

**KRONKOSKY CHARITABLE FOUNDATION
ROUNDTABLE DISCUSSIONS**

TOPIC: Alzheimer's Roundtable
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PREPARED BY: Fred B. Cardenas, Grants Manager

PARTICIPANTS

Invited Agency Representatives

Sharon Lewis	UTHSCSA – School of Nursing and Medicine
Donald Royall	UTHSCSA – Department of Psychiatry
Nancy Rheams	Alzheimer's Association – South Central Texas Chapter
Adrienne Linton	UTHSCSA – Department of Chronic Nursing Care
Ginny Funk	Alzheimer's Association – South Central Texas Chapter
Marcia Katz	Morningside Ministries

Foundation Staff

Palmer Moe	Managing Director
Fred Cardenas	Grants Manager

KEY ISSUES

General Information

- There are regions of the brain that are minimally affected by the environment and they tend to be in the frontal lobe. The white matter around the neurons and connections seems to be developed early on in life and environmental factors may have little affect on it later in life. There is a strong association between education and dementia. The link seems to be connections made in early childhood, lead to improved propensity for learning, lead to better educated person, lead to a decreased propensity for developing Alzheimer's.
- There may be a need to consider the number of persons affected by dementia who are incarcerated. 88% of persons in the Bexar County Jail have problems with executive functioning.
- Executive functions are “those cognitive processes which orchestrate relatively simple ideas, movements, or actions into complex, goal-directed behaviors.”
- Plaques and tangles in the frontal lobe increase the development of Alzheimer's in a person.
- Dementia usually affects all clients/residents in nursing home care to some extent or another.

- The African-American and Latino communities in San Antonio do not seem to access resources or services for Alzheimer's as much as the rest of the community (at least not in the same manner). They tend not to seek support and the availability of extended family may play a role in this. A needs assessment may be needed to gauge the level of impact of Alzheimer's on these populations and to identify strategies to reach these families, especially given the level of stress typically experienced by family caregivers. Issues that may impact reaching these populations may include more limited insurance, language barriers, and availability of time off from work.
- Resources for people affected by Alzheimer's are very limited in San Antonio. Some cities offer more support and resources than San Antonio including programs, funding and transportation.
- There are assessments used to measure reduced functioning – decision-making ability and executive functioning.
- Insulin may be correlated with the development of dementia.
- Drug companies are now looking at executive functioning to assess vascular dementia.
- The Hispanic population does not typically access services addressing Alzheimer's. Service providers have a difficult time reaching this population and there is a lack of information about Hispanics affected by Alzheimer's.
- Alzheimer's minimizes insight early on so the person affected will not initially complain about problems as being associated with Alzheimer's. The person affected loses a sense of the "big picture", much like autistic children, who may be oblivious to their surroundings and a social life.
- There is a sequence of loss of function in Alzheimer's that includes loss of insight, loss of orientation, memory loss, and dementia.
- For every person in a nursing home there are three living in the community with a caregiver.
- Drug companies may overemphasize the effectiveness of drugs "fixing" Alzheimer's. A cure is not available so much emphasis should be placed on prevention.
- People are placed in out of home care, usually not because of the severity of the problems associated with Alzheimer's, but rather based on the caregiver's availability, and their ability and capacity to care for the person affected.

Statistics

Statistics compiled by the Alzheimer's Association include the following:

- 10% of people over age 65 and 50% of people over age 85 have Alzheimer's.
- 14 million of Americans will have Alzheimer's disease by 2050 unless a cure or prevention is found.
- One in 10 persons over 65 and nearly half of those over 85 have Alzheimer's disease.
- 70% of people with Alzheimer's live at home with 75% of them being cared for by family and friends.

- The number of people with Alzheimer's disease in Texas will double by the year 2030 to over 500,000.
- Texas is ranked fourth in the US in residents over age 65 which makes up 10% of the total Texas population.
- There are about 39,000 people affected by Alzheimer's in Bexar County.

Services/Resources

- When Alzheimer's is first identified it is helpful for the family to turn to the Alzheimer's Association, as they are a main resource for information and support. Some doctor's who may initially help identify Alzheimer's in a patient do not necessarily address all the related issues accompanying the disease such as the stress experienced by caregivers and various resources available from legal to respite care.
- San Antonio has about 40 adult day care programs with only Grace Place (with a 1 month waiting list) focused on serving persons with Alzheimer's. Boerne, Seguin and New Braunfels also have programs available for people affected by Alzheimer's.
- The V.A. offers 2-3 week respite care in Kerrville.
- Education is essential for family members and caregivers, for nurses and other professional caregivers, and for doctors.
- It is usually the family doctor who initially helps to identify dementia in a person. Some doctors may have not been as attentive to Alzheimer's in the past as Medicare did not cover Alzheimer's until recently. A person may be referred to a specialist who may provide medication but not address the many related issues.

Research

- Recent research conducted locally by UTHSCSA indicates that the impact of Alzheimer's on cognitive functioning explains dementia across all functional areas. This local research is being done with many retirement communities and also has a focus on examining transitions.
- Longitudinal studies that examine aging offer much more significant findings than studies that primarily involve reviewing records to collect data.
- Some studies indicate that individuals may experience 20-30 years of dementia before developing full Alzheimer's.
- Local researchers (UTHSCSA), using a population from local retirement communities have done a 10-year lead research study which focuses on executive functioning (EF). EF deteriorates over time and it disables people. Diminished executive functioning explains ¼ of loss of all functioning. While executive functioning may be decreasing a person may not necessarily experience any loss of memory.

- One finding indicates that Alzheimer's affects the brain's control over the heart and people dying from apparent heart problems may have in fact been victim to Alzheimer's affecting their heart.
- Research has also shown that people with dementia under age 70 are significantly different than those over age 80. The extent of decline in functioning above age 80 is disproportionately higher than all the losses in functioning prior to age 70. Research examining executive functioning should look at the transition.

Family Caregivers

- Caring for persons affected by Alzheimer's causes overwhelming stress for caregivers due to some of the problematic behaviors and other symptoms.
- Family caregivers generally avoid institutionalizing their senior family members.
- The mortality rate of caregivers is 63%, with the average caregiver dying an average of 2 years before the Alzheimer's patient dies.
- There is a tremendous need for respite care for the caregiver, but respite must be chronic and long-term as caregivers need more than once or twice per year respite. For some caregivers that do have regular respite, the respite is something that keeps the person going as they have something to look forward to.
- Caregivers have several issues that contribute to their stress. Sometimes they have much difficulty in "letting go" of the family member affected by Alzheimer's. They may feel guilty considering placement or using out of home help, thinking that they may be "abandoning" their loved one. Men are especially vulnerable to not seeking help, as they may want to portray themselves as being strong enough to handle the stress. When some caregivers finally seek help, they have sometimes waited too long and the care or resources they seek or find are no longer helpful because Alzheimer's has entered the advanced stages.
- In many cases, caregivers themselves may be cognitively impaired because of their advanced age, such as in the case of an elderly spouse. They impaired caregiver is then placed in a role of caring for a difficult to handle person and may need to remember the medication regimen, scheduled appointments, etc. The caregivers themselves may be affected by dementia.
- Adult children caregivers are more stressed than other caregivers. They often have to make significant changes in their lives to be able to care for their family member; they may still be raising children themselves; they may have to deal with additional financial burdens and limited resources; they are usually still working, etc. Older caregivers may not be as stressed as they may not understand or be oblivious to what is happening with their spouse or loved one. Additionally, there is also a high incidence of spousal abuse among families that care for someone with Alzheimer's with the affected person being the victim or perpetrator of the abuse. Spousal abuse is a major issue in families affected by Alzheimer's.
- Older spouses of persons affected by dementia may themselves be affected. There are many instances where the caregiver may have the cognitive ability of a 6th grader but he/she drives, cares for the family member, and monitors appointments, medication, etc. The difference is that a 6th grader has better vision, hearing, mobility, etc.

- Spouses caring for persons affected by Alzheimer's may be concerned about being perceived as disloyal if they seek help outside the home, especially if they seek out of home placement.
- Seniors with Alzheimer's and their spouses may be reluctant to tell their children.
- Many caregivers are affected by depression and take anti-depressants.
- It is important than when a person with Alzheimer's is receiving services that the caregiver also be assessed not only for the stress level and related problems but also for executive functioning.

Professional Caregivers

- The US is experiencing a nurse shortage in all areas of medicine, but particularly in nursing for programs serving seniors, which is usually perceived to be a less attractive field.
- Along with a shortage of nurses is a shortage of faculty which impacts the quality of education and the number of students that can be trained/educated. UTHSCSA's School of Nursing only has two faculty members in gerontology.
- Recent additional funding to the School of Nursing is not yet significantly addressing the need for additional nurses or the faculty shortage but is causing larger numbers of students per class.
- Professional caregivers also experience a great deal of stress due to the demands of the job, the care needed by seniors, the behaviors of seniors affected by dementia, staff turnover and the low pay.
- In-home care is very expensive averaging about \$13/hour, while assisted living costing about \$3-\$4,000 per month. Medicaid does not pay for assisted living but does pay for skilled nursing care.
- It is important to educate all medical professionals about Alzheimer's as they may see patients affected by heart problems, diabetes or other illnesses who are also affected by Alzheimer's. CNA's (Certified Nurse's Aide) are the primary caregiver in out of home care. Licensed Vocational Nurses (LVN's) and other more trained nurses may be used as administrators or lead staff, and are sometimes placed in positions for which they are not fully prepared or trained.
- Professional caregivers need better pay, better training and health promotion to help them take care of themselves. Happy and healthy caregivers = improved caregiving ability.
- Seniors often have too many doctors involved in providing care and usually no one coordinates all these services.