Early Alzheimer’s intervention: A holistic Approach to Care

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Sixteen Million affected by 2050

- Currently 5.2 million (Alz. Assoc. 2008)
  - Early onset represents 2.6 million of those with the disease

- Last 10 years new information focusing on the Early Stages of Dementia
  - Improved awareness of unique issues faced by Early stage dementia
  - Early stage support group development
  - Care Partnerships
Studies involve the care partner

- New research involves persons with the disease directly

- **GOAL** for the growing population with Alzheimers will be that the disease is identified sooner and remain in early stage longer.
Theoretical Model of Prevention

Brain Reserve

Dementia Threshold

Age

60 70 80 120
Altering the Landscape of the disease

• Proportion of those with early stage Alzheimer’s will likely increase

• Will need a different experience where they can be defined by their remaining abilities rather than their memory losses or functional decline.
Keeping this in mind:

Discussion of project

Beginning

Community initiated interest

Interest from agencies and churches

Develop a program that was easily available

Serve early stage Alzheimer’s persons and their care partners
• Series of Sessions – informative, educational and social
  • 8 sessions repeated every two months
  • Focus on dyads

• Locations
  • Public access at municipal building
  • Church community room

• Schedule 1½ hour afternoons
  • Thursdays
What was said: Early Stage Alzheimers Perceptions

• Public Stigma and negative perception
  • Hiding the challenges – denial
    – Job performance unable to work at high level
    – Perception of “old person’s disease”
  • Beneficial to recognize disease as early as possible- prolonged, frustrating
  • Abandoned and isolated

• Need for direct link from Dr. to resources
• Improved quality of life with medications
  • Hope for others
  • Additional research – younger excluded?

• Changes in Independence
  • Need to maintain
  • Connect with others
  • Separation from “normal” lifestyle
  • Cope with changes

• Need for physical activity
• Frustration with relationships
  • Care partner fear
  • Social Isolation
  • Friend abandonment
  • Changing work interactions

• Where to get help?
  • Connecting with others through Support Groups

• ALL PROMPTED THE PILOT STUDY OF HOLISTIC CARE IN EARLY ALZHEIMER’S
What we had to offer

• Community and Church based Program
• Address needs of Early Alzheimer's Disease
• Inclusion of CarePartners (caregiver)
• Based on research interventions for Cognitive maintenance
• Include whole person aspects
• Collaboration with community and support groups

• Finding the participants
  • N= 15 with care partners (30)
  • N=1 no care partner
  • Age range (41- 69) Early stage

• Developing a plan of interventions based on needs
  • Nurse and Social Worker, University Faculty and potential for student volunteers
ALZHEIMER’S CARE IN NON-URBAN AREAS HAS MANY CHALLENGES
• Agendas
  • “Let me Talk” – relating experiences
  • Interacting with the team- news items, information about medications, any clinical trials, group POSITIVES
  • Practice for Maintaining – started with creative and memory building
    » Crossword puzzles
    » Stitchery
    » Newspapers and discussion
    » Projects for others – stuffing bags is a great conversation builder
    » Counting money
    » Recording data
    » Computer Chat
• Care Partners have opportunity for private mini session with Social Worker on “How to Cope”
• Lunch and cleanup– by the attendees

• Sessions repeated every 2 months for 8 sessions
  – Determine if cognitive levels are maintained
  – Try to maintain socialization as well
### Table 1. Demographic Characteristics of Subjects with Mild Cognitive Impairment

<table>
<thead>
<tr>
<th></th>
<th>Patients</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of patients (15 pairs)</td>
<td>30</td>
<td>9</td>
<td>21</td>
</tr>
<tr>
<td>Age</td>
<td>61.4</td>
<td>58.6</td>
<td>63.4</td>
</tr>
<tr>
<td>Age of Onset of MCD</td>
<td>57.1</td>
<td>54.4</td>
<td>59.8</td>
</tr>
<tr>
<td>Length of Disease</td>
<td>6.9</td>
<td>6.8</td>
<td>7.0</td>
</tr>
<tr>
<td>Positive Family History MCD</td>
<td>23/30</td>
<td>7/9</td>
<td>16/21</td>
</tr>
<tr>
<td>Received Treatment</td>
<td>29/30</td>
<td>9/9</td>
<td>20/21</td>
</tr>
<tr>
<td>Medication</td>
<td>21</td>
<td>9</td>
<td>12</td>
</tr>
<tr>
<td>Exercise</td>
<td>17</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>Memory Support</td>
<td>28</td>
<td>9</td>
<td>19</td>
</tr>
<tr>
<td>Other (nutrition/alt. medicine)</td>
<td>7</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Employment status</td>
<td>9</td>
<td>9</td>
<td>0</td>
</tr>
<tr>
<td>Baseline BDI</td>
<td>27.5± 9.2</td>
<td>20.6± 6.7</td>
<td>31.9±7.9</td>
</tr>
</tbody>
</table>

Values± standard deviation, BDI=Beck Depression Inventory, MCD=Mild Cognitive Disease (mild impairment)
“Getting to Know You”

Beginning the Project
You are not alone! Your journey is shared with others!
Socialization and less Isolation

Cooking and Cleaning Activities
Not feeling Alone and frustrated

Responding to Needs to help with the frustration!
Interests of the Early Alzheimer’s persons are included in the plan of activity, exercise and support.

A farmer and his son look at the crops
Doing for and with Others Makes you feel better!

Gardening activity and sharing the fruits of labor!
Another Activity

- He helped grow this and now helps at Farmer’s Market.
Working with Words and News
Activities
Scatter plot of Early Mild Cognitive Impairment Showing Regression Line

- Patients with Dementia Diagnosis
- Patients with early dementia Diagnosis
### TABLE 2. SUMMARY OF COGNITION OVER TIME – CARERECIPIENT

<table>
<thead>
<tr>
<th>T1</th>
<th>T2</th>
<th>T3</th>
<th>T4</th>
<th>T5</th>
<th>T7</th>
<th>T6</th>
<th>T8</th>
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</thead>
<tbody>
<tr>
<td>63</td>
<td>83</td>
<td>56</td>
<td>80</td>
<td>54</td>
<td>28</td>
<td>91</td>
<td>10</td>
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</table>

**Department of Veterans Affairs Mental Status inventory**

**Measure of Cognition (Baseline)**
Informant Questionnaire on Cognitive Decline in the Elderly

Average Maintenance over Time Intervals by Group

- Male: High score
- Female: Moderate score
## Caregiver responses to Care Effectiveness and Satisfaction

### Caregiver Responses to Care Effectiveness

Measures perceptions of Caregiving effectiveness (n=30)

<table>
<thead>
<tr>
<th>Question</th>
<th>Response Options</th>
<th>1</th>
<th>2</th>
<th>27</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How satisfied are you with the present arrangement for caring for your [relative]?</td>
<td>Not Satisfied at all; Somewhat Satisfied; Satisfied; Very Satisfied</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>1</td>
<td>2</td>
<td>27</td>
</tr>
<tr>
<td>2. How satisfied are you with the way in which decisions concerning your [relative] are made?</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>2</td>
<td>28</td>
<td></td>
</tr>
<tr>
<td>3. How successful do you think you’ve been in achieving your goals in caring for your [relative]?</td>
<td>Not Successful at all; Somewhat Successful; Successful; Very successful</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>2</td>
<td>28</td>
<td></td>
</tr>
</tbody>
</table>

(Noelker & Townsend, 1987) p=.64
What was found?

• Initial assessment of Early Alzheimer’s confirmed
• Intervention was perceived as helpful but did not maintain over the eight time periods.
• Male care recipients tended to do better with cognitive maintenance over time.
• Helped inform attendees care partners about new things and coping.
• Through conversation and interaction with others in the same situations - socialization and less isolation occurred.
Looking at the Broad Scope of Early Alzheimer's Care in non-urban settings

Challenge to develop a program that was easily available and serve Early Stage Alzheimer’s persons and their carepartners
Difficulties in Early Alzheimers Caregiving in non-urban settings

• Limited use and availability of services non-urban areas.
• Significant impact of caregiving on non-urban workplaces.
• Financial hardships non-urban caregivers with low incomes face.
• Stress of non-urban caregiving and related coping mechanisms.
• Level of availability of technical resources.
• Safety in cognitive disability related to non-urban farming and ranching operations.

(Caregiving in Rural America – NARC & Easter Seals)
THE END IS ONLY THE BEGINNING!