Caregiver Well-Being: Assessment, Interventions & Community Resources

2013 Geriatric Update
Meharry Consortium Geriatric Education Center

Inter-Professional Panel

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Disclosures

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Objectives

- Describe how to assess caregiver well-being and potential treatment of caregiver depression.
- Identify community resources for caregiver support.
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Objectives

- How to assess caregiver well-being and potential treatment of caregiver depression
- Identify community resources for caregiver support
Caregiving Statistics

- Caregiving can take as little as few hours per week to 43 hours a week providing care
- 20% of caregivers provide fulltime or constant care
- Responsibility of care giving does not go away

Jamaevidence.com/content accessed 8/26/13
Case Studies

Case 1

- 82 yo male with mechanical aortic valve on warfarin, recent admission L MCA ischemic stroke. Discharged home with nephew and his wife with whom the patient resides after his rehabilitation. Bounces back to ER in 24 hr, family states they cannot manage him at home and provide 24 hr supervision. Past medical history CAD-s/p CABG,AFIB,RA,OA,HTN,COPD and new dx of Dementia. Prior to this hospitalization he was able to complete his daily needs and independent. However, he neglected his medication and stayed out at bars until 4am.Family states he stayed up all night, burned a hole in the family’s couch, locked himself in the bathroom.

- Safety is a concern for himself and others
  - Physical
  - Financial
  - Emotional

GEM unit
Case 2

- 94 yo female who resides with her son and his wife for past 20yrs. She has early dementia. She is independent with her daily needs and had daytime sitter service. She fell and broke her right arm and no longer able to meet her needs. Both son and daughter are practicing physicians and unable to provide 24 hr supervision.

  - Physical
  - Emotional

Community

Case 3

- 68 yo male with dx of end stage dementia, HTN, alcohol abuse, right shoulder deformity, glaucoma, no right eye and BPH. Dropped off by ex-wife as she is unable to care for him any longer given worsening mental status. He is tx for UTI and mental status cleared. No other acute medical issues identified upon workup. Now daughter who is the POA is requesting additional rehab and refusing to take pt home.

  - Physical
  - Financial
  - Emotional

GEM unit
Case 4

- 84 yo male pleasantly demented initially admitted with back pain 3/8/13. He was found to have cervical and lumbar spinal metastases from hepatocellular carcinoma suspected on CT done in August of 2012 and confirmed by biopsy 3/11/13. Palliative xrt for 7 days was initiated but unable to tolerate. Patient is eligible for hospice and remained in the hospital. For past six yrs his step-daughter has been the care taker and remains at bed side. She is very emotional and not sure of his spiritual health. She has been strong support for him and pleased with her caregiving. Patient’s two sons who are out of state now joins the care team. From day one they have been very verbal, aggressive in their behavior towards nurses and medical team. They are very displeased with care and everything.
  - Emotional
  - Spiritual

Causes of Caregiver Burnout

- **Role confusion**: separate role as caregivers from the role of spouse, child, friend etc
- **Unrealistic expectations**: caregiver expect their involvement to have a positive effect on the health and happiness of their loved ones and it may not be always realistic
- **Lack of control**: frustration due to lack of money, resources and skills to effectively plan, manage and organize their loved ones care.
- **Unreasonable demands**: some caregivers place unreasonable burden upon themselves-exclusively their responsibility.

(webmd.com/heart/disease/recognize/caregiver/burnout-6/25/13)
Health Implications of Caregiving

- Physical injury
- Emotional burden
- Mental health risk
- Mortality risk 63% (in a study of >400 caregivers and non-caregivers as control; 66 yrs older who experienced mental or emotional strain)
- Intense family care - 21 hrs of care per wk

Warning Signs and Symptoms of Burnout
Physical

- Feeling tired and drained most of the time
- Lowered immunity, feeling sick
- Frequent headaches, back pain, muscle aches
- Change in appetite and sleep

Emotional

- Sense of failure and self doubt
- Feeling helpless, trapped and defeated
- Detachment, feeling alone in the world
- Loss of motivation
- Cynical and negative outlook
- Decreased satisfaction and sense of accomplishment
Behavioral

- Withdrawing from responsibilities
- Isolating from others
- Procrastinating
- Using food, drugs or alcohol to cope
- Taking out frustration on others

Stress vs. Burnout

- Over Engagement
- Over Active Emotions
- Urgency/ Hyperactivity
- Loss of Energy/Ideals
- Anxiety
- Damage is Physical
- May Die Prematurely

- Disengagement
- Emotions are Blunted
- Helplessness
- Hopelessness
- Loss of Motivation and Hope
- Depression
- Damage is Emotional
- May Make Life Seem Worthless

Source: Stress and Burnout in Ministry
How to Assess Caregiver Wellbeing

- Assess by simple screening questions
- How is the care giving going for you?
- How is the family doing?
- Are you depressed?

Individual Attention:

- Speak less and listen more
- Plan to give 10-15 min of your daily time
- Let caregivers open up fears, concerns, guilt etc
Dealing with Burnout: 3 R Approach

- **Recognize**-watch for the warning signs
- **Reverse**-undo damage by managing stress and seeking support
- **Resilience**- build resilience to stress by taking care of physical and emotional health

Prevention

- Relaxing ritual
- Healthy eating, exercise, sleep
- Set boundaries
- Daily break from the routine
- Nourish your creative side
- Manage stress
Recovering from Burnout

- Slow down: rest, reflect, and heal
- Get support: tendency is to isolate but turn to your loved ones-share your feelings
- Re-evaluate your goals and priorities: it can be an opportunity to rediscover what really makes you happy and change course

References

- The experience of burnout among home caregivers of patients with dementia; relations to depression and quality of life: Archives of gerontology and geriatrics (2009 July-Aug 49 1)
- Overcoming burnout: how to revitalize your career: Journal of continuing education in nursing (2006 July Aug 4 178- 84)
- Burnout and stress of conscience among healthcare personnel; Journal of advance nursing (2007 Feb 57 4 392-403)
- Burnout and Compassion fatigue among hospice care givers: The American Journal of Hospice and Palliative care (2002 May June; 19 3: 200-5)
Caregiver Well-Being: Assessment Interventions Community Resources

Carolyn K. Smith, Licensed Master Social Worker

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Who is a Caregiver?

- Caregiver (defined): Providing daily living assistance to a loved one who is unable to care for themselves

- The average Caregiver is:
  - Female
  - 48 years old
  - Married
  - Employed
  - Frequently provides care for elders and children simultaneously

(TN Respite Coalition, Date Unknown) (National Alliance for Caregiving, 2009)
Caregiver Statistics

- Approximately 29% of adults are Caregivers.
- The number of Americans who will suffer functional disability due to arthritis, stroke, diabetes, coronary artery disease, cancer, or cognitive impairment is expected to increase at least 300% by 2049.
  - This means an increase in Caregivers and/or services needed.


New Caregivers Checklist

- **Education**
  - Disease/Condition/Illness
  - Medications
  - Special Skills
- **Options**
  - Family Medical Leave Act (FMLA)
  - Patient/Caregiver Needs
- **Community Resources**
- **Recruit Others**
  - Delegate
  - Self Care
- **Immediate Care Plan**
  - Living Will
  - Future Planning
  - Family Point of Contact
- **Organization**
  - Finances
  - Documents
  - Names, Numbers
- **Future Planning**
  - Long Term Care
  - Legal needs

[Department of Veterans Affairs, 2012]
Education

- VA Caregiver Support
  - Information sheets
- Area Agencies on Aging and Disability
- Administration on Aging
- Eldercare Locator
- Council on Aging of Greater Nashville
- Alzheimer’s Assoc.
- Mental Health America
- National Institute on Aging Information Center
- American Geriatrics Society Foundation for Health in Aging

Advance Care Planning

What are your loved one’s wishes for what will happen next, or if they are unable to care for themselves in the future?

- Less than 50% of severely or terminally ill patients have an advance directive in their medical records
- Between 65% & 76% of providers who patients had an advance directive were not aware that it existed
- Most patients have not participated in advance care planning, yet many are willing to discuss end-of-life care

(Agency for Healthcare Research and Quality, 2003)
**Advance Care Planning**

- Legal
- Power of Attorney
- Living Will
- Advance Directive
- Fiduciary/ Finances
- End of Life Care
- Will / Estate
- Conservatorship

- www.OnlineTNJustice.org
- Legal Aid
  - www.tals.org
  - www.las.org
- Elder Law
  - www.tn-elderlaw.com
  - www.elderlaweducation.com
- Veterans Administration
- Social Security Administration
- Mental Health Agencies
- Probate Court

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**Evidence Based Practice**

- Caregivers participating in a treatment program (support group, counseling, etc) or educational seminars maintained a higher tolerance to patient memory and behavioral problems and fewer symptoms of depression
- Using respite services can reduce Caregiver burden and allow Caregivers to provide care for a long period of time instead of deferring to an institution
- Utilizing Caregiver relief services for an extended period of time increases the effectiveness

(Sorensen, S., Pinquart, M., Habil., & Duberstein, P., 2002)
(Gaugler, J.E., Roth, D.L., Haley, W.E., & Mittelman, M.S., 2008)
Overwhelmed?

- Ask for Help
- Express your Feelings
- Take care of your Health
- Avoid Isolation
- Talk with Professionals
- Look for Signs of Burnout
- Give yourself a Treat
- Take a Time-Out

(Richmond, 2007)

Relief Statistics

- As of 2011, there are 41.4 Million Adults over the age of 65 in the US

- Almost 25% of those individuals are in poor or fair health and living in a private residence
  - 10.35 Million

- In 2007 there were only 1 Million individuals using in-home help

(Center for Disease Control and Prevention, 2013)

Why not ask for more help?
Relief Programs

- Home Health Aide
  - Personal Care
- Homemaker
  - Householder Assistance
- Respite
  - A break
- Medical Alert
  - Emergency Assistance
  - Therapy
- Meals-on-Wheels
- Senior Centers
  - Socialization
- Home Modifications
- Adult Day Health Care
  - Skilled Services
  - Socialization
  - Meals
- Caregiver Support Groups
  - Technology

Relief Resources

- TN Respite Coalition
  - Caregiver Help Line (TN): 1-888-579-3254
- Area Agency on Aging and Disability
  - 1-877-973-6467
  - Meals-on-Wheels
  - Home Based Services
  - Support Groups / Classes
  - National Family Caregiver Support Program
- Tennessee Disability Pathfinder
- Human Resource Agencies
- United Ways: 2-1-1
Transportation

- **Driving**
  - AARP Driver Safety Class
  - Disabled Person License Plate, Placard and/or Decal
  - Request for Special Examination

- **Community Transportation**
  - Insurance Provider coverage
  - MTA Access Ride
  - Mid-Cumberland Human Resource Agency
  - American Cancer Society

- **Vehicle Modifications**
  - Occupational Therapy Assessment

Veterans

- **Veterans Affairs**
  - Veterans Health Administration (VHA)
    - Not an insurance provider, but a healthcare facility
    - Contact the VA Business Office to enroll in the VA
      - 615-873-7030
    - Primary Care
      - Post Deployment Clinic
      - Primary Care Clinic
      - Geriatric Evaluation & Management Primary Care
  - Veterans Benefits Administration (VBA)
    - Financial Benefits
    - Aid & Attendance
  - Burials and Memorials
Veterans

- Geriatric Extended Care
  - Homemaker Services
  - Home Health Aide
  - Respite Services
  - Adult Day Health Care
  - Telehealth
  - Home Based Primary Care
  - Rehabilitation
  - Medical Foster Home
  - Residential Care Home
  - Long Term Care / Nursing Home (Service Connected Disability)
  - Palliative Care / Hospice Care

http://www.va.gov/GERIATRICS/

Placement Options

- Relocating to a New Community
  - Independent Living Facilities
  - Assisted Living Facilities
  - Nursing Homes

- Cost Coverage
  - Medicare
  - Personal Assets
  - Long Term Care Insurance
  - VA
    - Highly Service Connected Veterans
  - Medicaid / TNCare / Choices
    - Handicap Assessment
    - Financial Assessment
Carolyn's Frequently Used Resources

- State of Tennessee Area Agencies on Aging and Disability: http://www.tn.gov/comaging/localarea.html
- Tennessee Disability Pathfinder: http://kc.vanderbilt.edu/pathfinder/
- Legal Aid Society: Legal Help Booklets: http://www.las.org/booklets/
- TNCare – Health Care Facilities: http://health.state.tn.us/HCF/Facilities_Listings/facilities.htm
- United States Department of Veterans Affairs: http://www.va.gov/GERIATRICS/

References

- Center for Disease Control and Prevention http://www.cdc.gov/nchs/fastats/older_americans.htm
- Gaugler, JE; Roth, DL; Haley, WE; Mittleman, MS. “Can counseling and support reduce burden and depressive symptoms in caregivers of people with Alzheimer’s disease during the transition to institutionalization? Results from the New York University Caregiver Intervention Study.” Journal of the American Geriatrics Society 2008; 56: 421-428.
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- National Alliance of Caregivers http://www.caregiving.org/
- TN Respite Coalition http://www.tnrespite.org/
- United States Department of Veterans Affairs, Geriatrics and Extended Care http://www.va.gov/GERIATRICS/index.asp