

Expert Caregiver Panel

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Disclosures

- None



Dementia

- Cognitive impairment that affects activities of daily living (ADLs)
 - Basic ADLs: feeding, bathing, dressing, toileting
 - Instrumental ADLs: telephone, shopping, cooking
- Assistance with ADLs generally provided by one primary caregiver



Prevalence and Cost of Caregiving

- 15.9 Million Americans providing unpaid care to Alzheimer's disease patients
- Caregivers provide >18 Billion hours of unpaid care
- \$221 Billion in cost

Caregiving in the United States. AARP and Family Caregiving Alliance., 2015. Facts & Figures, Alzheimer's Association, 2016.



Who Are Caregivers?

- 2/3 are women
- 1/3 are daughters
- 65% are under age 65
- 23% “sandwich generation”
- 66% live with the care recipient
- 41% have a household income of < \$55,000

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Burden

- Adverse effect on emotional, social, financial, physical, and spiritual functioning as a result of caregiving
 - Higher among women than men
 - Associated with behavioral symptoms
 - Higher among DLB and FTD compared to AD



Dementia Caregivers

- Caregivers of persons with dementia report
 - Higher levels emotional stress and depression
 - Reduced physical health (increased risk of coronary heart disease, poor sleep)
 - Poorer health behaviors (less healthy food/ less exercise)
 - Negative effect on employment
 - Increased financial difficulties
 - More ambiguity about the future



Progressive Changes in Relationships with Person with Dementia

- Growing closer
- Becoming a better person
- Opportunity to give back
- Filling role
- Satisfaction/fulfillment



Discussion Topics

- How did your relationship with your loved one change?
- What was the most rewarding part of being a caregiver?
- How did being a caregiver impact your personal life?
- What role did healthcare providers/supportive services/research play in your life as a caregiver?



Conclusions

- Caregivers bear tremendous burden that differs from case-to-case, especially among differing types of dementia
- Caregiving requires coping strategies and support
- Educational and supportive services are available
- Don't forget to care for yourself



Questions?

