Working with People in Early Stage AD

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Defining Early Stage

- Initial presenting symptoms: mild forgetfulness, losing and misplacing things
- Difficulty with complex tasks
- Inability to use reasoning strategies
- Difficulties finding words
- Loss of initiative
- Disorientation with time and place

Changes

- Gradual withdrawal from activities
- Inconsistent performance of ADL’s
- Deterioration of abstract thinking
- Depression or anxiety
- Sexual dysfunction
- Weight loss
- Decreased tolerance of new ideas or routines

Interactions with others

- People who are in frequent interaction may notice changes
- Those with less interaction may not notice
- Person with symptoms may be unaware
- Often changes noticed first at work

Communication

- Difficulty finding words and losing thoughts
- Comprehension difficult in groups
- Need for eye contact, direct conversation

Responses by Individual

- May try to conceal symptoms
- Spouses may also use denial
- Assessment can be distressing
- Emphasize remote memories
- Want to avoid the label
- What does the diagnosis imply
<table>
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<tr>
<th>Fears and Losses</th>
<th>Obtaining Diagnosis</th>
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| - Fear of becoming a burden  
- Fear of loss of independence  
- Loss of insight and perceived threats to autonomy  
- Grief and anger and confusion  
- Loss of self  
- Frustration and suspicion | - Denial and lack of awareness by person and family  
- Delay in diagnosis as much as 36 months  
- Families may need encouragement  
- Necessity of ruling out reversible dementia  
- Physicians may not recognize  
- Conspiracy of silence, just aging |

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<tr>
<th>Barriers to Diagnosis</th>
<th>Disclosing the Diagnosis</th>
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| - Fear of stigma  
- Failure of person and family to recognize symptoms  
- Failure of physicians to recognize symptoms particularly in younger people | - Encourage families to disclose with relatives  
- Most have already noticed symptoms  
- Can begin to discuss it openly and constructively  
- Can help to promote independence  
- Can help with support |

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<tr>
<th>Significance of Diagnosis</th>
<th>Clarifying treatment</th>
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| - What does diagnosis mean to the person and in the culture  
- Labeling and its impact  
- Denial may be reinforced by partner to avoid distress  
- May feel ignored  
- Role change and self esteem | - Physicians may not communicate  
- May not agree on care options  
- May not refer to community programs such as support groups, information and education programs |
Voices of AD (A Town Meeting)

- Diagnosis can be frustrating process
- Feel abandoned by physicians
- Difficult to maintain independence while anticipating changes
- Concerns over driving
- Involvement and activities
- Exclusion by friends
- Not aware of support services

Support Groups for Early Stage AD

- Learning about AD and how to cope
- Helps in accepting diagnosis
- Less isolation and less anxious
- Increasing knowledge improves coping

Early Stage Group

Goldsilver and Grunier

- 8 week closed group of 12 persons
- Facilitators must be trained, empathetic
- Participants fluctuate in affect, behavior, communication
- Need to keep focus
- Task centered activities, memory games
- Participants responded positively

Memory Club

S. Zarit

- 10 session group related to empowering partners
- Goals to increase information, improve communication, help with planning, build relationships
- Emphasizes problem solving in dyad
- Group meets together and separately
- Encourage active role in planning and decision-making

Dyadic Interventions

C. Whitlatch

- Early diagnosis dyadic intervention
- Counseled as couple and individually
- Develop goals
- Dyad works together on plan

Objectives of 9 Sessions

- Understanding of care preferences
- Practice communication
- Discuss discrepancies
- Discuss care preferences/expectations
- Explore relationship issues
Format of Sessions

Sessions:
1  Information, future planning
2-3  Assess care, prioritize and compare values, preferences
4-6  How to find services, communication
7-8  Challenges and barriers to help and solutions
9  Review, unresolved issues, where to get help

Results

- Couples satisfied
- Counselors like protocol
- Older caregivers and spouses most likely to complete program
- Proactive persons more engaged

Time-Limited Support Groups

R. Logsdon

- Early diagnosis means earlier treatment
- Negative effects of diagnosis
- Support groups can be helpful
  - Decrease isolation
  - Education
  - Cope with changes
  - Make future decisions

Seminars for partners

- Introduction and overview
- Coping with memory loss
- Medical update
- Social and family relationships
- Daily living skills
- Self esteem
- Future planning
- Legal and financial issues
- Health concerns and stress management

Results

- Improved quality of life
- Decreased family conflict
- Younger caregivers and adult children less likely to complete program
- Has not been used with ethnically diverse groups
- May not be effective with young onset

Case Management

Chu

- Case management and other services provided in home
- Prepare clients for later crises
- CM made monthly contacts and gave education, referrals, skill training
- Information had to be repeated
- Decreased CG stress
Multimodal Intervention
Burgener

- Tai chi exercise
- Cognitive behavioral therapy
- Memory exercises
- Support group
- Improvements in physical outcomes and self-esteem
- No increase in depression after 40 weeks

Early Onset AD

Specific Problems
- Difficulty getting diagnosis
- Loss of employment and income
- Major role changes
- Loss of self esteem
- Lack of support services

Emotional responses

- Anger
- Denial
- Depression
- Fear
- Frustration
- Isolation
- Sense of loss

Main Concerns

- Difficulty getting accurate diagnosis
- Finances, work
- Dependency
- Changing relationships
- Social isolation/marginalization
- Need for physical activity
- Concerns about genetic transmission

Needs

- Greater awareness among physicians and other professionals
- Greater awareness among employers
- Possible job restructuring
- Services specifically for younger people
- Assume capability rather than incapability

Conclusions

- Persons in early stages have distinct issues to be addressed
- Interventions for both partners can be helpful as they assist with planning, communication, reduce isolation
- Educating health care professionals about issues
- Persons want to be treated with dignity and respect
- Important to remember that it is a person with an illness who wants to be heard not a disease to be studied