

PRISMA HEALTH®

62nd Annual Greenville Postgraduate Seminar

Spotlight: Primary Care

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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 1/2
 - \$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

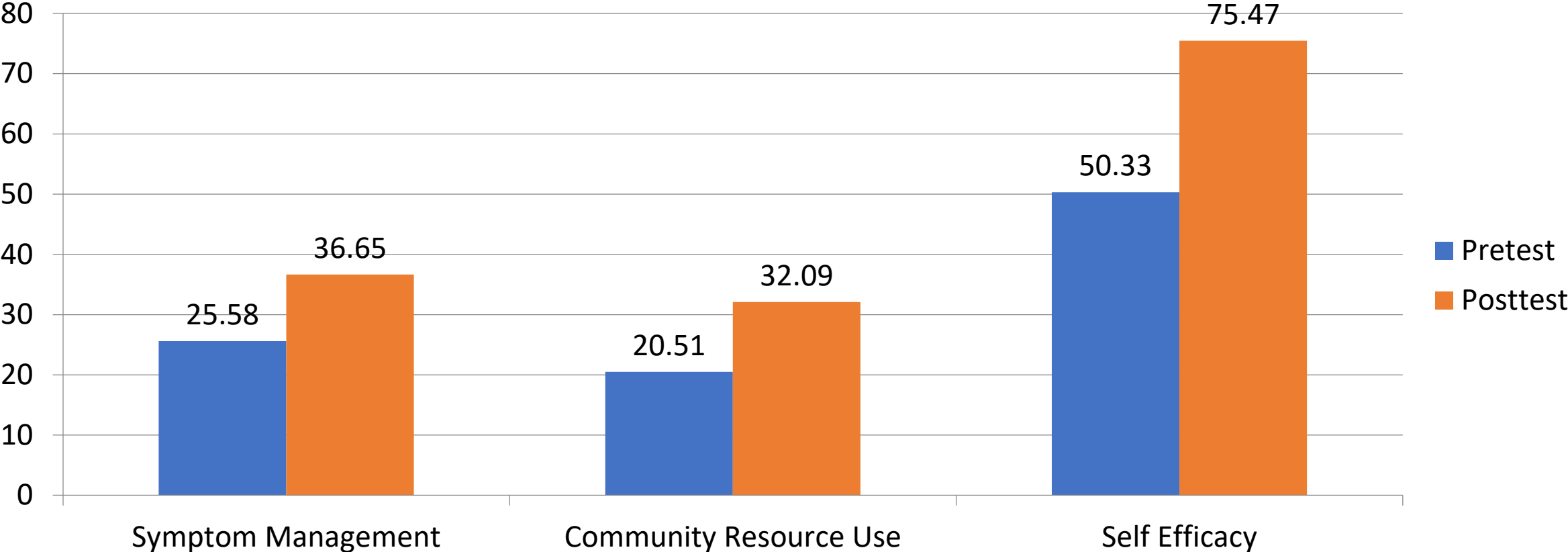
Prisma REACH – What we do:

- 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)
<i>Caregiver Measures</i>			
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
<i>Health Measures</i>			
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



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)

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