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Determining Caregiver Needs and Well Being

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Featured Speaker

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Learning Objectives

- List a minimum of five statistics/characteristics specific to Alzheimer's and dementia caregivers
- Describe a minimum of five components contained in a thorough Alzheimer's Caregiver Assessment
- Identify a minimum of three elements contained in a "person-centered" plan designed to promote caregiver well-being

Key Definitions

- Dementia: loss of memory and cognitive ability serious enough to interfere with daily activity
- Alzheimer's Disease:
 - Most common form of dementia
 - Progressive brain disease causing problems with memory, thinking and behavior
- Caregiving: the act of providing unpaid assistance and support to family members or acquaintances who have physical, psychological, or developmental needs

Focus on Caregiver Well-being

- Caregiving:
- Can result in physical, emotional and financial challenges
 - Consequences for both the patient and caregiver
- People Living with Alzheimer's Disease/Dementia:
- Increasing number choosing to remain at home
 - Overall health depends on the caregiver

Caregiver Demographics

- More than 15 million Americans provide unpaid care for people with Alzheimer's disease and other dementias
- In 2016, Alzheimer's Caregivers provided an estimated 18.2 billion hours of informal care valued at \$230 billion (9x total revenue of McDonald's)

Who are the Caregivers?

- Approximately one third (1/3) are 65 or older
- Approximately two thirds (2/3) are women
- Over two thirds (2/3) are married
- More than two thirds (> 2/3) non-Hispanic white (10% African American, 8% Hispanic, 5% Asian)
- Almost half (41%) annual household income less than \$50,000
- Majority of caregivers (66%) live with the care recipient & 23% are reported to be "sandwich generation" caregivers

Effects of Caregiving

- An estimated 40% of family caregivers suffer from depression (compared with 5-17% who are not caregivers)
- 38% of Alzheimer's caregivers rate the physical impact of caregiving as high-to-very high
- Of employed caregivers:
 - Approximately 9% have quit their jobs to provide care
 - 54% go in late or leave early
 - 15% have taken a leave of absence

Caregiver Assessment

- Systematic process of gathering information about caregiving situation
- Identifies problems, needs, concerns, and resources of the family caregiver
- Determines caregiver ability to meet the needs of the care recipient

Caregiver Assessment

Can help to:

- Maintain well-being
- Maintain ability to provide care
- Prevent or postpone placement of loved one
- Produce better outcomes for the care recipient

Family Caregiver Alliance reports that caregivers who have their needs assessed often feel acknowledged and better understood by health care practitioners

Caregiver Assessment

- Assessment includes:
 - Caregiver Self-Assessment Tool
 - Comprehensive Assessment Interview conducted by a Health Care Practitioner

Caregiver Self-Assessment Tools

- Alzheimer's Association Caregiver Stress Check (www.alz.org/care/alzheimers-dementia-stress-check)
- AMA Caregiver Self –Assessment Questionnaire (www.CaregiversLibrary.org)
 - This tool is also valid for identifying caregiver depression

Caregiver Stress Check

Caregiving can be stressful. Get the help you need.
 Are you a caregiver for someone with Alzheimer's or dementia? Do you feel overwhelmed? You may be putting your own health at risk. Take our Caregiver Stress Check and get resources that can help.



Do you regularly...

1. Feel like you have to do it all yourself and that you should be doing more Yes No
2. Withdraw from family, friends and activities that you used to enjoy Yes No
3. Worry about the safety of the person you care for Yes No
4. Feel anxious about money and health care decisions Yes No
5. Deny the impact of the disease and its effects on your family Yes No

Elements of Assessment Interview

Background on caregiving situation

- Relationship and its quality
- Environment and household composition
- Financial resources and employment

Assessment Interview

Caregiver perception of patient

- Diagnosis: present state and future expectations
- Personality or behavioral changes
- Safety considerations
- Medication administration
- Instrumental Activities of Daily Living (IADL) and Activities of Daily Living) ADL skills, limitations and needs
- Medical follow up recommendations, doctor/patient relationship

Assessment Interview

Caregiver values and preferences

- Has the caregiver accepted the role?
- Is the patient willing to accept the care and assistance?
- Are there cultural, moral, or personal issues impacting care?
- Are there restrictions or preferences for scheduling the care?

Assessment Interview

Caregiver well-being

- Chronic or acute health conditions or symptoms
- Caregiver fatigue (duration of caregiving)
- Depression or other emotional factors
- Overall quality of life

Assessment Interview

Caregiver skills and abilities

- Knowledge about disease, symptoms, and progression
- Competencies (communication skills) and confidence
- Coping skills

Assessment Interview

Caregiving consequences

- Financial strain
- Family relationship strain
- Difficulties with formal providers or caregivers

Assessment Interview

Caregiver resources

- Informal and formal support networks
- Legal and financial resources
- Community resources and services

Assessment Interview

Signs of caregiver stress

- Denial
- Depression/anxiety/irritability/anger
- Social withdrawal
- Sleeplessness/exhaustion
- Lack of concentration
- Health problems

Caregiver Plan

- Uses data collected in the assessment
- Creates a person-centered plan for the caregiver
- Promotes caregiver well-being

Caregiver Plan

- If a diagnosis has not been made or confirmed, refer to diagnostician
- Provide disease specific information in manner caregiver can understand and is ready to accept

Caregiver Plan

- Describes necessary legal, financial, safety and emergency planning/plans
- Provides resources

Caregiver Plan

Identify formal and informal support for caregiving

- Assist caregivers with “making the ask”
- Identify care resources and help to implement plan if ready

Caregiver Plan

Identify emotional support for the caregiver

- Informal: family and friends
- Community resources: Alzheimer’s Association programs and services

Caregiver Plan

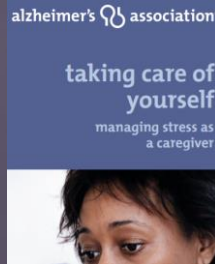
Stress the importance of caregiver "self-care"

- Doctor visits
- Exercise and lifestyle
- Stress management



Resources


- From Alzheimer's Association
- *Take Care of Yourself* brochure
 - 2017 Alzheimer's Disease Facts and Figures
- *Caregiver Self-Assessment Questionnaire* (CaregiversLibrary.org)
 - *Who Should Assess the Needs of and Care for a Dementia Patient's Caregiver?* AMA Journal of Ethics (12/2016, 18:12)



Conclusion

- Offer caregivers your support and acceptance
- Remind them how important their well-being is to the overall health and well-being of the person with Alzheimer's disease/dementia




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