62nd Annual Greenville Postgraduate Seminar
Spotlight: Primary Care
Dementia Caregiver Burnout – Panel Presentation

Spotlight Primary Care
August 17, 2019
Panel Participants

- Melanie Brown - Caregiver
- James Davis, M.D – Medical Director – Prisma Memory Health Program
- Katharine Few, F.N.P. – Care Manager – Prisma Memory Health Program
Learning Objectives:

• Define Dementia Caregiver Burnout
• Understand the role of the Caregiver in Dementia Care
• Be able to recognize Caregiver Burnout and risk factors for Caregiver Burnout in the patients and caregivers in your practice
• Be able to make appropriate referrals and interventions to support caregivers in your practice
Caregiver

• A caregiver is simply someone (friend or relative) who provides unpaid care to someone with a chronic condition.

• Not limited to dementia. Other conditions require caregiving: Stroke, cancer, heart failure, Parkinson’s, HIV/AIDS, developmental disabilities, psychiatric conditions etc.

• You could see this person accompanying your patient or you could see them as a patient independently.
Caregiver Burnout

- **Caregiver burnout** is a state of physical, emotional, and mental exhaustion that may be accompanied by a change in attitude -- from positive and caring to negative and unconcerned. Burnout can occur when caregivers don't get the help they need, or if they try to do more than they are able -- either physically or financially. Caregivers who are "burned out" may experience **fatigue**, stress, **anxiety**, and **depression**. Many caregivers also feel guilty if they spend time on themselves rather than on their ill or elderly loved ones.
Caregiver Statistics

• 43.5 million adults in the US provided care to an adult or child
• In 2014, friends and family of dementia patients provided an estimated $17.9 billion hours of unpaid care, a contribution to the nation valued at $217.7 billion.
  • This is approximately 46% of the net value of Walmart sales in 2013 and nearly eight times the total revenue of McDonald's in 2013.
• Caregivers of a spouse spend 44.6 hours/week caring for them (average)
• Approximately 2/3 of caregivers are women and 34% are age 65 or older
• 41% of caregivers have a household income of $50,000 or less
• Approximately 250,000 young adults and children between ages 8 and 18 provide help to someone with dementia
Caregiver Statistics

• Alzheimer's takes a devastating toll on caregivers
  • Nearly 60% of dementia caregivers rate the emotional stress of caregiving as high or very high
  • About 40% suffer from depression
  • Caregivers had $9.7 billion in additional health care costs due to the physical/emotional toll of caregiving
  • 6 out of 10 caregivers made a change in their workplace due to the strain of caregiving (commonly cutting back on hours)
  • 22% of caregivers indicate worsening health due to caregiving
Melanie’s Story
Common Dementia Caregiver Responsibilities

- Shopping, preparing meals, transporting
- Managing finances and legal affairs
- Supervising for safety
- Assisting with bathing, dressing, toileting, etc.
- Managing living arrangements
- Managing behavioral and personality changes
- Managing medications, equipment, wound care
- Advocacy
Caregiver Stressors

- Loss of time and freedom
  - Even for the basics of nutrition, exercise, sleep and fun
- Loss of self
- Job and financial issues
- Family conflicts
Implications of Caregiving

• Responsibility for managing another person’s life goes unrecognized by others

• Requires you to always vigilant and prepared
  • 24/7 job

• Necessitates a wide spectrum of care, often learning new skills.

• Can potentially be harmful to the caregiver’s wellbeing and health
  • Tasks and responsibilities
  • Demand on caregiver increases as care recipient’s health declines
Warning Signs of Caregiver Depression

- Somatic complaints
- Irritability – easily angered, short fuse, decreased patience
- Problems with eating and weight
  - Over or under
- Fatigue
- Sleep changes
  - Insomnia/hypersomnia
- Feeling empty or sad
- Excessive feelings of guilt
- Apathy/withdrawn
Golden Rule of Caregiving

You can’t help someone else if you’re not okay.
Time for Self

• **It’s OK** to say “No” to requests from others

• **It’s OK** to get help

• **It’s OK** to go out and do something pleasant

• **It’s OK** if you lose your patience sometimes
Caregiver Burnout in Your Practice – Who may be at risk?

- Persons who accompany an older patient.
- Persons with depression and anxiety who may also be caregivers
- Screen at annual visits (annual wellness) – Are you caring for someone with dementia or Alzheimer’s disease?
What works to reduce burnout:

• Alternative Care
  • Respite Care
  • Day programs (Ex-Senior Action, Elite, Active Day)
  • PACE

• Support Groups – Alzheimer’s Association

• Memory Health Program
  • Co-management with Primary Care
  • REACH – evidence based in home intervention for caregivers
  • ABC’s of Dementia – Six two hour educational sessions open to the public recurring three times a year or 1 hour abbreviated lunch course
Dementia Co-Management Programs

• Partners with primary care to provide multidisciplinary care to dementia patients
  • Physician, APP, social worker, caregiving coaches
• Numerous programs throughout the United States
  • UCLA Alzheimer’s and Dementia Care Program
  • Indiana University Wishard Health System Aging Brain Center
  • Dementia Care San Diego
Dementia Co-Management Programs

- Indiana Healthy Aging Brain Center
  - Decreased caregiver stress by ½
  - $2,856 in net savings per patient
- UCLA Caregiver Feedback
  - 95% of caregivers felt supported
  - 74% indicated education materials were helpful
  - 93% felt their concerns were listened to
- UCLA Referring Physician Feedback
  - 60% saved physician time
  - 83% valuable behavior interventions
  - 66% strengthened provider/patient relationship
Prisma REACH

A translation of the REACH II Caregiver Intervention:
- Resources to Enhance Alzheimer’s Caregiver Health

Funded by the Alzheimer’s Disease Supportive Services Program Evidence-Based Initiatives in the Administration on Community Living
Key Elements

- Safety
- Social Support
- Emotional Health
- Problem Solving
- Self Care
Prisma REACH – What we do:

• 12 Visits – 9 of these are visits in the home or location of choice. 3 are telephone conferences
  • Intake and comprehensive assessment - safety
  • Educational Sessions
  • Problems Solving Techniques
  • Self Care, Stress Reduction, Relaxation Exercises
• Phone calls as needed for scheduling and review.
• Resources and referrals
# Outcomes – Prisma REACH

| Types of Measure | T1 (session 1 of intervention) | T2 (last session of intervention) | Change (positive change is **bold**, negative change is **red**)
|------------------|-------------------------------|-----------------------------------|------------------------------------------------------
| **Caregiver Measures** |                               |                                   |                                                      |
| Zarit Burden Scale (average score) | 22.2                           | 15.5                              | - 6.7                                                |
| Behavior Problems (No. of) | 10.3                           | 9.1                               | -1.2                                                 |
| Behavior Problems (Negative Reaction to...) | 1.7                            | 1.2                               | -0.5                                                 |
| Self-Efficacy to obtain respite | 56.6%                          | 65.6%                             | 9.0%                                                 |
| Self-Efficacy to respond to behavioral problems | 72.6%                          | 85.2%                             | 12.6%                                                |
| Self-Efficacy for controlling upsetting thoughts | 64.9%                          | 81.7%                             | 16.8%                                                |
| Self-Efficacy (total score) | 65.1%                          | 77.37%                            | 12.27%                                               |
| Desire to Institutionalize | 4.6                            | 4.7                               | 0.1                                                  |
| **Health Measures** |                               |                                   |                                                      |
| Self-Reported Health (higher = higher quality) | 3.13                           | 3.10                              | -0.03                                                |
| Self-Reported Health (comparison w/ 6 months ago) | 3.13                           | 2.71                              | 0.42                                                 |
| Number of Chronic Health Conditions | 1.75                           | 1.55                              | -0.2                                                 |
| PHQ9 (Depression) | 6.7                            | 4.6                               | -2.1                                                 |
Caregiver ABCs

<table>
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<tr>
<th></th>
<th>Pretest</th>
<th>Posttest</th>
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<tbody>
<tr>
<td>Symptom Management</td>
<td>25.58</td>
<td>36.65</td>
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<tr>
<td>Community Resource Use</td>
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<td>32.09</td>
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<tr>
<td>Self Efficacy</td>
<td>50.33</td>
<td>75.47</td>
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Memory Health Program for Consultation or Co-Management – Clinician Referral

• In system - Epic Order– Ambulatory Referral Geriatrics Memory Health

• Out of system - referral form – website https://www.ghs.org/healthcareservices/medicine/geriatrics/centerforsuccessinaging/

• Phone – (864) 454-8120

• FAX – (864)454
Prisma REACH and ABC’s of Dementia

• No clinician referral required
• Phone – (864) 454-8120
• Website - https://www.ghs.org/healthcareservices/medicine/geriatrics/centerforsuccessinaging/
Additional Resources for Caregivers

• Appalachian Council of Governments – Senior Advocacy
  • www.scacog.org/aging-services
  • Phone 864-242-9733

• Alzheimer’s Association
  • Respite program www.alz.org/sc
  • Caregiver Center www.alz.org/care
  • Phone 1-800-272-3900 (toll free)

• Family Caregiver Alliance
  • www.caregiver.org

• AARP Family Caregiving
  • https://www.aarp.org/caregiving/

• Community Long Term Care - Medicaid
  • Intake / Referral 1-855-278-1637 (toll free)

• Private Geriatric Consulting Groups – (Ex. Browning Geriatrics, Geriatric Resource Services)
PRISMA HEALTH