Understanding the Psychiatric Symptoms of Dementia

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Dementia

- Recognized since ancient times as consequence of aging
- Today it is a major public health concern.
- Approximately 5.2 million people in US with Alzheimer's Disease at all ages
- One in nine individuals 65 and older (11 percent) have Alzheimer's Disease.
- If no cure, 14 million will be affected by 2030.
Costs of Dementia

- Dementia costs this country $157 – $215 billion annually making the disease more costly than either heart disease or cancer. (Rand Corporation and University of Michigan, 2013)

- Greatest economic cost is providing institutional and home-based long-term care rather than medical services.

- If age-specific prevalence rates remain constant, with the growth of the aging population this cost will double by 2040. (New England Journal of Medicine, April 4, 2013 Funding by National Institute of Aging.

Dementia Care Sites

- Nursing Home Care – 2008, 68% of all nursing home residents had some degree of cognitive impairment.

- Assisted Living Care – Estimates vary: 45–67% of residents of assisted living facilities have Alzheimer’s disease or other dementias.

- Adult Day Center Services – At least ⅔ of elderly participants in adult day centers have Alzheimer’s disease or other dementias.

- Home care – more than 1/3 (37%) of older people who receive primarily non-medical home care services have “cognitive impairment” consistent with dementia. (*Taken from State Home Care Programs from Connecticut, Florida and Michigan)

- 70% of individuals with Alzheimer’s disease are taken care of at home. (2011 Alzheimer’s Diseases Facts and Figures)
Alzheimer’s Disease

✓ Statistics – 5.2 million Americans
  ▪ The majority of those with the disease are women
    ▪ Age-specific incidence, however is the same for men and women
  ▪ People with lower levels of education appear to be at higher risk of Alzheimer’s and/or other dementias
  ▪ African-Americans are twice as likely to develop Alzheimer’s disease and/or other dementias
  ▪ Hispanic individuals are 1½ times more likely to develop Alzheimer’s disease and/or other dementias

2013 Alzheimer’s Diseases Facts and Figures

Diversity and Rural Population Issues

• Alzheimer’s disease and other dementias are under-diagnosed in rural and minority populations more than in urban or white populations.
• Lack of diagnosis seriously reduces an individual’s access to available treatments and information.
• Active medical management, information and support, and coordination of medical and community services have been shown to improve quality and outcomes of care for people with dementia.
Issues of Rural Populations

- 65+ are 13.17% of USA population, but 20% of this age group live in non-metropolitan designated areas
- Most counties in PA are rural
- Limited access to health care and social services for prevention, diagnosis, management & treatment of chronic conditions
- Limited access to needed assistance with ADLs and IADLs, and long-term care options
- Increasing diversity: large concentrations of Hispanics (especially migrant labor areas) and African Americans (particularly in South)

Issues of Rural Populations

- Research (2012) found that rural living is associated with an increased risk of Alzheimer’s disease, with suggestion childhood rural residence increases risk.
- Research found over ½ of caregivers of rural patients with AD reported their patients experienced unmet service needs in 1 or more ADL and/or IADL (2013).
- Data show that nursing home use is more prevalent in rural communities than urban ones (2004).
- Video-telemedicine in memory disorders clinics: Being used for evaluation and management of rural elders with cognitive impairment
Diversity Issues: African-Americans

- African-Americans are about 2 times more likely than white Americans to have Alzheimer’s and other dementias.
- However Medicare data show they were only 32% more likely to have a diagnosis (i.e., they were less likely than whites to have a diagnosis and less likely to say a doctor had told them they had a “memory-related disease”).
- Diagnosis is typically in the later stages of the disease, when they are more cognitively and physically impaired (so medical costs higher at that point).

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Diversity Issues: African-Americans

- 65% of African-Americans have hypertension; higher risk of stroke; 60% higher risk of type 2 diabetes (contributes to vascular disease)
- Better management (or prevention) of these medical conditions, especially if treatment started in midlife, could reduce Alzheimer’s and other dementia risk.
- Ethnic and cultural bias in current screening and assessment tools lead to higher rates of false-positive results
Diversity Issues: African-American Care-giving

✓ Most frequently documented cultural differences were:
  • Better psychosocial health of caregiver
  • More positive appraisals of caregiving
  • Greater spirituality or use of prayer
  • More social support for care-giver
  • Stronger beliefs about filial responsibility
  • Higher value placed on extended family networks
  • Greater aversion to institutionalization of relatives

Diversity Issues: Hispanics

• One and ½ times more likely than whites to have Alzheimer’s and/or other dementias
• Less likely to have a diagnosis of the condition
• When diagnosed typically in later stages of disease, so more impaired and need more medical care
• Hispanics with dementia are low users of formal service; less likely to see a physician and much less likely to receive services to help monitor and control their chronic conditions
Diversity Issues: Hispanic

- High incidence of diabetes – 64% higher than non-Hispanic white Americans; diabetes is one of the vascular risk factors related to risk of AD and other dementia in absence of stroke
- Study of older Mexican Americans found diabetes and hypertension contribute more to dementia in this ethnic group than in non-Hispanic whites
- Again, better management of these conditions (or prevention) beginning in midlife may reduce higher risk of AD and other dementia

Diversity Issues: Hispanic

- Hispanic community of USA represents people from over 17 Spanish-speaking countries, but culturally-based attitudes and behaviors unite them.
- Lack of Spanish-language abilities and cultural sensitivity in many health care systems:
  - Instills distrust
  - Limits access to care
  - Adversely affects quality of care they do receive
  - Imposes further burdens on extended family as interpreters
Diversity Issues: Hispanic

• Cultural biases in cognitive testing and inadequate translation of diagnostic tools may skew diagnosis of dementia in Hispanics
• Significant progress in developing culturally sensitive tools, but not standardized or normed across subgroups of Hispanics, and not widely used
• Older Hispanics have far less health insurance than non-Hispanic contemporaries

Diversity Issues: Hispanic Care-giving

• Strong cultural value of family responsibility
• High acceptance of cognitive impairment and dementia as a normal part of aging to be managed within the family
• Thus families provide more care, for longer periods, and at higher levels of impairment than non-Hispanic families.
Diversity Issues: Hispanic Care-giving

- Accept stress as a normal, expected part of the familial role
- Resistance to sharing familial problems with outsiders
- Reluctant to use formal services until overwhelmed
- Services must be provided in way that reinforces family values and overcomes cultural barriers

Caregiving and Depression

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Family Caregiving

• It is a myth that most the elderly in the United States are cared for in nursing homes and health care institutions. Family and friends provide 80% of the long-term care of older adults in the United States.

  *National Alliance for Caregiving, 2009*

Family Caregiving

• The majority (83%) are family caregivers—unpaid persons such as family members, friends, and neighbors of all ages who are providing care for a relative (Family Caregiver Alliance, 2005)
Family Caregiving

• Almost 15.2 million Americans provide unpaid care for a person with Alzheimer’s Disease (Family members, friends and neighbors).

• In 2011, they provided 17.4 billion hours of unpaid care – an economic value of $210.5 billion dollars. (Based on “care valued” at $12.12 per hour.)

Alzheimer’s Association (2012)
Alzheimer’s Disease Facts and Figures

Family Caregiving

• Since 2004, the proportion of caregivers of adults who mention Alzheimer's or dementia as the main problem has risen (from 6% to 12%), this may be due to the increase in the care recipients age 75 or older.

• The presence of Alzheimer's or mental confusion is associated with a higher burden of care.

“Caregiving in the US (2009)” - National Alliance for Caregiving in collaboration with AARP
Incidence and Prevalence of Depression among Caregivers

- 61 percent of family caregivers of individuals with Alzheimer’s and other dementias rated the emotional stress of caregiving as high or very high.

- 33 percent report symptoms of depression.

  Alzheimer’s Association (2012) Alzheimer’s Disease Facts and Figures

Family Caregiving

- It is not surprising then that these Alzheimer’s caregivers report a greater physical strain than do others (with an average rating of 2.3 on a 5-point scale vs. 2.0). They also perceive their caregiving situation to be more emotionally stressful (3.1 vs. 2.7).

- Caregivers whose recipient has emotional or mental health problems are more likely than others to report a decline in their own health as a result of caregiving (28% vs. 12%).

  “Caregiving in the US (2009)” - National Alliance for Caregiving in collaboration with AARP
Incidence and Prevalence of Depression among Caregivers

- Family Caregiver Alliance 1997 – 58% of caregivers showed clinically significant depressive symptoms

Incidence and Prevalence of Depression among Caregivers

- 1/3 family caregivers of individuals with dementia have symptoms of depression
  
  (Alzheimer’s Association, 2008; Yaffe and Newcomer, 2002)
Incidence and Prevalence of Depression among Caregivers

- 40 – 70% of family caregivers have clinically significant symptoms of depression with 25% meeting the diagnostic criteria for major depression.


Caregiving and Depression

- Family caregivers face a range of health risks and serious illnesses themselves
- Family caregivers experience high rates of depression, stress and other mental health problems
- Elderly spousal caregivers experiencing mental or emotional strain have a 63% higher risk of dying than non-caregivers.

*Family Caregiver Alliance 2007
National Policy Statement*
Incidence and Prevalence of Depression among Caregivers

- 20 – 50% of caregivers report depressive disorders or symptoms
- Higher rates of depression are attributed to those caring for individuals with dementia
  - 30 – 40% of dementia caregivers suffer from depression and emotional stress
- Caregivers use prescription and psychotropic medications more than non-caregivers

Family Caregiver Alliance 2003

Incidence and Prevalence of Depression among Caregivers

- Care recipients behavior is an overwhelming predictor of caregiver depression.

Shultz and Colleagues 1995
Key Findings

• Caregivers predominantly female (66%)

• Average of 48 years old

• One-third take care of two or more people


Key Findings

Figure 4: Main Problem or Illness of Care Recipient Identified by Caregiver

Q18. What would you say is the main problem or illness your [relation] has/has had for which he/she needs needed your care?

<table>
<thead>
<tr>
<th>Top Mentions</th>
<th>Caregivers of Recipient Age 18+</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2004</td>
</tr>
<tr>
<td>Old age</td>
<td>12%</td>
</tr>
<tr>
<td>Alzheimer’s/Confusion</td>
<td>10%</td>
</tr>
<tr>
<td>Cancer</td>
<td>7%</td>
</tr>
<tr>
<td>Mental/emotional illness</td>
<td>7%</td>
</tr>
<tr>
<td>Heart disease</td>
<td>5%</td>
</tr>
<tr>
<td>Stroke</td>
<td>5%</td>
</tr>
</tbody>
</table>

Base: 2006 All caregivers [n=1,480]
Key Findings

Figure 2: Duration of Care for Recipient

Q21. For how long have you been providing/did you provide care to your [relation]
[FOR CHILD RECIPIENT: for his/her condition]?

<table>
<thead>
<tr>
<th>Duration</th>
<th>2004 (n=1,247)</th>
<th>2009 (n=1,307)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 6 months</td>
<td>18%</td>
<td>18%</td>
</tr>
<tr>
<td>6 months to 1 year</td>
<td>14%</td>
<td>13%</td>
</tr>
<tr>
<td>1 to 4 years</td>
<td>34%</td>
<td>34%</td>
</tr>
<tr>
<td>5 to 9 years</td>
<td>17%</td>
<td>18%</td>
</tr>
<tr>
<td>10 years or more</td>
<td>15%</td>
<td>15%</td>
</tr>
<tr>
<td>Occasionally</td>
<td>3%</td>
<td>3%</td>
</tr>
</tbody>
</table>

Caregiver Burden

- Assessment for caregiver burden – The Zarit Burden Interview

- Alzheimer’s Association Stress Check - [http://www.alz.org/stresscheck/](http://www.alz.org/stresscheck/)
Symptoms of Caregiver Stress

- Denial
- Anger
- Social withdrawal
- Anxiety
- Depression
- Exhaustion
- Sleeplessness
- Irritability
- Lack of concentration
- Problems with physical health

2011 Alzheimer’s Association

Resources

- Alzheimer’s Association – www.alz.org
- ADEAR – adead@alzhimers.org
- Family Caregiver Alliance – www.caregiver.org
- Geriatric Mental Health Foundation – www.gmhfonline.org
Resources for Families


• **Still Alice**, Lisa Genova. (2009)

• **Contented Dementia**, Oliver James. (2008)

• **Dementia Reconsidered: the Person Comes First**, Thomas Kitwood. (1997)

Citations

• Family Caregiver Alliance - [https://caregiver.org/depression-and-caregiving](https://caregiver.org/depression-and-caregiving)


• Mayo Clinic - [http://www.mayoclinic.org/healthy-living/caregivers/in-depth/caregiver-depression/art-20047051](http://www.mayoclinic.org/healthy-living/caregivers/in-depth/caregiver-depression/art-20047051)

What makes the engine go? 
Desire, desire, desire. 
The longing for the dance 
Stirs in the buried life. 
One season only, 
and it’s done. 

Stanley Kunitz