The Dementia Care Triad: Understanding the Partnership

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Overview

- The Caregiving Role
- Study of Caregiver Satisfaction
- Evolution of Triad
- Study of Family Caregivers and Healthcare Providers Involved in Dementia Care
- National Guidelines for Caregiver Assessment
- "Caring For You, Caring For Me"
- Resources for the Triad
- Adding Others to the Team

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"There are only four kinds of people in this world: those who have been caregivers, those who currently are caregivers, those who will be caregivers, and those who will need caregivers."

-----Rosalynn Carter

Caregiverosis

The Caregiving Role

- Defining Caregiving
  - Primary and Secondary Caregivers
  - Family, Professional, Volunteer Caregiver
- Challenges
  - Relationship to CR
    - Spouse vs. Adult Child
      - Sandwich Generation
    - Impact on children and adolescents
  - Emotions & Reactions
    - Guilt
    - Denial
    - Embarrassment
    - Stress
    - Anxiety
    - Compassion Fatigue
- Employment
- Residence
- Co-Residence
- Long-distance caregiving
- Financial & Legal Issues
- Long-Term Care Placement
- Navigating Community Resources
The Caregiving Role

**Advantages**
- Renewed relationships
- Serving as a family role model
- Pride
- Self-Discovery
- Humor
- Sources of Support & Well-Being
  - Other family
  - Friends & Neighbors

**Sources of Support (cont.)**
- Church
- Community services
  - Disease-specific organizations
  - Respite
  - Support Groups
  - Educational Programs
- Journaling
- Physical and Mental Exercise
- And........ THE Physician

“The identification of positive aspects of a situation – the silver lining effect – may be one of the most powerful cognitive coping strategies of all.”


Reasons to Study Caregiver Satisfaction and Well-Being
- To recognize that elder care is associated with more than burden and stress
- Caregivers who have positive feelings about their experiences are more likely to provide a higher level of quality of care for their elder relative
- To examine how caregiving can be mutually beneficial
- To investigate what factors are most associated with positive perceptions of caregiving so that interventions with caregivers who are highly stressed can be modified
- Do interactions with physicians enhance caregiver well-being or make it tougher to achieve?

2005 ARDRAF Study: Background
- Caregivers depend on primary care physician for clarification on all aspects of dementing illness (Miller, Glasser, & Rubin, 1992)
- Research has investigated the critical role of communication between family caregivers and healthcare providers
  - (Alzheimer’s Association, 2001; Fortinsky, 2001)
- Insufficient number of geriatricians (Barry, 2003; Butler, 2002)

Purpose of Study
- Identify primary source of diagnosis
  - Hypothesis 1: Diagnosis of memory loss will more likely be provided by primary care physician than specialist.
- Characterize needs of family caregivers
  - Hypothesis 2: Local family caregivers will report there is information they have not received but would find helpful to have from the healthcare provider.
- Determine needs of healthcare providers
  - Hypothesis 3: Healthcare providers will report certain types of tools more helpful to them in working with family caregivers.
- Proposal of solutions to strengthen family caregiver – healthcare provider partnership

Funding from the Alzheimer’s & Related Diseases Research Award Fund (#06-3)
Methods

- Family Caregiver Survey
  - Eligibility and recruitment
  - Telephone and web-based
  - Avg. completion time: 20 mins.
- Focus Groups of Primary Care Physicians and Nursing Staff
  - 3 focus groups
  - 12-item survey

Demographic Data: Caregivers (N = 128)

- 64% completed online survey
- 24% male
- Mean age = 62.5 years, range of 29 to 88
- 82% Caucasian, 8.6% African American
- 51.5% reported college degree or higher
- 47.6% adult children/children-in-law, 36.5% spouses
- 43.8% rated own health as “excellent” or “very good,” 37.5% “good,” and 13.3% “fair” or “poor”

Demographic Data: Caregivers & Care Recipients

- 68.3% caregiving for three years or longer
  - Modal response “between 3-5 years” (38.9%)
- 54% involved in caregiving duties for more than 30 hours each week
  - Modal response “more than 79 hours each week” (34.7%)
- Mean age of CRs = 79.3 years, range of 52 to 98
- CR health reported as “good” (30.5%), 32.2% rated as “fair” or “poor”

Care Recipient’s Diagnosis

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>N</th>
<th>%</th>
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</thead>
<tbody>
<tr>
<td>Alzheimer’s disease</td>
<td>68</td>
<td>53.1</td>
</tr>
<tr>
<td>Probable Alzheimer’s disease</td>
<td>15</td>
<td>11.7</td>
</tr>
<tr>
<td>Dementia</td>
<td>33</td>
<td>25.8</td>
</tr>
<tr>
<td>Other (e.g., Parkinson’s disease)</td>
<td>12</td>
<td>9.4</td>
</tr>
</tbody>
</table>

ARDRAF Study: Healthcare Provider Who Diagnosed Dementia

<table>
<thead>
<tr>
<th>Provider</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary Care Physician</td>
<td>42</td>
<td>32.8</td>
</tr>
<tr>
<td>Neurologist</td>
<td>48</td>
<td>37.5</td>
</tr>
<tr>
<td>Geriatrician</td>
<td>11</td>
<td>8.6</td>
</tr>
<tr>
<td>Psychiatrist/Psychologist</td>
<td>5</td>
<td>3.9</td>
</tr>
<tr>
<td>Other</td>
<td>11</td>
<td>8.6</td>
</tr>
<tr>
<td>Not Reported</td>
<td>11</td>
<td>8.6</td>
</tr>
</tbody>
</table>

Hypothesis 1: PCP as Source of Diagnosis

- Diagnosis more likely provided by specialist (64.2%) than by family doctor (35.8%) [based on N = 117]
- 9% reported diagnosis was made by assessment team
- Not all caregivers were given the “Alzheimer’s disease” diagnosis for the care receiver
Family Caregiver Comments

- "I think the medical community takes a hands-off approach. I have some experience with this as I have lost two sisters with memory problems. There aren’t even any geriatricians in our area. I’ve really had trouble getting any reports or information from the doctors she has seen. Another thing that concerns me is the change in administration in the long-term care facility where my wife is."

- "I guess I really didn’t expect the doctor to have a lot of resource information to deal with things on a day-to-day basis. The support group has provided a wealth of information on how to cope and keep your loved one safe."

- "I think generally the doctors do a very poor job of the dynamics of the disease on the family. There is very little advice or even what to expect given to the family. It is kind of… I have even had doctors be a little flippant saying everyone is different. It has been a major source of frustration that you are left out there hanging."

Hypothesis 2: Caregivers’ Needs

- CGs’ primary source of information was their doctor
  - 64.5% received information about medications
  - What advice was needed
    - Course of treatment
    - Types of services to utilize
    - Handling CRs other health problems
    - Financing the care
- Other sources utilized
  - Alzheimer’s Association
  - Support groups
  - Books/magazines
  - Websites


Hypothesis 3: Healthcare Provider Needs

- 26.6% always and 36.7% sometimes distinguish between dementia and AD when diagnosing
- Most commonly used tools in assessment
  - MMSE (90%) and Clock Draw Test (63.3%)
- Primary challenges:
  - Time with patients and families
  - Awareness of community services
  - Less than 40% routinely distribute tools to assist CGs
  - 35% need additional tools in treatment plan and communication
  - 53% schedule additional time with CGs
  - Role of nursing and ancillary staff


Excerpts from Focus Groups: What’s the Healthcare Providers Experience?

- Nurse: “They don’t have the time to spend with these patients/family members.”
- MD: “The nature of medicine is going towards specialization. The goal of PC is to assess and then refer. They will give information, but they are really constrained by time.”
- MD: “30-35 patients per day for PC v. 12-20 with a specialist.”
- Nurse: “Some of the patients don’t understand, won’t take no for an answer. They come back day after day after day. Have to repeat scenario over and over again. Takes a lot of time. They ask the same questions over and over again.”

Proposed Solutions: Addressing Health Literacy

- Education and Training
  - Dementia Care Coordinator serves several primary care practice sites
  - Mentoring Program for Junior Physicians
  - Geriatricians Loan Forgiveness Act
- Support for Primary Care Physicians
  - Prompts in Clinical Standards
    - Annual Medicare Wellness Exam requires cognition screen (ACA, 2011)
  - Incorporation of a TRIAD Approach to Care
  - Checklist/Order Set (80% of healthcare providers expressed interest)

Guidelines for Caregiver Assessment

- AARP Public Policy Institute
  - Assessing Family Caregiver Needs
Family Caregiver Alliance

- Proposed in two parts
  - 7 principles for assessment
  - 7 domains of assessment
  - Context, CG’s perception of CR, CG values, CG well-being, CG skills, consequences, potential resources
  - Connecting CG assessment with CR treatment plan

Assessment Process:
http://caregiver.org/caregiver/jsp/content_node.jsp?nodeid=2569

Selected Caregiver Assessment Measures: A Resource Inventory for Practitioners (December 2012)

Resources

Do you have SEIA?
- Support
- Education
- Information
- Access

Caregiver Assessment Tools: Would Physicians Use Them?

- Caregiver Self-Assessment Questionnaire: How are YOU? (American Medical Association)
- Checklist for Caregivers: Do You Take Care of Yourself? (Bass, 1990)
- Caregiving Appraisal Scale (Lawton, et al., 2000)

“Caring For You, Caring For Me”

- Education and support program developed (1996) by the Rosalynn Carter Institute for Caregiving (GA)
- 5-week course, weekly objectives
- Evaluations completed Week 1 and Week 5
- Includes family, professional, and volunteer caregivers
- First time in Virginia, Fall 2009
  - 165+ caregivers have completed course
  - Impact Factor: Reached an estimated 2000 care recipients
    - “Ripple Effect”

“Taking Care of Yourself”

- December 13, 2002
- “The healthiest way to care for another is to care for yourself.”
  - Dr. James Miller
  - The Grit and Grace of Being a Caregiver
Assessment and Reflection

- Assessment of Self-Care Skills
  - Adapted from: ”Checklist for Caregivers: Do You Take Care of Yourself?” (Bass, 1990).
  - Scores range from 12-60, with higher scores indicating risk for personal health problems
- Coping with Negative Emotions
  - Circumstances, persons, future responses
- Social Support Inventory
  - Who, How, Why not, steps to remove barriers
- Have you told your physician you are a CAREGIVER?

Barriers to Accessing the System

- Inability to access “live” assistance
- Cycle of “dead ends”
- Obtaining unhelpful response
  - Language barrier
  - Staff turnover
  - Different responses from same agency
- Phone calls not returned in timely manner
- Unclear eligibility requirements

Findings: Caregiver Participants

- Mean Length of Caregiving = 6.65 years
- Caregiver Type: 67% family
- Employment Status: 46.9% retired, 33% employed part-time or full-time
- Income: 42% reported Annual HHI $50,000 or less
- Health: 90% rated as good, very good, or excellent
- Need to Learn: 81.82% how to take care of myself
- Need to Improve: 90% in preventing/solving problems, 91% accessing resources
- Wish to Increase: 100% agree/strongly agree with Interacting with Other Caregivers
  - 90% believed it would be “very helpful” to participate with both family and professional CGs

Findings: Caregiver Participants

- Recommend to Other Caregivers: 100%
- Overall Rating: 70.21% Excellent, 29.79% Very Good
- Greatest Impact: 92.47% Knowledge of Resources, 87% Feeling of Community Support, 83.7% Better Equipped to Take Care of Oneself
- Confidence in Caregiving as Result of Program: 80% Very Good or Excellent

Physician Engagement

- Physicians often fail to identify cognitive impairment until it becomes quite severe. This failure to diagnose may be due to time constraints, a focus on other health measures, or the lack of appropriate and usable tools. Reliance on patient self-report is also likely to be a flawed approach. A recent study found that most patients with dementia in a community sample denied they had memory problems” (Clionsky & Clionsky, 2011, p. 653).
What Do Physicians Want From Caregivers?
- Be prepared with a list of medications
- Be prepared to discuss the specialty care the care receiver is receiving
- Be prepared to discuss the care receiver’s medical history and possibly family history
- Be prepared with a log of changes in behaviors, to include mood and memory
  - When first detected
  - Progression
- Be prepared with a list of questions, both more immediate concerns and longer-range issues
- Don’t expect the physician to have all the answers

Resources for the Triad: Technology
- Electronic Medical Record
- HIPAA
- Health-E Link
- Medication Compliance
- Remote Monitoring
  - Center for Technology and Aging
  - Smart Home
  - Telemedicine

Resources for the Triad: Community
- Alzheimer’s Association, Chapter Office
- Neurologists, Neuropsychologists, Geriatricians
- Assessment Centers
- Area Agency on Aging
- Department of Social Services
- Community Services Board
- Coalitions focused on senior services
- Various senior service providers, respite agencies
- Support Groups, in-person and virtual

Should the Triad be Expanded? Adding Others to the Team
- Physical or occupational therapist
- Fall assessment
- Home assessment
- Psychologist or psychiatrist
- Neuropsychologist
- Social worker
- Geriatric care manager/coordinate