national visibility as a public health issue in large part because of the aging of our country's population. Age is the greatest risk factor for the development of AD [8]. Currently, African Americans represent the nation's largest minority group of older Americans, with African Americans 85 and older the most rapidly growing age group [9]. Increased numbers of older African Americans will create increased numbers of African Americans with AD.

The risk for the development of AD symptoms is greater for African Americans than Caucasians, with estimates of increased risk ranging from 15 to 100 percent [1-5]. Multiple genetic, environmental and social factors likely contribute to this risk. For example, African Americans have hypertension prevalence rates that are among the world's highest [10]. It is known that hypertension and elevated cholesterol may double the risk of AD [11]. Also, African Americans are 43% more likely than their white counterparts to have a biological first degree relative with AD [12], thus increasing their chances of developing AD because of a potential genetic predisposition. Finally, African Americans have higher rates of Type II diabetes, a factor that influences the development of vascular disease and vascular dementia [13]. Brain injury due to vascular factors may compound AD. Dietary patterns also are implicated as contributing to disease development with dietary habits being tied not only to cultural traditions but to economic factors [14].

Research supports the strong role of religion and family, and the importance of community in the development of healthcare programs for African Americans [15]. African Americans prefer to care for their loved ones at home; often utilizing extended family in a care process that is largely female dominated [15]. Research suggests that over the course of AD African Americans receive services later than whites and sometimes do not seek medical care at all, suggesting that African Americans more frequently view AD as a normal part of the aging process and are less likely to institutionalize a loved one [16]. Dilworth-Anderson and Gibson suggest that the variance in cultural beliefs about dementia contributes to various factors including who offers care, why that person offers care and whether or not to institutionalize [17]. They state that, depending on the particular cultural group, the behaviors of a demented older person may not be brought to the attention of medical professionals, and instead these behaviors may be considered normal or treated at home [17].

In spite of their greater need, African Americans did not seek diagnosis, treatment or support at the UK-ADC during its first fifteen years. Slavery, segregation, and racism, both blatant and subtle, had created barriers of trust between African Americans and our research center. University faculty, health care staff and research scientists were predominantly white. Moreover, a majority of African Americans were aware of the Tuskegee study [18] where research into the long term effects of syphilis involved deceiving African American participants and providing no treatment, creating a general distrust of Caucasian conducted research [19]. Additionally, it was not uncommon for federally subsidized health care programs to be feasibility or pilot programs, and these programs were often dropped when funding ended, creating a sense of impermanence and lack of long-term commitment to the health of African Americans.

The National Institutes of Health recognized the limitations of research that did not include a sample population representative of the general population and began requiring racial and ethnic representation in federally funded research. UK scientists at the ADC were aware of this need and made numerous unsuccessful attempts to recruit African Americans, the largest minority group in the service area, to use established dementia care programs and to participate in AD research. Despite these efforts, in 2003, only 3 percent of patients being evaluated at

the UK-ADC memory disorders clinic were African American in an area where African Americans constituted 13 percent of the local population. African American participation in research was even smaller.

Although underutilization of health services and lack of representation in research by African Americans were nationwide issues, the dementia care program in Kentucky faced local barriers. Despite legislation against racial discrimination, economic factors remained, and neighborhoods in Lexington remained largely segregated by race. As a border state during the Civil War, Kentucky became a primary stop on the Underground Railroad. With emancipation, many former slaves went north for a better life, leaving behind encapsulated community enclaves that are perhaps unique to border states. In the nineteenth century, Kentucky's Berea College was open to individuals of any race until Kentucky passed the Day Law which forbade blacks and whites from attending the same school. More recently, within living memory for many older African Americans, the first black student to attend UK, Lyman T. Johnson, had to file a lawsuit in order to do so. Given this history of discrimination within our nation and state, UK-ADC health care providers faced serious mistrust from the African American community.

Approach

The first step in the Kentucky plan to provide dementia care to African Americans was to place quality treatment and services in a north side neighborhood. We acquired the use of exam rooms in an existing clinic run through UK located in the Lexington neighborhood with the highest proportion of African American residents. We then recruited an African American nurse from the local community to assist with clinical activities. During the first two years of operation, we found that simply opening a dedicated dementia clinic and hiring an African American nurse were not sufficient to attract and serve those in need of care. During year one, 20 individuals were evaluated and in year two, ten. Clearly, barriers to African Americans making full use of the clinic remained.

In 2003, with three years of funding provided by an Administration on Aging (AOA) grant, we refined our approach to the development of dementia care and created the African American Dementia Outreach Partnership (AADOP). Expanded interrelated objectives were developed to accomplish the goal of making quality dementia care available to all segments of the community. Program objectives were: 1. To identify and overcome barriers that inhibited the use of available clinical and support services for dementia patients and their families. 2. To increase awareness of AD and foster greater understanding of the importance of research, and 3. To provide quality care that was sensitive to the unique needs and values of the African American community.

An essential element of the expanded effort involved community collaboration. The AOA effort was designed to establish a partnership among groups and agencies with a shared commitment to providing equal healthcare access to African Americans with dementia. The original partnership consisted of UK's ADC, the Commonwealth of Kentucky's Division of Aging and Independent Living, and the Greater Kentucky and Southern Indiana Chapter of the Alzheimer's Association. Representatives of the partnership met monthly to discuss program plans and activities. Decisions were made as a group.

Objective 1

To identify barriers and accomplish AADOP's first objective, we turned to leaders within the African American community and families, and we listened. Focus groups identified African American attitudes and beliefs in addition to the suspected distrust of the white, university culture. Barriers that were identified included a lack of awareness of the disease and confusion

in those we sought to reach about what changes in memory were normal and what changes might indicate a medical disorder. Stigma was found to be associated with AD and other mental health problems, making families hesitant to seek help. Families felt that problems with their older relative were personal business and their task to shoulder, and their unwavering respect for elders made them hesitant to seek outside assistance. Many were unaware of the newly established neighborhood clinic.

We decided to turn to the most trusted institution in African American families, the church, for help in reaching our target population. Six large African American churches were identified and contact with their senior pastors was established. After two meetings with the ministers, with one meeting providing requested information to the ministers on the latest findings on AD and its impact on the African American community, the six churches became active members of the outreach partnership and formed an Advisory Council of Ministers to guide the program. A separate advisory council of diverse community leaders and family representatives was established and also met quarterly.

The Council of Ministers endorsement of AADOP did not happen at the first meeting with them. Ministers voiced concern that AADOP efforts might end when funding ended, and only when they were assured that financial arrangements had been made to continue the clinic did they begin to recognize the sincerity of the outreach for their people. Ministers also expressed their concern about working with the university and questioned our motives. We acknowledged earlier injustices and emphasized the need for their help with this effort to improve healthcare for African Americans.

Objective 2

In planning educational activities so that they would successfully increase awareness of AD among the local population, we used findings from our focus groups and sought input from our advisory boards. Recommendations were that we broaden our outreach by attending festivals and other local events targeted to older African Americans in addition to continuing presentations at churches and senior centers. They suggested that we become a visible presence in the community we were serving by attending health fairs and offering free memory check-ups. They told us that how the message was presented was important in determining how it was received, urging us to keep it simple. For example, they suggested talking about memory loss, a symptom that African Americans would understand immediately, rather than dementia or AD in initial publications and outreach. To ensure that the community surrounding the clinic was aware of the new memory care services, they suggested an Open House to introduce the program.

Objective 3

Our clinical approach was designed to minimize the amount of time the patient and family spend in a medical setting. We wanted the clinic to be as non-threatening and friendly as possible. Neuropsychological testing and the collection of standardized social and medical data took place in the patient's home by African American clinicians. By completing the testing in the home and having an examiner of the same race, patients were more comfortable with testing and the clinician developed a better understanding of what services might be appropriate for the family. Home evaluations allowed rapport to be established between AADOP health care professionals and families before the first clinic visit which minimized the number of individuals who cancelled or did not appear for clinic. During the initial home visit and testing of individuals who live alone, our clinical staff also checked the home for potential safety threats using a standardized checklist we developed. If problems were identified they were discussed with the individual, and with the individual's approval, the family.

As suggested, we incorporated memory screenings into our work in the community. Individuals who were not ready or willing to see a physician for suspected memory problems often felt comfortable having a free check-up. Once the screening and brief medical history was completed, all information on individuals who performed below norms for the given tests was reviewed by clinic physician, and a decision was made regarding follow-up neuropsychological testing. If the physician decided that further testing was warranted, an in-home appointment for the testing was scheduled along with a meeting with the family member who served as the informant. The Uniform Data Set battery of tests used by federally funded ADC's was completed, and the physician again reviewed results to determine who should be scheduled for a complete neurological work up.

Many cognitive tests are culturally and educationally biased. Consequently African Americans and those with low education levels may score low on these tests despite normal cognition, resulting in false positives on measures such as the Mini Mental Status Examination [20]. Recent normative data for older African Americans suggest that the expanded and modified Mini Mental Status Exam (3MSE) is a more sensitive measure with African Americans [21]. We have used the 3MSE to screen patients for memory problems since 2005. After review of the literature for measures that might allow us to identify early problems with memory in African Americans, we selected the Fuld Object Memory Test [22] as our second screening measure for use in combination with the 3MSE. We eliminated other tests from consideration because of a lack of validation with African Americans, strong correlations with education, or because of excessive time requirements [23-26]. Individuals who performed 77 or below on the 3MSE and 18 or below on total retrieval for three administrations of the Fuld were referred to our clinic physician.

Findings

The accomplishment of AADOP's three objectives required gaining the trust of the African American community. Without the development of trust, the community would not attend educational presentations and conferences. Without education, older African Americans and their families would not be aware of the early symptoms of dementia and would not request memory check-ups. Without confidence in the quality of available care, persons with memory problems who had received memory check-ups or who were referred by their physicians would not seek clinical evaluations and follow-up care. Further, without trust and confidence, family members would not participate in support groups or utilize other needed services.

Our first evidence that we had begun to remove barriers was community participation in our educational activities. When our Branch Out Kentucky conference on AD on a Sunday afternoon in the fall of 2005 attracted over 330 participants, most of whom were African American (95%), we knew that we had gotten the community's attention related to the health importance of AD. Enthusiasm by the Advisory Council of Ministers for this large conference had grown as they became more informed about the health impact of AD. The 2005 conference focused on the importance of early diagnosis and treatment, innovative counseling techniques with patients and family members, creative caregiver solutions to difficult behaviors and the importance of African American participation in research.

Building on information from the conference, caregiver responses and encouragement and direction from the ministers, a resource document, *The Book of Alzheimer's Disease for African American Churches*, was written so that our church partners would have a readily available guide for their church libraries. This resource publication was suggested by the ministers and reviewed by them, and includes a chapter on the importance of maintaining the patient's spirituality. Surprisingly, the book has been requested by communities across the

nation. Brochures explaining clinic services and providing contact information were printed and have been widely distributed in the local community.

We have made over 150 presentations reaching more than 7,000 individuals since 2003. These numbers include four local conferences, one designed specifically for ministers and their wives and church health leaders. Administrators and staff at retirement communities and nursing facilities serving African Americans were offered small group lectures on the symptoms of AD, and memory check-ups were offered to group members and their clients. With the increased visibility that presentations, publications and conferences provided AADOP, instead of staff making calls to request a time for presentations and memory check-ups, groups were calling AADOP. African American graduate students and volunteers were trained on testing techniques that screened for the need for further cognitive testing and neurological evaluation and assisted with the memory check-ups.

In our work in the community, we found that when discussions of AD and dementia were framed in terms of personal safety, families more readily accepted the message than when we approached the disease symptoms directly. We emphasized the warning signs of AD in terms of how these symptoms affected the individual's personal safety and ability to live alone in family meetings and in our promotional materials.

With the relationships established through AADOP, the number of patients being cared for at the clinic increased dramatically over the four years. The clinic, operating one day per week with two physicians, currently serves over 100 primarily African American patients (82% of clinic) each year. An Open House at the clinic has been held yearly to introduce and reinforce our community presence. At the 2003 Open House event, 45 persons were screened for problems with memory with over half requiring follow-up testing. Even though the Open House did not begin until 10, people were standing in line at 9:30. Many had found out about the event through their churches.

The most frequent diagnosis at our clinic has been AD (52%), with mild cognitive impairment, the earliest detectable form of memory loss, the largest other group of patients evaluated (28%). The mean age of patients was 76.8 years; and generally, the patient population was less educated than individuals in other programs at UK's ADC. Approximately 20% have eight years or less of education, and 64% have twelve years or less.

Sixty six in-home safety checks were conducted for individuals with suspected memory loss who were living alone. The most common outcome associated with safety checks (21% of cases) was for the family to become aware that there was a medical problem and increase their involvement with the older person's daily care, often acquiring power of attorney.

A total of 330 individuals received free memory check-ups at various community sites. Of those individuals receiving memory screenings, approximately 180 (53%) required further evaluation through the memory clinic. A surprising finding was that a larger than expected proportion of those screened (15%) were found to have mild cognitive impairment, often an early precursor of AD. Our earlier experience in the clinic was that most African American patients with AD were identified in the moderate to severe stage of disease. Identifying individuals early by screening and outreach enabled patients to fully benefit from available medications and have meaningful involvement in planning their own future care. This was an important goal of the program.

Offering counseling and support to family members and friends who care for those with dementia was a part of our overall program goal. Before AADOP was created, African Americans did not attend support groups offered through the local Alzheimer's Association. Even after we identified an African American facilitator and formed a new group, only one or

two persons attended each month. We brought this lack of participation to our advisory groups, and they suggested a name change to “Fellowship Hour,” because they explained “African Americans are very independent and do not want to acknowledge a need for support.” We changed the name to Fellowship Hour and membership soared. Our evening group has 25 active members, and a second requested daytime group has three to six members with participants driving from surrounding counties to attend.

Five Lessons Learned

1. Keep program design flexible and seek community input. We used focus groups and advisory councils to guide our program development and to evaluate what we were doing. Careful listening and a clear response from the program to what is heard was the key to this approach. The original outreach strategy was changed several times to fit local culture and needs based on such feedback. For example, we had not planned educational conferences with national caliber speakers for a layperson audience; however, our Advisory Council of Ministers recommended conferences and with their sanction, our conferences were extremely successful and allowed us to reach larger audiences than possible without them. Ongoing evaluation and use of feedback from the served population was critical. This clinical outreach would not have worked had we not listened to our community.
2. Keep language simple and avoid the use of terminology specific to the medical field before the community is educated about dementia. We used our advisory councils to review flyers, brochures and resource materials. One of the initial brochures used “cognitive impairment,” terminology that is standard in our work. Council members immediately commented that such jargon was not standard or understandable to the community we were attempting to reach. We replaced “cognitive impairment” with “problems with memory and thinking”, a simple but critical change. Similar potential language barriers were corrected because of suggestions from the advisory councils.
3. Education can combat the negative stigma associated with dementia and remove the code of silence often practiced by African Americans and their families. Mental health problems in the African American community are often hidden because families are embarrassed. The community learned that changes in behavior and personality that accompany AD and other forms of dementia are caused by diseases of the brain and require medical attention and treatment.
4. Education can increase the early identification of African Americans with AD and related dementias. Memory screenings by trained staff with measures appropriate to the population can offer reassurance to those who are concerned about changes in memory that their changes are normal and can offer the advantages of early identification to others who have changes significant enough to warrant follow-up treatment and care.
5. When feasible, involve families, not just the primary caregiver, in the care process. In African American families, decision making often involves multiple individuals from extended family and friendship networks. Respect for older persons is strong and may be shown by attention to how decisions are made for them. Families should be told that seeking healthcare support for their older family members is not disrespectful, but allows the older person with disease to improve their personal safety and have a better quality of life.

Synopsis

Kentucky's AADOP has shown that African American patients will seek dementia care if a clinic is conveniently located and families are educated about the distinction between normal aging and signs of disease. African Americans have not always had equal access; and, with dementia care, African American families have tended to wait longer if they seek help at all. The early identification of dementia allows African Americans access to pharmaceutical treatments that work best early in the course of the disease and provides the opportunity for the patient to plan future care. AADOP teaches the value of learning from a small program. In this model, a conveniently located clinic and access to the patient's home were first steps in achieving equality of care. The trust that was built in the community through collaboration with African American churches has allowed patients and their families to receive help with memory problems and to feel comfortable seeking help for other medical problems. Maintaining this involvement and responsiveness to the community over the long term is the next challenge for our program.

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