

Culture matters: Dementia in Senegal by Soda Lo

As a Memory and Aging Project intern, I often contrast information about the USA with my home country of Senegal. There is a word for old-age forgetfulness in the Wolof language; however, I had never heard of Alzheimer's disease in Dakar. Does it exist there?

Traditionally, diseases are understood as seasonal or resulting from a hex. Most Senegalese prefer to engage in traditional medicine because it is less costly, largely available and more in line with their beliefs. Interface with physicians and hospitals is typically limited to acute episodes of communicable ailments or advanced stages of chronic illnesses, and a Western scientific understanding of disease is limited to the formally educated minority.

The extended family is the building block of society. Traditionally, persons live within intergenerational compounds where child rearing, housekeeping, and caregiving are communal tasks. Insofar as caring for elders is expected of adult children or other relatives, there is virtually no need for formal care facilities. Any sentiment of burden would be attenuated by the availability of many helping hands within a family and community, and the fact that this care is an integral part of one's social role.

Elders are valued members of society. They anchor the community by educating it about its culture and past, often passing down wisdom and knowledge through oral history. While there is significant stigma associated with mental illnesses and, particularly, their behavioral manifestations, elderly people losing their way around the village are simply said to be "becoming child[ren] again"¹; this is thought to be a normal and integral aspect of (the full circle of) life. These elders may require additional help but remain highly respected.

The context

There exists strong evidence that higher levels of formal education are a protective factor against dementia and Alzheimer's disease². Education is, however, not only an indicator of cognitive stimulation and surrogate of intelligence quotient, but also a proxy indicator of early life circumstances such as household socioeconomic status². SES also determines nutritional status, another factor in cognitive performance, and malnutrition has been associated with cognitive deficits³.

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WUSTL to Lead New International Alzheimer's Disease Research Network by Michael Purdy

The Alzheimer's Disease Research Center (ADRC) at Washington University School of Medicine in St. Louis will lead a six-year, \$16 million international research collaboration dedicated to understanding inherited forms of Alzheimer's disease. The National Institute on Aging (NIA) will fund the project.

Forms of Alzheimer's disease linked to inherited mutations are rare but have provided scientists

with many important insights into the more common "sporadic" forms of the disease. Because individuals with these inherited forms of Alzheimer's are widely dispersed geographically, there have been too few at any one center to conduct extensive research. Through the newly created Dominantly Inherited Alzheimer's Network (DIAN), investigators hope to organize and enroll a broad pool of qualified volunteers.

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Volunteers Needed for ADRC Studies

Do you know of someone who might consider volunteering for a research project on cognitive aging?

Two primary projects of the ADRC are in need of new volunteers:

The **Memory & Aging Project** enrolls persons aged 65+, both those with mild memory problems and those who are cognitively healthy.

The **Adult Children Study** needs volunteers between the ages of 45-74 for whom neither parent had AD.

If you know of a potential volunteer, please ask that person to call the ADRC at 314-286-2683. Thank you!



HELP US GO GREEN (AND SAVE SOME GREEN)

Tired of throwing away loads of paper when you're finished reading the mail? Then opt out of our paper newsletter and sign up to receive the ADRC Newsletter electronically via an e-mail list! You'll not only be helping the environment, but you'll also be helping us to save money on printing costs so that our resources can be put to other uses in the fight against Alzheimer's disease.

All you need to do is send an e-mail to Ron Hawley at hawleyr@abraxas.wustl.edu or call him at 314-286-2468 and include your name and the e-mail address where you'd like the newsletter sent.

E-mail addresses will not be shared with any other parties and will be used only to send you our ADRC Newsletter.



AWARDS & HONORS

2008 Poletsky Award Winner

The Richard & Mildred Poletsky Education Fund was established in 1995 to award a \$1,000 gift to support education and career development for a promising graduate student or postdoctoral fellow working in the field of Alzheimer's disease or related dementias.

The 2008 Poletsky Award winner is Nupur Ghoshal, M.D., Ph.D, an ADRC fellow who recently received her Board Certification in Neurology. Dr. Ghoshal serves as a clinician for the Memory & Aging Project and the Memory Diagnostic Center, and she also serves as a sub-investigator for four clinical trials.

Two African American Advisory Board Members Receive Exceptional Honors

Brenda Battle, Director of the Center for Diversity and Cultural Competence at Barnes-Jewish Hospital, has been recognized with the 2008 Most Influential Minority Leader Business Award by the St. Louis Business Journal. Each year, the Business Journal recognizes 25 outstanding ethnic minority business leaders in the St. Louis community. Honorees were featured in the Sept. 12 issue of the Business Journal.

Ida Goodwin Woolfolk, a 38-year veteran of St. Louis Public Schools and a dedicated contributor to numerous boards and organizations, was honored with a community track at the Monsanto Family YMCA named for her.

Randy Bateman, MD, was awarded an R-01 for the study of CNS amyloid-beta metabolism in participants with AD and age-matched controls. He was also awarded the Ruth K. Broad grant for measuring amyloid-beta metabolism in plasma.

David Carr, MD, James Galvin, MD, MPH, and Joy Snider, MD, physicians who practice at the Memory Diagnostic Center, were named among the top 43 doctors in the University-wide practice for highest patient satisfaction.

James E. Galvin, MD, MPH, was elected Chair of the Steering Committee for the Education Cores of all 29 federally-funded Alzheimer's Disease Centers.

David Holtzman, MD, Andrew & Gretchen Jones Professor and Chair of Neurology, was elected to the Institute of Medicine of the National Academy of Sciences.

Henry "Roddy" Roediger III, PhD, will receive the Arthur Holly Compton Faculty Achievement Award from Washington University in December.

Jeffrey Zacks, PhD, was awarded the Frank J. McGuigan Young Investigator Prize by the American Psychological Foundation.

In Senegal, the rate of formal education is low, meaning that few have the opportunity to learn basic science and also that many are at increased risk for cognitive decline. Out-of-pocket expenditure remains the primary method of health financing³; in a country where 54% of the population lives below the poverty line, this causes delayed or forfeited care-seeking and results in poor health outcomes.

The public health system and its education campaigns are focused on acute, communicable diseases: diarrhea, malaria, tuberculosis, etc. There is little public awareness of and little effort spent on chronic illnesses, and even less investment in preventive care³. Many of the country's resources are tied to the subsistence economy and to repay foreign debt, and most are centralized in urban areas, stunting access for the majority of the population who live in rural areas. There is a lack of health professionals in many areas of sub-Saharan Africa; a severe lack of neurologists is part of this shortage³.

Allopathic principles are imported from the West and may be at odds with traditional health beliefs. The same is true for research. There is limited understanding of (and sometimes disbelief about) the motives of research: why categorize as an illness something that is believed to be normal (e.g. dementia), why draw attention to "problems" which have no cures, and finally, why participate in research if direct benefits are not guaranteed, imminent needs are not addressed, and existing treatments are not accessible to the locals because of very high cost or

no availability locally?

Next steps

Regional data on Africa have shown lower prevalence and incidence rates of dementia than other regions², but we must wonder how accurate these numbers are and what might explain them. Genetic factors have been hypothesized, but with development and globalization, lifestyles are rapidly changing, thus increasing, for instance, vascular risk factors for dementias². Yet, with 90% of the population-based research worldwide geared toward the 10% of the human population living in industrialized nations, countries like Senegal remain understudied.

Medical and research advances have allowed us globally to live better and longer. Cost-effective therapies for otherwise devastating conditions exist today. However, until we commit to, and indeed practice, collaborative international and local research, health disparities will continue to plague our world.

References

1. Beiser, M. (2003). Why should researchers care about culture? *Canadian Journal of Psychiatry*, 48, 154-160.
2. Qiu, C., De Ronchi, D. and Fratiglioni, L. (2007). The epidemiology of the dementias: an update. *Current Opinion in Psychiatry*, 20, 380-385.
3. Aarli JA, Diop AG, Lochmüller H. (2007). Neurology in sub-Saharan Africa: A challenge for

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Around the world

There are about 25-30 million persons living with dementia around the world, an estimated 2/3 of whom are in developing countries.

10% or less of population-based research is carried out in low or middle income countries where 90% of the world population lives.

The developing world's share of the worldwide aging populations will increase from 59% to 71% by 2030.



Senegal

République du Sénégal, in French
Population 12,853,259 (July 2008)

Dakar, the capital city, is the westernmost point on the continent of Africa

75% of Senegalese are rural

All Senegalese speak an indigenous language, of which Wolof has the largest usage. French is the official language.

Soda M. Lo was a social work practicum student with the Memory and Aging Project/ADRC in the summer of 2008. Soda is a soon-to-be graduate of the George Warren Brown School of Social Work, Washington University. Feedback on this article may be sent to slo22@wustl.edu.

3rd Annual Norman R. Seay Lecture Draws Researchers, Key Community Members

On October 7th, 2008, the ADRC hosted its 3rd Annual Norman R. Seay Lecture in honor of Mr. Seay, a civil rights activist, longstanding supporter of Alzheimer's disease research, and founding chairman of the ADRC's African American Advisory Board. Each year, the series features a different minority scholar renowned for research and practice pertaining to Alzheimer's disease, aging, and/or minority health issues.

The lecturer this year was Dr. James S. Jackson from the University of Michigan. He is the Daniel Katz Distinguished University Professor of Psychology, Professor of Health Behavior and Health Education for the School of Public Health, and the Director of the Institute for Social Research.

Dr. Jackson's lecture, entitled, "Race, Ethnicity, and Cultural Influences on Mental Health: A Life-Course Framework," explored social and health differences between Blacks born in the U.S. and Black Caribbeans who immigrate to the U.S., further exposing some of the behavioral patterns that exist in our socioeconomic structures.

During the following reception, Washington University faculty, staff, and students and members of the St. Louis community had the opportunity to converse with Dr. Jackson. Several ADRC investigators were also on hand to present their research via poster presentation. Presenters included Dr. Consuelo Wilkins, Dr. Monique Williams, Dr. Jim Galvin, Dr. Cathy Roe, and Dr. Keoni Kauwe, and topics ranged from understanding the perceptions of African Americans about AD to using cerebrospinal fluid for genetic studies of AD.



L to R: Dr. Consuelo Wilkins, Mr. Norman Seay, Dr. James S. Jackson, Dean Larry Shapiro, Dr. John C. Morris

Breakfast Forum Feeds Excitement for Tackling Minority Health Issues

On the morning of the Norman R. Seay Lecture, Dr. Jackson lent his expertise to a breakfast forum that involved key leaders in the African American Community. Moderated by Dr. Consuelo Wilkins and Dr. John Morris, guests discussed, among other issues, the prevailing mistrust voiced by African Americans that medical professionals are not applying the optimum scientific principles for their care, due in part to the underrepresentation of African Americans in research studies. The discussion continued with questions regarding how the local medical community will respond to the challenges of limited Medicare and Medicaid funds.

A few of the many community leaders in attendance included Gwen Packnet - Director of Multicultural Affairs at UMSL, David Price - President of the Metro Board YMCA, Charles Shelton III - President of the Retired Teacher's Association, and Ruby Harriman - President of the Archway Links.

Breakfast Forum guests were appreciative of the ADRC's outreach into the community to open up a forum at which to discuss such issues. Furthermore, the guests spoke passionately about their concerns and ideas and seemed excited to take that exuberance back to their niches within the community and share it with others who are in positions to make real, forward-moving changes.

Comings

- Molly Aeschleman - Psychometrician
- Jane Sundermann - Psychometrician

Goings

- Vivien Gardner - left to pursue an opportunity with Transplant Research in the Department of Surgery

"For treatments now in development to be optimally beneficial for patients, we have to find ways of diagnosing Alzheimer's disease as early as possible," says DIAN principal investigator John C. Morris, M.D., the Harvey A. and Dorismae Hacker Friedman Distinguished Professor of Neurology and director of the ADRC. "That's likely to happen much more quickly as we move from studying the few family members in St. Louis with inherited Alzheimer's to the 300 family members with those conditions who will be accessible through the DIAN."

DIAN will include Washington University; a consortium involving Harvard University, Massachusetts General Hospital and Brown University; Columbia University; Indiana University; the University of California at Los Angeles; the University College of London's Institute of Neurology at Queen's Square; and a consortium of universities in Sydney, Melbourne, and Perth in Australia.

DIAN is modeled after the Adult Children Study at the ADRC. That study regularly conducts detailed physical and mental assessments of healthy middle-aged children whose parents have been diagnosed with Alzheimer's. Researchers hope this will help them to identify telltale changes in the central nervous system decades before the symptoms of Alzheimer's disease become apparent.

"The Adult Children Study is another genetic investigation, but it's focused on less overtly inherited forms of the disease," says Morris. "If a parent develops Alzheimer's disease at a relatively young age in a family with no known mutation that causes the disease, a genetic factor that we have yet to identify may be present, and this can notably increase the risk to the children of developing Alzheimer's."

Scientists are aware of inherited mutations in three genes that can cause Alzheimer's disease: amyloid precursor protein, presenilin 1 and presenilin 2. Changes in all three genes cause Alzheimer's to develop early, potentially pushing the age of onset down into a patient's 50s, 40s or even 30s. Researchers believe all the mutations lead to increased production of amyloid beta 42, a protein fragment that is the principal ingredient of brain plaques found in Alzheimer's patients. This has made amyloid beta a primary target for researchers developing new drugs for Alzheimer's disease.

Scientists already have several potential indicators, known as biomarkers, of the early onset of Alzheimer's disease. However, the only current way to confirm their validity is to wait years or decades and see whether volunteers who have the biomarkers eventually get the

disease. DIAN may help scientists shorten this process dramatically by allowing them to look for the potential biomarkers in individuals who have inherited a known mutation from an affected parent and are almost certain to develop the disease.

To get important clues about how and why the disease develops, scientists plan to closely monitor possible biomarkers in DIAN volunteers age 18 and older.

"The most exciting aspect of DIAN is that we have a chance to determine the type and order of brain changes that herald the onset of dementia in years to come," says Morris. "If we're going to develop preventive therapies, we have to know when to target each of the mechanisms in the brain that may be contributing to the beginnings of Alzheimer's disease."

If DIAN volunteers become demented, they will be monitored closely to assess how comparable the inherited and sporadic forms of Alzheimer's are. Investigators eventually may extend the DIAN study to allow volunteers to participate in tests of experimental treatments, but there are no formal plans for such studies at present. As volunteers develop the disease, scientists will monitor their condition closely to better understand how comparable the inherited and sporadic forms of Alzheimer's are. In addition, volunteers may be able to participate in studies of new treatments.

The grant includes travel funds to allow DIAN volunteers who enrolled at one network site to travel to another network site in order to participate in research unique to the other site.

The range of the seven sites raises a challenge for DIAN in ensuring that all research and diagnostic procedures are standardized so that data can be appropriately compared across all centers.

"If one institution obtains cerebrospinal fluid at 6 a.m. to test brain protein levels and another obtains samples at 6 p.m., it may be impossible to compare results because protein levels naturally fluctuate throughout the day," Morris explains.

Morris has been a leader in the process of standardizing assessment procedures and practices. In 2005, he led the development of a comprehensive set of patient assessment procedures for the 29 federally funded Alzheimer's disease research centers in the United States. He plans to work with other DIAN investigators to integrate these standards and others already developed for Alzheimer's research into the new collaboration.

HORIZONS is the newsletter of the **Alzheimer's Disease Research Center (ADRC)** — a research program in the Department of Neurology, Washington University School of Medicine, funded by grants from the National Institute on Aging and private donations. The ADRC supports and promotes interdisciplinary research on Alzheimer's Disease. The Memory & Aging Project (MAP) — the clinical research office of the ADRC — provides expert clinical assessments of cognitive functioning in normal aging and dementia.

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