Reducing Disability in Alzheimer’s Disease: An Exercise Intervention for Caregiving Families

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Overview of Evidence-based Programs in Ohio
Objectives of Session

• Understanding the intervention components of an evidence-based exercise and behavior management program for individuals with dementia and their caregivers.

• Strategies used to translate the evidence-based program to a community organization.

• Areas of evaluation that identify the broader impact of the evidence-based program being offered in a community organization.
Evidence-based Disease Prevention

- Movement throughout the country in medical, social service, nursing, and aging network arenas to implement evidenced based programs.

- Health and Human Services (HHS) agencies including Administration on Aging (AoA), Centers for Disease Control (CDC), and Centers for Medicare and Medicaid Services (CMS) are partnering to develop, test and support the widespread adoption of evidenced-based interventions (Tilly, *Generations*, Spring 2010). Veteran’s Administration is also examining evidence-based programs.
Evidenced-based Disease Prevention and Health Promotion

• In December 2009, $27 million made available by Administration on Aging (AoA) for Health, Prevention and Wellness Programs (Tilly, *Generations*, Spring 2010).

• Ohio’s 2008-2011 Strategic Plan on Aging included developing a statewide training infrastructure to support local implementation of at least three evidence-based disease prevention and health promotion programs.

• With funding through grants from the Administration on Aging (AoA), support from the Ohio Department of Health (ODH) and Ohio Health Care Coverage and Quality Council (OHCCQC), we are well on our way to reaching our state plan objective.
Programs in Ohio

- Stanford Chronic Disease and Diabetes Self-Management Program (CDSMP/DSMP) Programs
- Healthy IDEAS (Identifying Depression, Empowering Activities for Seniors)
- A Matter of Balance (Falls Prevention)
- Active Living Every Day
- Reducing Disability in Alzheimer’s Disease (RDAD)
Ohio's Evidence-Based Disease Prevention Programs

Map showing the distribution of disease prevention programs across various counties in Ohio, marked with different symbols and colors.
The Program: Reducing Disability in Alzheimer’s Disease (RDAD)

- Developed and tested at the University of Washington: Linda Teri, Sue McCurry, Rebecca Logsdon, and colleagues.

- Original Program Goals:
  - to help reduce functional dependence,
  - to reduce frailty and thus delay institutionalization of the person with dementia

- Intervention uses home-based exercise and caregiver training in behavioral management techniques.
The Replication: Reducing Disability in Alzheimer’s Disease in Ohio

Funding from AoA via the ADSSP Program - Ohio receives 3 year grant. Partner agencies include: Alzheimer’s Association, Northwest Ohio; Benjamin Rose Institute on Aging; and Ohio Department of Aging.

Implementation began in Northwest Ohio.

Expansion sites training - 17 additional clinicians trained from 3 additional Alzheimer's Association Chapters in Ohio – Central Ohio Chapter; Greater East Ohio Area Chapter; and Miami Valley Chapter.

Implementation began in expansion site areas (64 counties in Ohio being served).

AoA awards Ohio additional grant for statewide expansion of program.

September 2008
March 2009
April 2009
February 2010
April 2010
October 2010

7 Northwest Ohio clinicians trained.
Partners

Northwest Ohio Chapter
Central Ohio Chapter
Greater East Ohio Area Chapter
Miami Valley Chapter

Hamilton County Health Department

University of Washington
– Linda Teri
– Raymond Houle
Ohio Replication

- Over 20 Alzheimer’s Association staff members have been trained on the program components
- Over 240 families have participated in the program to date
- Program offered in 64 out of 88 Ohio counties
What are the program components and implementation strategies?

Salli Bollin, MSW
Reducing Disability in Alzheimer’s Disease Components

- 12 1-hour sessions over 3 months, then monthly follow-up for 3 months
- Exercise training
  - Aerobic/endurance activities
  - Strength training
  - Balance
  - Flexibility training
Reducing Disability in Alzheimer’s Disease Components (cont’d)

• Problem-solving/behavior management techniques
  – Maximize cognitive function
  – Learn how to address problem-solve difficulties
  – Pleasant events
  – Enhance caregiver resources and skills
Benefits of Program

• Behavior Management
  – Helps families cope with disease
  – Initial intervention – decrease in institutionalization due to behaviors

• Exercise
  – Engaging activity, better sleep, improved mood
  – Potential improved range of motion, mobility, balance
  – Research mounting of benefits of regular exercise programs
Implementation Strategies

• Challenges Implementing Evidenced Based Programs (Bass & Judge, *Generations*, Spring 2010)
• Community Characteristics
• Intra-Organizational Characteristics
• Evidenced Based Program Characteristics
• Staffing and Training
• Marketing, Cost, and Payment Sources
• Fidelity
Replication in Ohio – Identified Target Population

• Individual with dementia and primary caregiver
• Individual community dwelling or assisted living, primary caregiver daily caregiving responsibilities
• Diagnosis of Dementia
  – Program adapted to various dementia diagnosis and stages of the disease
  – co-existing health conditions
Replication in Ohio – Defined Target Population

• Ambulation
  – Can use walker, cane
  – Limited mobility
• Primary Caregiver
• Exercise buddy/buddies
• Urban, suburban, and rural areas
Exclusion from RDAD Program

- Does not have a diagnosis of Alzheimer’s disease or related disorder
- Unable to ambulate
- Caregiver was unable to be involved on regular basis
- Co-existing health conditions prohibited ability to participate in program
- Individual with dementia refused to participate in exercises
Intra-Organizational Relationships

- Included staff in planning and implementation from the beginning and throughout the entire implementation
- Communication ongoing, regular basis – written and verbal – before and during implementation
- Integrate staff suggestions and ideas in program
Internal Engagement and Integration of Program

• Share aspects of program with all staff and leadership of organization
• Integrate into service menu of the organization and incorporate existing organizational resource materials when implementing RDAD
• Cross refer families to additional programs and services of the organization
Evidenced Based Program Characteristics

- Bass and Judge identify that
  - Needs to be compatible with the mission of the organization.
  - Strength of the research findings
  - Program Recruitment
Staffing and Training - Ohio RDAD Staff

- **Evaluators**
  - Background in dementia
  - Experience working with organizations
- **Program Administrator**
  - Experience working with evaluation and community organizations
  - Knowledge of best practices and evidenced based programs
  - Awareness of trends and focus at state and federal levels
- **Clinical Staff**
  - Knowledge of dementia
  - Experience in fields of gerontology, nursing, and social work
  - On average, initial staff had over seven plus years working in dementia care
  - Participated in intensive training initially and follow-up trainings
  - Staff were offered the opportunity to participate in the program, not required
Provide Vehicles for Staff Communication

Staff Supervision

• Ongoing, regular communication
• Bi-weekly staff meetings (could attend in-person or by conference call)
• Three trainings within 12 month time period (included evaluation staff)
• Monitoring of individual family files provided one-on-one time with program administrator to problem solve, discuss concerns, issues
Ohio RDAD Staff

• Supervision
  – Provided by program administrator
  – Ongoing feedback and consultation with evaluators
  – Formal and informal mechanisms
  – Staff had pre-existing relationship with supervisor
  – Supervisor in position twelve years
  – Enthusiastic response to program
Training

- Training Curriculum
- Written processes, manuals, and training curriculum
- Integrate experienced staff into the training of new staff
Recruitment Approaches

• Created Recruitment Plan and Resource Materials
• Constant and ongoing to external and internal referral sources
• Identify Benefits
  – Person with dementia
    • Established exercise routine
  – Caregiver
    • Coping with and managing behaviors
  – The entire family
    • Better understanding about the disease
    • Planning for future
    • Linkages to resources
    • Establishment of exercise routine

• Follow-Up
  – Regular updates to staff regarding progress and to partner agencies
  – Thank You’s
External Engagement and Interaction with Community Partners

- Engaged Area Agencies on Aging during writing of grant proposal
- Discuss RDAD when discussing other services of Association to external agencies
- Incorporated into Chronic Disease Management Menu of Services
- Another vehicle in rebalancing of long term care services with an increase in home and community based services
## Plan Example

<table>
<thead>
<tr>
<th>Event</th>
<th>Frequency</th>
<th>Promotional Method</th>
<th>Responsibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Media</td>
<td>Monthly</td>
<td>Press Release generated to all local newspapers</td>
<td>Communications Director</td>
</tr>
<tr>
<td>Staff Meetings</td>
<td>Monthly</td>
<td>Provide update or specific about program</td>
<td>Program Administrator</td>
</tr>
<tr>
<td>Education Conference</td>
<td>Annually</td>
<td>Written flyer, verbal mention during conference</td>
<td>Education Director</td>
</tr>
<tr>
<td>Promotional Meeting with Area Agency</td>
<td>Annually</td>
<td>Verbal discussion about program, flyer, after first year, annual update on progress</td>
<td>Program Administrator</td>
</tr>
</tbody>
</table>
Media

• Press releases
  – Newspapers including local community papers
  – Radio stations
  – Local television and cable community programs
  – Sent out monthly and with different angles or approaches
Cost and Payment Source

• Cost Analysis
  – Examining both direct and indirect expenses
  – Determining unit rate

• Payment Source
  – Building upon current success of EBP in Ohio
  – Examining potential Third Party Payment/Reimbursement
  – Cost Sharing with Consumer
Intervention

• RDAD Manual
  – Adaptations
    • Including local information
    • Supplementing with additional agency resources
    • Re-organization and additional information about program administration

• Created Referral and Screening and Discharge Processes

• Revised Agency and Evaluation Forms
How are we evaluating the program?

Heather L. Menne, PhD
What is RE-AIM?

• Systematic way to estimate the potential impact of an intervention
• Focuses attention and critical thinking on those program elements that can improve the adoption and implementation of an intervention

Reach
Effectiveness
Adoption
Implementation
Maintenance

www.re-aim.org
Reach

The number and representativeness of individuals who are willing to participate in a program.

Reach for RDAD in Ohio

• Tracking where, when, and how the program is promoted
• Tracking who participates in the program and to what extent they participate
• Understanding if participants are “typical” clients of provider agency
## Program Progress

<table>
<thead>
<tr>
<th>Family Status</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referred</td>
<td>359</td>
<td>100.0%</td>
</tr>
<tr>
<td>Assigned</td>
<td>44</td>
<td>12.3%</td>
</tr>
<tr>
<td>Not eligible</td>
<td>72</td>
<td>20.1%</td>
</tr>
<tr>
<td>Active</td>
<td>163</td>
<td>45.4%</td>
</tr>
<tr>
<td>Discharged</td>
<td>45</td>
<td>17.6%</td>
</tr>
<tr>
<td>Completed</td>
<td>6</td>
<td>4.5%</td>
</tr>
</tbody>
</table>
## Participant Description

<table>
<thead>
<tr>
<th></th>
<th>Care Receiver</th>
<th>Care Giver</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Avg. Age</strong></td>
<td>81.0 yrs</td>
<td>69.6 yrs</td>
</tr>
<tr>
<td><strong>% Female</strong></td>
<td>50.3%</td>
<td>72.2%</td>
</tr>
<tr>
<td><strong>% White</strong></td>
<td>93.3 %</td>
<td>92.8%</td>
</tr>
<tr>
<td><strong>% Married/Living with Partner</strong></td>
<td>68.7%</td>
<td>87.3%</td>
</tr>
<tr>
<td><strong>% Spouse/Sign. Other is Caregiver</strong></td>
<td>63.3%</td>
<td></td>
</tr>
<tr>
<td><strong>% Living with Caregiver</strong></td>
<td>80.3%</td>
<td></td>
</tr>
<tr>
<td><strong>Avg. Length of Time Providing Care</strong></td>
<td></td>
<td>4.0 yrs</td>
</tr>
<tr>
<td><strong>% with Alzheimer’s Disease Diagnosis</strong></td>
<td></td>
<td>60.1%</td>
</tr>
</tbody>
</table>
The impact of an intervention on important outcomes (e.g., negative effects, quality of life).

Effectiveness for RDAD in Ohio

<table>
<thead>
<tr>
<th></th>
<th>Baseline</th>
<th>3 months</th>
<th>6 months</th>
<th>12 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Health &amp; Functioning</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Affective Status (CES-D)</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Activities &amp; Behaviors</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Cognitive &amp; Functional Performance</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>
## Preliminary Baseline Results

<table>
<thead>
<tr>
<th></th>
<th>Time 1</th>
<th>Time 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with dementia (n = 85)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CES-D (10-item)</td>
<td>5.93</td>
<td>6.43</td>
</tr>
<tr>
<td>Number of Minutes Walking or in Other Aerobic Activity in Past Week</td>
<td>125.6 min</td>
<td>152.6 min</td>
</tr>
<tr>
<td>Health (caregiver report)*</td>
<td>2.75</td>
<td>2.91</td>
</tr>
<tr>
<td>Walking Speed (avg trial 1 and 2)</td>
<td>8.05 sec</td>
<td>6.82 sec</td>
</tr>
</tbody>
</table>

* p < .01
Adoption

The number and representativeness of settings and agents who are willing to initiate a program.

Adoption for RDAD in Ohio
• Understanding the background and context of the agencies and trainers
• Identifying program challenges and benefits from the agency and trainer perspectives
Adoption

- 4 Alzheimer’s Association chapters in Ohio
- 24 trained clinicians across Ohio
  - Trainer educational background:
    - Nursing
    - Social Work
    - Gerontology
  - Trainer professional experience, working:
    - With older adults: average 18.7 yrs (range: 5-36)
    - With persons with dementia: average 16.3 yrs (range: 5-36)
    - With current employer: average 6.9 yrs (range: 2-12)
Comments from trainers about the program:

This program has so many benefits to me as a clinician and to care recipients. Face to face interactions are invaluable and provide so much more information than phone conversations (i.e., helplines). I have been impressed with how quickly clients can gain strength, flexibility, and balance and how quickly it can be lost as well.

As a trainer, participation has been very rewarding. Most families really appreciate being involved with this program.
**Implementation**

In settings this refers to intervention agents’ fidelity to an intervention’s protocol. For individuals this refers to clients’ use of the intervention strategies.

**Implementation for RDAD in Ohio**
- Completion of treatment compliance documents by trainers after each session
- Fidelity monitoring and review of family charts
- Regular group calls/meetings with trainers to address concerns
Maintenance

The extent to which a program becomes institutionalized or part of the routine organizational practices. For individuals, maintenance is the long-term effect of a program on outcomes.

Maintenance of RDAD in Ohio
• 12 month assessment of caregiver and care receiver outcomes and program satisfaction
• Ongoing feedback and dialogue with trainers
• Input on sustainability from the agency perspective
# Preliminary Participant Satisfaction Results

<table>
<thead>
<tr>
<th>How satisfied are you with:</th>
<th>Very Satisfied</th>
<th>Satisfied</th>
<th>Dissatisfied</th>
<th>Very Dissatisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>1) The information covered during sessions?</td>
<td></td>
<td></td>
<td></td>
<td>3.84</td>
</tr>
<tr>
<td>2) The exercises the trainer taught you and your relative?</td>
<td></td>
<td></td>
<td></td>
<td>3.79</td>
</tr>
<tr>
<td>3) The supportive assistance and skills the trainer has provided you?</td>
<td></td>
<td></td>
<td></td>
<td>3.84</td>
</tr>
<tr>
<td>4) The Reducing Disability in Alzheimer’s Disease program overall?</td>
<td></td>
<td></td>
<td></td>
<td>3.81</td>
</tr>
</tbody>
</table>
Preliminary Trainer Reaction

• 100% are Satisfied/Very Satisfied:
  – with their role in the program
  – with the services delivered by the program

• 92.3% Disagree/Strongly Disagree:
  – the program is too time consuming for clinicians working in clients’ homes
  – the program is too much of a burden on clients and caregivers because of the number of sessions
  – the program is too much of a burden on clients and caregivers because of the exercise and behavior “homework” between sessions
Conclusion

- Understand intervention components
- Strategize implementation processes
- Determine the broad impact of the program