BROOKLYN ALZHEIMER'S DISEASE ASSISTANCE CENTER

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Rates of Dementia and Its Accompanying Symptoms: Emerging Patterns and Public Health Challenges

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Increasingly, we hear about the growing crisis with respect to dementia. In this newsletter, I present data on the prevalence of dementia at the local, national, and global levels as well as data on the prevalence of neuropsychiatric symptoms such as psychotic symptoms, depression, and agitation.

First, it is necessary to define dementia and mild cognitive impairment. Dementia is a syndrome consisting of objective memory deficits and at least one cognitive deficit such as problems in language, motor skills, recognition, or executive skills (e.g., fluency. sequencing word and planning. abstraction), and impairment in daily functioning. Alzheimer's disease (AD) is the most common dementia disorder (about two-thirds of cases), with other causes including Vascular Dementia (VaD), Lewy Body Dementia, Frontotemporal Dementia, and Parkinson's Disease with dementia. Mild Cognitive Impairment is a condition in which there is objective deficit in one or more cognitive areas most commonly memory—but daily functioning is not impaired. There also can be noticeable cognitive declines in other areas such as attention or language.

As seen in Table 1, the prevalence of dementia doubles approximately every 5 years, and by age 90 the prevalence rate is nearly 50%. There is evidence that the prevalence of dementia does not plateau but continues to increase as people age. In 2006, Gondo and colleagues found that among centenarians in Japan 24% had no dementia, 14% probably had no dementia, and 62% had mild to severe dementia. Studies of dementia have found prevalence rates of ranging from 2.5% to 23%, with the majority in the 5% to 10% range. There is some evidence that if

milder cases of dementia were included the prevalence rate might double. Thus, the prevalence rates of dementia might rise to about 10 to 20 percent among persons 65 and over. This would be consistent with estimates of about 5 to 5 ½ million persons with Alzheimer's disease in the United States Dementia rates in nursing homes are much higher with reported levels at two-thirds to three-quarters of residents.

Most community studies have found Blacks to have higher rates of AD and/or all dementias than Whites. African Americans have prevalence rates of dementia of 14% to 500% higher than Whites (overall dementia rates of 3% to 27%). Vascular dementia appears to be more common in African American than Caucasian community residents. This finding has been attributed to the increased prevalence of known risk factors for vascular dementia in African Americans such diabetes hypertension. mellitus. and stroke. Parkinsonian dementia has been found to be less prevalent in blacks than in Caucasians. The North Manhattan Study (as seen if Figure 1) found prevalence rates of dementia were consistently higher at all ages among Latinos and Blacks than Whites elders. Some of these differences may reflect measurement bias such as education. socioeconomic status, and cultural differences. However, in a few studies, race had an independent effect on the measurement of cognitive status, i.e., it was independent of education and socioeconomic status. Measurement issues not withstanding, the high dementia prevalence rates among minorities is of special concern because minority elders are the fastest growing segment of the population in the United States

With respect to the projected increase of Alzheimer's disease, the number of persons with dementia is expected to rise from about 5 million today to 14 million in 2050. In Brooklyn alone, the estimated number of persons with dementia will approach 120,000 in 2050. Worldwide, the number of persons with dementia is expected to rise to over 80 million in 2040, which is approximately triple current levels, with roughly two-thirds of cases being in developing countries. For example, the number of persons with dementia in China will quadruple to 26 million in 2040.

The prevalence rates of dementias differ worldwide with rates of AD exceeding VaD in North America, but VaD exceeding AD in Japan and China. In 1993, Chang and coauthors reported prevalence rates of dementia ranging from 0.5% to 10.3% in 7 countries. They believed that these prevalence differences may be due to fewer older persons (remainder are survivors), genetic and biological differences, and stigma, so the disorder may not be reported. With respect to genetic risk, APOE 4 allele, which has been found to be an important risk factor in AD among Whites in the United States, is attenuated in Blacks and Latinos. Moreover, it varies cross-nationally; it may be stronger in Japanese, but having essentially no impact in Nigerians.

In looking at neuropsychiatric symptoms, although symptoms vary across the dementia spectrum, the approximate mean prevalence rates for verbal and/or physical aggressivity is 50%, depression is 25%, and psychoses (delusions &/or hallucinations) is 50%. There are interesting ethnic differences in the prevalence in neuropsychiatric symptoms. In general, Blacks have the lowest rates of depression, but they have the highest rates of delusions. Whites have lower rates of hallucinations than Blacks and Latinos. Among outpatients, behavioral disturbances are higher among Blacks and Latinos than Whites. There are various reasons for the ethnic differences in neuropsychiatric symptoms. These include:

(1) Racial/cultural differences in type of presenting symptoms; consequently, we have seen racial differences in neuropsychiatric symptoms disappear in our center in recent years; (2) Possible genetic differences; (3) Premorbid differences, e.g.,

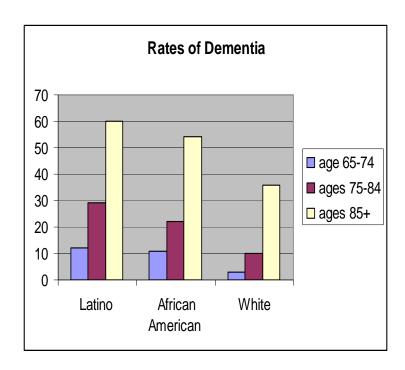
higher rates of paranoia and psychotic symptoms are found among Blacks in general, particularly among African Caribbean.

Changes in the prevalence of dementia, especially with respect to minorities in this country and large increases in the developing world, will pose major public health challenges over the next several decades. At the local level, the aging of the population, in tandem with the proportionately high numbers of minority elders, will place considerable burden on families and the health care delivery system. In New York City, the residents of the outer boroughs are especially at-risk because of the paucity of dementia programs.

Table 1. Prevalence of Dementia Among All Elderly Persons with Dementia (Community & Nursing Homes)

Age 65 2% Age 70 4% Age 75 8% Age 80 16% Age 85 32% Age 90+ 50-60%

Figure 1. North Manhattan Study White/Black/Latino Prevalence Rate Differences (in 1990s)



Update: Antipsychotic Medication Warnings in Persons with Dementia

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There has been accumulating evidence on potential harmful effects of antipsychotic medications in persons with dementia, particularly with regard to cardiovascular and cerebrovascular events, and mortality. While prospective studies, retrospective studies, and meta-analyses continue, sufficient evidence has been compiled for the Food and Drug Administration (FDA) to issue a black box warning, and for professional bodies to issue statements guiding practice. Here, I will summarize the history of these medication warnings, and identify the key results of some recently published analyses. While a review of the parent publications will reveal the names of the specific drugs investigated, this article focuses on the established categories conventional (typical) and atypical antipsychotics. I have not included extrapyramidal and metabolic side effects.

In 2002, reports began to surface of increased stroke risk in patients on atypical antipsychotics. By 2003, the FDA took action to warn prescribers about "increased risk of cerebrovascular accidents including stroke" in dementia patients, and by 2005 the FDA had issued a black box warning on atypical antipsychotics. This decision was based on a metaanalysis of 17 trials, and majority of deaths were of cardiovascular or infectious causes. The risk of death was 1.6-1.7 times that seen in placebo-treated patients. The warning has since been extended to include typical antipsychotics. Since additional studies have supported the contention that antipsychotics are problematic, especially in elderly persons with cognitive impairment.

In 2008, Rochon and coauthors (*Archives of Internal Medicine*) used healthcare databases comprising over 41000 persons, divided into community-based and nursing-home based cohorts. They found that in both groups, subjects on antipsychotics had an increased risk of all-cause serious events compared to controls, with those on typical antipsychotics having the highest risk. Serious events were defined as either hospital admission or death. The relative risks versus no medication were 3.8 (typical) and 3.2 (atypical) in the community sample, and 2.4 (typical) vs. 1.9 (atypical) in the nursing home group.

Beyond the concept of all-cause serious events, there is great concern about these medications influence on the cerebrovascular events. In 2008. using the General Practice Research Database in the UK, Douglas and Smeeth (British Medical Journal) assessed the risk the incidence of stroke in the same patients during periods when they were exposed and not-exposed to the drugs of interest. Thus, individuals served as their own controls. The period of exposure to antipsychotic medication was divided into the time of full exposure and then increasingly distant time periods of post-exposure. The results revealed an increased rate ratio for stroke in patients receiving any antipsychotic (1.79). The rate ratio was greater for atypicals (2.32) than for typicals (1.73), and was higher for those with dementia (3.50) than for those without dementia (1.41). The time-stratified post-exposure periods showed decreased rate ratios with increasing time.

One drawback of the studies mentioned above is their retrospective design. A British prospective study recently addressed the question of mortality related to antipsychotics was the "Dementia Antipsychotic Withdrawal Trial" (DART-AD) (Ballard et al. Lancet Neurology, 2009). The design was a randomized, placebo-controlled, parallel, two-group treatment discontinuation Participants (n=165) were randomly assigned to continue with their antipsychotic treatment for 12 months or switch their medication to an oral placebo. The results showed lower survival rates for who continued their antipsychotics compared with those on placebo (respectively 70% vs 77% at 12 months; 46% vs. 71% at 24 months; 30% vs 59% at 36 months; 26% vs. 53% at 42 months). There was no increase in cerebrovascular deaths in the antipsychotic-treated patients.

In light of the results of these studies that were published after the FDA black box warning, a critical question is whether there is any clinical utility of antipsychotic medication in elderly patients. One study addressing this question, specifically in Alzheimer's Disease (AD), was published by the CATIE-AD Study Group (Schneider et al. NEJM, 2006). This was a 42-site double-blind, placebo-controlled trial involving 421

patients with AD and psychosis, aggression, or agitation. The principal outcome measures were discontinuation of medication for any reason, and the number of patients with improvement in the Clinical Global Impression of Change scale (CGI-C). The results showed that time to discontinuation due to lack of efficacy favored medication, but time to discontinuation due to adverse events favored placebo. On the CGI-C scale, there was no significant statistically difference between medication and placebo groups. The authors concluded that adverse effects of the antipsychotic medication offset advantages in efficacy.

A frequent question, when results as those noted above are obtained, relates to their applicability. Are there differences between the elderly population with long-established psychiatric illness successfully treated with antipsychotics, and those elderly with new-onset psychosis (often caused by delirium, dementia-related psychosis, or both)? accumulating evidence Should the antipsychotics' adverse effects lead to changes in prescribing practice for the average psychiatrist, or warnings more appropriate these consultation-liaison psychiatrists and internists? The American Psychiatric Association guidelines emphasize considering the risk/benefit ratio, and the importance of nonpharmacological approaches. The Association of Geriatric Psychiatry consensus statement acknowledges the absence of a "magic pill" within the current armamentarium, and stresses the continuing re-evaluation of the need for medication for non-cognitive neuropsychiatric symptoms of dementia, with attempts to withdraw the medication.

A few bits of information gleaned from research on dementia are worth noting here. First, antipsychotic administration may be associated with accelerated cognitive decline. Another is that data suggest dopaminergic deficits in dementia. Given these findings, what is the role of medication where the mechanism of action is dopaminergic blockade? Furthermore, different behaviors are subsumed and treated under the umbrella term of "dementia-related psychosis", e.g., agitation. Should we be targeting non-dopaminergic systems? Various non-neuroleptic treatments have been attempted. These include antidepressants, anticonvulsants, cognitive enhancers, and benzodiazepines. The antidepressant trials have targeted serotonergic mechanisms. There

is a theoretical basis for targeting the serotonergic system since the serotonergic and cholinergic systems may work in concert in dementia, and there is evidence that agitation is related to serotonergic deficits. An additional appeal of serotonergic drugs is their favorable safety profile. A large trial testing the benefits of serotonergic anti-depressants is currently underway.

Finally, it is important to emphasize that in most dementia clinical research, there are extremely high placebo response rates, often around 40%. This strongly suggests a role for non-pharmacological approaches in providing symptom control, while avoiding medication side-effects.

In conclusion, the treatment of dementia-related psychosis is a rapidly shifting terrain, with long-established patterns of medication prescribing being called into question. In the mean time, clinicians must make complicated risk/benefit assessments on individual patients while observing what the data suggest about groups of patients.

Editor's Note (Dr. Cohen): Dr. Saunders has presented an excellent update concerning use of antipsychotic agents in dementia. However, as a practical matter, clinicians should consider the following:

- 1. Determine how easily the agitated behavior or psychotic symptoms can be managed by the caregiver, and how often symptoms occur. If agitation is periodic or psychosis is not causing appreciable behavioral disturbances, medication may not be needed.
- 2. During each visit, the continued need for antipsychotic medication should be assessed. Always encourage behavioral approaches, especially day programs.
- 4. Remember, in patients without substantial side effects, medication works better than placebo.
- 5. Except for the recent British study in nursing homes cited Dr. Saunders, there are no individual prospective studies in which antipsychotic agents increased mortality rates. Retrospective mortality studies are difficult to assess, and it is unclear whether patients on placebo who drop out due to agitation may have had increased mortality rates; they are not included in the analyses. Increased mortality rates come from pooled retrospective data. Even then, the increased mortality risk is only about 1 in 50.
- 5. Caregivers have higher mortality rates than controls. Consider their well-being.

An Intervention for Cognitive Health

Sharon McKenzie-Reece, Ph.D., CTRS SUNY Downstate Medical Center, Department of Psychiatry

There is a growing interest in education-based interventions that may improve memory or delay the transition from mild memory impairment to early-stage dementia. These interventions can be a way to educate older adults (65+) who are still living at home about the identified risk of memory impairment. Older adults can be taught to recognize early symptoms and how to distinguish between normal age-related declines and those resulting from a disease process.

The Health Promotion for the Mind, Body and Spirit, developed by Fitzsimmons and Buettner, is an example of such a program for individuals with newly diagnosed dementia. This course was designed to provide interactive information about normal aging, dementia syndromes, and healthy behaviors. This 12-week educational program focuses on the patient rather than the caregiver and provides detailed information to improve preventable health problems. Two Hour Class Modules include topics such as Healthy Behaviors, Dementia and Delirium, Cognitive Activities, Communications, Relationship, Depression & Coping, Physical Activities, Home and Travel Safety, Recreation & Leisure, Lifelong Learning, Medications & Talking to your Health Care Provider, Nutritional & Oral Health, and Future Planning.

This education-based intervention's curriculum presents information about changing health behaviors (i.e., lack of physical activities, decrease socialization, poor diet, etc.) that put individuals at risk for dementia and encourages healthier habits and positive lifestyles. It includes: extensive discussions about the importance of diet and its impact on a healthy brain; information about the research evidence regarding exercise and its effect on improving memory and flexibility; and practical examples of daily activities that can enhance cognitive health. Participants get an opportunity to review their current daily routines and come up with strategies to change their behaviors.

For individuals with early symptoms of memory impairment, the modules include information on how to identify resources within their communities and steps to access such services. Many older adults with memory impairments have difficulty communicating with their family doctors, and often, doctors do not take the time to explain the problems that may arise in the early-stages of dementia and AD let alone how to handle them. This education program includes information about communicating with health professionals, advocating for oneself, and maneuvering through the healthcare system.

The program stresses the importance of social networks and social engagement—particularly for the impaired individual—because they have protective effects against dementia. Individuals with a wide social network who are engaged with family, children, and friends tend to maintain cognitive function for longer periods and have a decreased risk of cognitive decline. Thus, the curriculum emphasizes the importance of keeping family ties and relationships with friends and extended family members, as well as maintaining affiliations with social clubs or community organizations. Several sessions focus on the relationship with family members, who are invited to participate. session provides education to the family members about the psychosocial impacts of dementia and its effects on persons with the disease. Case studies and/or real-life scenarios provide valuable illustrations of psychosocial manifestations of the disorder. Family members are taught how to recognize signs of isolation and disengagement (e.g., spending a lot of time watching television) in the person with the disease. They are encouraged to share examples from their own experience and to problem-solve each situation. Another session explores recreation and leisure activities that enhance positive engagements and family cohesiveness. A family that plays together tends to stay together.

Because social interaction involves exchanging of ideas, thoughts, and communication and taking the necessary steps to create community, this author suggests that two sessions should be included to enhance the social component of the intervention. The first of the two added sessions would facilitate an opportunity for participants (with the disease) to role-play social situations (some awkward, like

forgetting a person's name) and include strategies leading to positive exchange. Participants would learn relaxation and stress-reduction techniques to help decrease anxiety in such situations. These strategies can be practiced during the session, and then be included intermittently in the remaining sessions. By the end of the intervention, these techniques should become an integral part of dealing with daily life stressors.

The second added session would explore the use of support groups. Support groups are effective in providing emotional outlet and the opportunity to socialize with peers in a safe, comfortable environment, as participants are encouraged to identify and join a support group in their community prior to the end of the 12 weeks. This would assure the opportunity for social engagement post-program participation and an avenue for individuals to share the experience with others as the disease progress. They will hear and learn, vicariously, strategies on how to cope and an opportunity to have others support them through the difficult times.

Finally, Fitzsimmons and Buettner's education intervention includes lessons about specific cognitive stimulation activities. Research evidence suggests that cognitive recreation activities have protective effects against dementia. Mental stimulation activities increase cognitive reserve and decrease the rate of cognitive decline. Participants have an opportunity to explore various cognitive stimulation strategies, such as writing for pleasure, computerized-games (e.g., the Wii), the internet use, crossword puzzles, and other innovations that support and enhance cognitive function.

In 2003, a small pilot study by Fitzsimmons and Buettner testing this program described a transformation in the group that continued long after the intervention. A recent large-scale project by Fitzsimmons and colleagues (2009) used a quasi-experimental design to test 89 middle class Caucasian participants in Florida across four locations with a focus on uniform teaching methods for promoting and maintaining optimal health. The results suggested that providing education early in the course of the disease empowered the older adults and provided an element of personal control and dignity. This study reported a high level of participant satisfaction with the course, a significant

improvement in cognition, a decrease in depression, and increased perceived social support. This author presented results from a feasibility study testing this program with a more ethnically diverse urban population at the 60thAnnual Scientific Meeting of the Gerontological Society of America (2007). Participants felt that the content and materials learned were important and relevant to their lives. They reported that the information was very specific to healthy living and they gained insights about how to take control of their life.

This educational-based intervention is a positive approach to help older adults make the lifestyle changes that are integral to cognitive health. It offers an opportunity for the older adult to learn about strategies that will prevent or help to deal with potential problems that may develop should memory impairment or early-stage dementia occurs. Additionally, it invites family members to learn about early onset of memory impairment and develop strategies to assist the person with the disease to maintain a positive way of life.

- 1. Buettner, L. & Fitzsimmons (2009)Promoting Health in Early-Stage Dementia: Evaluation of a 12-Week Course, *Journal of Gerontological Nursing* Vol. 35 No. 3 March.
- Buettner, L. & Fitzsimmons, S., Atav, S. (2006). Predicting outcomes: therapeutic recreation for behaviors in dementia, *Therapeutic Recreation Journal*. Arlington: First Quarter . Vol. 40, Iss. 1; p. 33.
 McKenzie, S.E. (2007). Health ...community [Abstract]. The Gerontologist 60th Annual Scientific Meeting: "The Era of Global Aging: Challenges & Opportunities." (47) Special Issue

Congratulations to Dr. Carl Cohen

Dr. Carl Cohen, Director of Geriatric Psychiatry, has been promoted to the highest SUNY Rank as Distinguished Professor for Teaching and Service. Dr. Cohen is one of the nation's leading experts on the needs of older adults with schizophrenia and other forms of mental illness. He was one of the first in his profession to address the needs of mentally ill homeless people. At Downstate, he established one of the first geriatric divisions in the country, the first psychiatry fellowship in New York City in treating older adults, and the Geriatric Psychiatry Clinical Center, a principal center site for patient care, student education, and clinical research. He also founded the Brooklyn Alzheimer's Disease Assistance Center, the first of its kind in the Borough of Brooklyn.

Research Update

Carl I. Cohen, M.D.

Copper and Alzheimer's Disease (AD)

There is accumulating evidence suggesting an association between copper levels in the blood and deficits of AD. In a recent report by Squitti and coauthors (Neurology, 2009; 72: 50-55), free copper levels as measured by ceruloplasmin were correlated with lower functional levels. Clioquinol, a copper chelator that may prevent copper and zinc from binding the beta amyloid, was recently found to have beneficial effects on slowing deterioration in AD. These findings suggest potentially new avenues for clinical research.

B12 and Folate Deficiencies and Dementia

Two recent studies have pointed to alternative mechanisms of how vitamin B12 and folate levels may affect the incidence of dementia (Vogiatzoglou et al: Neurology 2008; 71: 826-832; Kim et al: J Neurol Neurosurg Psychiatry 2008; 79: 864-868). One study found that patients with the lowest B12 levels had the greatest declines in brain volume. There is a well-established association between brain atrophy and dementia. A second study found dementia was associated with greatest declines in folate and vitamin B12 levels over 2.4 years, and

the relationship to baseline levels was weaker.

Statins and AD

Haag et al (J Neurol Neurosurg Psychiatry 80: 1-2, 2009) conducted a 9-year follow-up assessment of 6992 non-demented Dutch individual aged 55 and over. Those persons who had ever used a statin cholesterol-reducing medication had significantly lower risk of developing dementia, after controlling for possible confounding variables. An accompanying editorial noted that two large studies with patients with cardiovascular disease did not find a reduction in dementia and two recent studies of statin use in persons with mild or moderate AD found no significant benefits.

Cardiovascular Risk Factors and Dementia

A longitudinal study in North Manhattan (Helzner et al, Arch Neuro 2009; 66:329-335) found persons with pre-diagnosis diabetes, higher cholesterol, and higher LDL levels had greater decline in AD after

diagnosis. These risk factors were thought to provide additional burden, increased oxidative stress, or trigger an inflammatory response. A second study (Kanya et al, Arch of Neurol 2009; 66: 343-348) found that non-demented men aged 70 to 79 in the upper third of body mass index showed significantly more cognitive decline whereas women did not show such a relationship. Timing may be also be important---midlife obesity (about age 50) may increase the risk of AD whereas latelife obesity(aged 65 and above) may not have as much impact.

Ginkgo Biloba to Prevent Dementia

A randomized control 6-year trial of over 3000 non-demented community volunteers (minimum age 75) found that Ginkgo biloba found no difference in the new dementia cases between placebo and ginkgo group (about one-sixth in both groups) (DeKosky et al JAMA 2008; 300: 2253-2262).

Hypertension and Late-Life Dementia

Two recent articles point to the role that hypertension plays in late-life dementia. One article(Hoffman et al: Neurology 2009;72: 1720-1726) found that persons treated for hypertension in mid-life were less demented clinically and had less AD pathology than persons who did not receive treatment or non-hypertensive. A second study (Haag et al: Neurology 2009; 72: 1727-1734) found that antihypertensive use was associated with reduction in dementia risk, especially in persons treated before age 75. Although hypertension in midlife seems to be a risk factor for cardiovascular and cerebrovascular disease in later life, in later life, low blood pressure seems to be a risk factor. Thus, there appears to be a J-shaped relationship between blood pressure and dementia. Perhaps this explains some of inconsistent findings between hypertension and dementia. Thus, in later life, may be around 75, treatment of hypertension has less value, because the balance between blood pressure, cerebral autoregulation, and brain metabolism may change. Thus, it appears that treatment of hypertension in midlife is a useful preventive strategy whereas

treatment in late life may have little or no impact on the incidence of dementia.

Predictors of Maintaining Cognitive Function in Older Adults

A recent study by Yaffe and coworkers(Neurology 2009; 72:2029-35) examined over 2500 black and white community elders over 8 years: 30% of participants maintained cognitive function, 53% showed minor decline, 16% had major cognitive decline. Significant predictors of maintenance of cognitive function included white race, high school education or higher, 9th grade literacy level or higher, weekly moderate or vigorous exercise, and not smoking. The findings show that there are many potentially modifiable factors that may reduce the chance of cognitive decline.

Donepezil (Aricept) and Galantamine (Razadyne) Treatment for Mild Cognitive Impairment(MCI)

Doody and colleagues (Neurology 2009; 72: 1555) conducted a 48-week randomized control trial of donepezil versus placebo with 821 with MCI. They found donepezil was not significant in improving the cognition and function measures used as primary end-points. Two of eight secondary measures favored donepezil, but adverse effects were nearly twice as high with donepezil than with placebo (47% vs 25%). Similarly, Winblad and coauthors (Neurology 2008; 70: 2024-35) found no difference in the 24-month conversion rate (23%) between galantamine and placebo based on studies involving 2048 subjects.

Mild Cognitive Impairment and Long-Term Outcome May Be Generally Optimistic

Manly and coworkers (Ann Neurol 2008; 63: 494-506) found that in large naturalistic follow-up study in NYC -- averaging about 3.3 to 6.7 years of follow-up in two large cohorts-- that 22% of persons with MCI developed AD, 47% remained stable, and 31% improved. Although MCI is a risk factor for AD, there are many persons who do not develop dementia.

Results of Recent Treatment Intervention Studies

1. The combination of memantine (Namenda) and a cholinesterase inhibitor (e.g. Aricept and others) was again found to be superior

- to monotherapy with a cholinesterase inhibitor or no treatment (Atri et al: Alz Dis Assoc Disorders, 2008; 22: 209-221).
- 2. Demebolin hydrochloride (an antihistamine) was found to have significant benefits in cognition over 26 weeks in Phase III trial. The results were similar to changes seen with cholinesterase inhibitors. The drug was well-tolerated with dry mouth and depressive symptoms being the most common side effects (Doody et al: Neurology 2008; 372: 207-15)
- 3. Post-mortem studies of 8 patients who received beta amyloid immunization showed significant increase in the clearance of amyloid (Holmes et al: Lancet 2009; 372: 216-223). The study had been terminated because of adverse effects including encephalitis. Newer studies, using different immunization strategies, are now in phase III trials.
- 4. Results of surgical shunt treatment that was thought to potentially clear amyloid and tau from the brain were found to produce no clinical benefits in a 215 patients (Silverberg et al, Neurology 2008; 71: 202-09).

Appointments

To make appointments for the evaluation and treatment of dementia, please call BADAC at 718-287-4806.

Support Group

Caregivers interested in participating in our weekly support group should call 718-287-4806.

Activity Group

Patients and caregivers interested in participating in our weekly activity group should call 718-287-4806.

Community Education and Training

BADAC offers free education and training sessions to professionals and lay persons. Please call Dr. Andreas Adams at 718-287-4806 for more information.

Donations

Please Help! No gift is too small. All funds are used for direct services. For tax exempt donations, make funds payable to the "Research Foundation of SUNY"

The Underutilization of Nursing Homes by English Speaking Caribbean American Elders

Lorna Walcott-Brown, M.S.

Nursing home placement is a taboo subject among most African Caribbean Americans. Family caregivers of elders with dementia find themselves in a bind because they promised to never put their loved one in a nursing home. Consequently, many biological caregivers endure very high levels of stressors while caring for a parent or other relative suffering from Alzheimer's disease or other dementia.

There are two important elements that affect Caribbean nursing home placement—culture and migration. First, most African Caribbean Americans are reared and socialized to care for their elders when they are no longer able to care for themselves. The fact that many were raised in extended family households, and taught to address elders as aunt, uncle, or cousin - related or not -solidified the concept of family bonding and responsibility. Therefore, the concept of responsibility for the elders is ingrained and is an integral part of their upbringing. African Caribbean Americans learn from these elders that the way to treat them in old age will determine how they are viewed by their peers, neighbors, associates, society at large, as well as how they themselves will be treated in old age.

Secondly, the few nursing homes which existed in the Caribbean and flourished during colonial times, catered to, and were patronized only by colonial masters and their underlings. Many of elders grew up when nursing homes were considered relics of colonialism. The elderly residents of such homes were viewed as being abandoned by their families of whom many resided abroad in England or other European countries. Moreover, many of the elders were past employees of these nursing homes and were often stigmatized with the assumption that they were abandoned by children and other family members. Therefore, many older Caribbean elders view nursing homes as dumping grounds. In their lifetime, many Caribbean parents voiced the fear of being placed in a nursing home and/or being cared for by strangers. In addition, Caribbean culture uses proverbs as teaching tools for the young. These proverbs were constantly repeated during childhood, and therefore become ingrained in ones memory. For example, many children born of Caribbean descent know the meaning of this adage: "What you sow is what you reap."

Thirdly, migration was always a source of survival for Caribbeans. It began with internal migration of former slaves who traveled from rural areas to cities in search of work to care for their families. Next was the external migration of those who left their respective islands to work on building the Panama Canal and on various plantations in South America. These two waves of internal and external migrations provided

economic relief for male migrants who left their families at home. However, the third wave of migration was to England, following WWII, during the 1940s through 1960s. During this period, being colonial subjects, Caribbeans had the opportunity to migrate to England. Many went as families because once they alighted on English soil they were considered "landed." Thus, this migration included many more women, who often brought along their elderly relatives to aide in the care of their children.

In the early 1960s, North America became the refuge for Caribbean migrants after Britain granted the islands political independence. During this wave of migration from mid 1960s to late 1980s, most were female, who left children in the care of fathers, grandparents, other elderly relatives, and in some cases with non-kin caregivers. For immigrant parents who were undocumented, it took several years for them to become legal residents. During this time, grandparents who cared for many of these children neglected their personal health and well-being. When many of these families eventually reunited. and grandma became ill with dementia, it was very difficult for the child or grandchildren to place her in a nursing home. Although the caregiver has many other demands, they may feel obligated to care for the parent who raised their children. For any child /caregiver in this position the only option would be if the parent had an illness that required skilled care that cannot be provided in the home. To do otherwise, would mean that one would have to endure the criticism and condemnation Research evidence suggests that Caribbean of others. caregivers often report less depression and feelings of stress than Caucasian caregivers in similar circumstances. One explanation of this may be evident in the pride and feelings of gratitude that Caribbean caregivers hold in caring for their family members and continuation of tradition.

Finally, despite these powerful cultural norms and traditions practiced for years, in the last decade there are increasingly more Caribbean families using nursing homes. This change is a result of several factors including: the enculturation of Caribbean children and grandchildren, the concomitant economic demands placed on families, greater life expectancy, greater prevalence of dementia, and the availability of nursing home care through Medicaid insurance. These factors have provided countervailing pressures to increase placement of elder kin. The close proximity of many of these nursing homes to Caribbean neighborhoods may provide opportunities for relatives to continue to maintain strong bonds with their elder family member.

Update: New Community Education and Outreach Endeavors

I. The Hellenic American Communities of Brooklyn:

With the \$33,000 grant support from the Brooklyn / Staten Island Philoptochos Charities, a bilingual (Greek-English) public health nurse and Dr. Andréas Adams have launched a bilingual support groups with older Greek-speaking caregivers and other interested caregivers at the Kimisis and Three Hierarchs Orthodox Churches. The participants' and clergy's responses have been very favorable. Several families have followed-up for appointments for older relatives who exhibit cognitive deficits.

The public health nurse and Dr. Adams provided an in-service workshop to 45 Greek Orthodox clergy at the Holy Trinity Cathedral (74th Street between 1st and 2nd Avenues in Manhattan). This event was arranged by Very Reverend Eugene Pappas, President of the Clergy Fellowship, who had previously interviewed these two clinicians on his radio show on Alzheimer's disease and caregiving. One participant wrote: "[It] was most informative and deeply appreciated. Our clergy left with a wealth of information."

On the evening of April 2nd, 2009, on the occasion of the 9th annual Dr. Flessas Memorial Lecture sponsored by the Hellenic Medical Society and the Hellenic Link at the Holy Trinity Cathedral, Dr. Adams addressed the attendees on, "The Non-Pharmacological Approaches to Managing the Alzheimer's Patient." Some of the strategies which he cited focused on the strengths of the diagnosed individual, the use of humor, music, spirituality, aromatherapy, and reminiscence therapy. The attendees also included many caregivers and lay persons.

On Sunday, May 10th, a health fair was held at the Holy Trinity Cathedral, which was organized by the Committee on Inclusion through Outreach and Education. Dr. Adams was an active participant in the committee's planning sessions. After the liturgy, there were exhibits and speakers on a variety of health issues such as physical disabilities, frailty, Alzheimer's disease, diabetes, and so forth. The attendees came from the various Greek-American

communities of New York City, and their reactions were very favorable.

II Brooklyn Alzheimer's Disease Assistance Center (BADAC) at SUNY Downstate – CUNY-NYU Collaborative Projects:

This past academic year, Dr. Adams provided direct clinical supervision to five senior students majoring in psychology at the College of Staten Island. Working with Dr. R. Blair, internship supervisor, these students (Greek, Creole and English speaking) worked directly with caregivers. They also attended various educational presentations on aging, the dementias, and multiculturalism presented by Dr. Adams to the various ethno-racial communities of Brooklyn. These individuals attended different seminars with their clinical supervisor offered by the New York City Alzheimer's Association, various institutions of higher education, and a host of agencies. Another graduate student from SUNY Downstate's Occupational Therapy interned with Dr. Adams during the academic year 2008-09. She participated in support groups and evaluation of older individuals with cognitive deficits.

A Chinese speaking (Mandarin and Cantonese) intern in social work from Hunter College, who was supervised by Dr. Adams in another field placement, volunteered her time and facilitated several workshops and groups for Chinese elderly at the Narrows Senior Center. Dr. Adams also facilitates a monthly support –wellness group at the facility.

In addition, an international social work scholarship holder from Spain participated in a unique field placement. She pursued a double specialization at NYU in global health policy and clinical practice. Her placements were at the World Association of Former United Nations Interns and Fellows (an NGO) and at BADAC. Her work at the former focused on diabetes and ageing in the Caribbean, and providing bilingual short-term didactic and clinical services to caregivers at BADAC. She received her MSW from NYU in May, 2009.

Working with Joan Manes, Ph.D., Director of Education Programs in the Division of Continuing Education at NYC College of Technology, Dr. Adams concluded the third (3rd) training program for College Level Immersion Program (CLIP) and GED students on issues of aging and providing direct care (physical and oral) to Alzheimer's disease patients. The program combines lectures. readings, case studies, students' work experiences (many have worked in homecare), guest speakers (clinicians from SUNY Downstate and other facilities) and visits to nursing homes, adult day programs, and senior centers. The program's duration is approximately 20 hours. It is followed by a graduation ceremony where certificates of completion are presented and each student comments briefly on the program. Hopefully, this program can begin to relieve the shortage of bilingual and culturally competent homecare /direct service workers.



Dr. Adams with graduates of the CLIP program

III The Intergenerational Program:

This academic year, four senior Haitian-American Creole speaking high school students were trained and placed with two Haitian families in the neighborhoods of Flatbush and Canarsie. These adolescents were trained by Dr. Adams on the nature of Alzheimer's disease (AD), and how to engage the AD patient using an array of recreational activities and reminiscence therapy. They are compensated financially (\$10/hour), and receive school credit for community service from their school, the Nazareth Regional High School. This relationship between BADAC and the school is now in its 7th year. Many of these students pursue higher education at public / private institutions in health care. The families have been extremely satisfied and helped by these students.

IV Hemispheric Outreach

Dr. Adams and three family caregivers were interviewed in Spanish on "Radio Maria," a Hispanic Catholic Radio Program. Firstly, Dr. Adams provided a clinical overview on Alzheimer's disease, and the physical and psychological consequences upon the caregiver. Then each caregiver related her own experiences, and what coping strategies each one utilized. The dominant responses focused on spirituality, religion, and family/community support systems. After the interview, calls were received from the listeners within the metropolitan area. The interview was also aired to countries in Latin America as well.

V Activity Group

For the past 18 months, Ms. Cassady Casey, a doctoral candidate in clinical psychology at Long Island University, CW Post campus, has been facilitating an activities group for Alzheimer's patients and their caregivers. Activities include reminiscences / life review, interactive board games (checkers, Connect Four, UN game), bingo, arts and crafts, music and so on. Patients also dialogue with each other. The group also serves as a learning opportunity for home attendants / caregivers who hone their skills on engaging the patient. This fall, Ms. Casey will be leaving to pursue her Ph.D. on a full time basis. BADAC wishes her success in her career. Dr. Adams will assume leadership of the group until a new facilitator is recruited.



Dr. Adams& staff with graduates & family members

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Director, Geriatric Medicine
Howard Crystal, M.D.
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