FAMILY CAREGIVING ISSUES

Kathie Bickerstaff, MSN, APRN-NP, BC
UNMC College of Nursing

Objectives
- Define caregiving
- Provide demographics related to caregiving
- Identify emotional, mental and physical consequences associated with caregiving
- To present various resources available
- Identify role of bereavement in the caregiver dynamic
- To present tools appropriate for the Advance Practice Gerontological Nurse role

Caregiving Defined
- According to AARP and NAC in 2004
  *"typical caregiver is a 46 y/o woman who has at least some college experience and provides more than 20 hrs of care each week to her mother.”


Family Caregiving
- Backbone of caregiving for older persons in the US are family members
- By 2030 will have 17% more elderly than in 1999
- Expect up to a 33% increased change in dementia from 2000-2025

For Whom Do Caregivers Care*

- Mother 38%
- Grandparent 11%
- Mother-in-Law 11%
- Father 11%
- Spouse 11%
- Other Relative 6%
- Non-Relative 6%

*From Newsweek June 18, 2007

Caregiver Burden
- Living longer >65
- Men 17 yrs
- Women 20 yrs
- Sandwich generation
- Overwhelmed with responsibilities
- High cost of care
  * $5,000 out of pocket cost
- High cost in health problems
- Twice rate of physical, high rate MH problems
- Time
  * Unable to enjoy experience and rejuvenate

  Cangelosi, P. Caregiver burden or caregiver gain: respite for family caregivers. JPN. 2009;47(9):19-22.
We Never Know What the Future Holds

Glenn and Gretchen Bickerstaff on their 50th anniversary. Even though my father-in-law did not have dementia or other serious mental health issues, Gretchen became his caregiver as his health declined about 3 years after this photo was taken. For the last 2 years of his life she primarily did all of the chores involved in the upkeep of the house they had built and owned together. As his prostate cancer progressed he had signs of depression and apathy in his final months. He passed away after 55 ½ years of marriage. Glenn's only sibling who lived past early adulthood, an older sister, spent the last 12 years of her life in a LTC facility as Alzheimer's Dementia took its toll on her. She and her husband had no children.

Caregiver Burden

- Caregivers of dementia patients have documented increase in distress and decrease in mental health and well-being.

- “Developmental” burden vs “objective” burden

Caregiver Burden

- Caregivers of depressed elders develop major depression themselves that lasts 6 months or more
  - McCusker, J., Latimer, E., Cole, M., Campi, A, & Sewitch, M. Major depression among medically ill elders: factors contributing to sustained poor mental health in their informal caregivers. Age and Ageing 2007; 36(4): 400-406

- Competing role responsibilities are an important dynamic in factoring the stress burden.


Caregiving

- “A spiritual practice as one human being dares to enter into relationship and service for the benefit of another”
  - Mary Pauluk, Chaplain St. John Lutheran Home, Springfield, MN

- “We’ve been called to tend to others, not to martyr ourselves in the process…….Caregiving is a truly spiritual practice, a nonlinear path with heart….we are asked to trust life in a way we never thought possible.”
  - Beth Witrogen McLeod, author of And Then Shall House-The Caregiver’s Companion.

Assessment of Caregiver Need

- Assessment of caregiver as well as older person with care needs
- POC works for both parties
- Coordination of formal services by the geri-psych nurse
- Ongoing assessment of the caregiver
- Encouraging the caregiver to address her/his own health promotion and health maintenance needs


Caregiver Stress Check

Do you regularly………………..

| Feel like you have to do it all yourself, and that you should be doing more | Yes | No |
| Withdraw from family, friends and activities that you used to enjoy | Yes | No |
| Worry that the person you care for is safe | Yes | No |
| Feel anxious about money and healthcare decisions | Yes | No |
| Deep the impact of the disease and its effects on your family | Yes | No |
| Feel grief or sadness that your relationship with the person isn’t what it used to be | Yes | No |
| Get frustrated and angry when the person with dementia continually repeats things and doesn’t seem to listen | Yes | No |
| Have health problems that are taking it all on you mentally and physically | Yes | No |

Caregiver Stress Check
Symptoms of Caregiver Stress

- Denial
  - I know mom is going to get better
- Anger
  - If he asks me that question one more time I’ll scream
- Social withdrawal
  - I don’t care about getting together with the neighbors anymore
- Anxiety
  - What happens when he needs more care than I can provide?
- Depression
  - I don’t care anymore

Symptoms of Caregiver Stress

- Exhaustion
  - I’m too tired for this
- Sleeplessness
  - What if she wanders out of the house or falls and hurts herself.
- Irritability
  - Leave me alone!
- Lack of concentration
  - I was so busy, I forgot we had an appointment
- Health problems
  - I can’t remember the last time I felt good

“Put YOUR Oxygen Mask on FIRST”

Caregiver Needs in Dementia Care

**Early-Mild Stage**

- Insight to help loved one feel productive
- Personal support from family and friends
- Community resources
- Friends to bring humor
- Someone to pick up some of the duties
- Someone to help celebrate life with the person who has the disease as well the extended family

*Adapted from Alzheimer’s Disease: the Dignity Within, A handbook for Caregivers, Family, and Friends, Callone, P. R., Vasiloff, B. C., Kudlacek, C., Manternach, J., & Brumback, R. A., 2006*

Caregiver Needs in Dementia Care

**Moderate Stage**

- Take care of self—socially, emotionally, spiritually
- Somewhere to go for fun and relaxation
- Someone to distract the provider from the caregiver duties
- Keeping up with medical and dental exams
- Time set aside for reflection, prayer and fun
- Review info on how the disease affects the brain
- Distinguish fact from feeling when interacting with loved one

*Adapted from Alzheimer’s Disease: the Dignity Within, A handbook for Caregivers, Family, and Friends, Callone et al. 2006*

Caregiver Needs in Dementia Care

**Severe Stage**

- Someone to listen without judgment or trying to problem-solve
- Persons who understand the needs of the caregiver
- Outlets for humor and enjoyment of life away from responsibilities of care-giving
- Kindness and compassion
- Support and reinforcement for the tough decisions that have to be made
- Workplace understanding when caregiver is distracted
- Encouragement to take time off to have the energy to manage responsibilities for all the roles that evolve.

*Adapted from Alzheimer’s Disease: the Dignity Within, A handbook for Caregivers, Family, and Friends, Callone et al. 2006*
Caregiver Needs in Delirium Care
- To be able to identify difference from dementia
- To understand the need to immediately access medical/nursing intervention and transport the patient if necessary
- To use techniques that validate and soothe patient
- Maintain patience
- Get support - call the nurse

Caregiver Needs in Depression
- Caregivers of elderly disabled are twice as likely to develop depression
- Predisposed if care recipient has behavioral problems/limited help
- Support after placement in LTC important
- Increased vulnerability in some individuals

Grief and the Caregiver
- Concepts
  - Loss
    - Lack of what was there before
  - Sorrow
    - Feelings of grief occurring as result of loss of normal lifestyle
  - Grief
    - Behavioral, social, physical, and psychological response to loss

The Grieving Process
- Lengthy and difficult process that can span years
- Two phases of bereavement called "dual dying": the time of care giving and the time after death
- Lengthy process can cause financial, emotional and physical problems for the family
- Hospice offers a minimum of one yr. bereavement services which may begin before pts. death
- Multiple focus
  - Education re: projected course of illness
  - Acknowledgment of the grief/support in grieving
  - Advanced planning around the anticipated loss
  - Addressing guilt often expressed by caregivers

Supportive Interventions
- Educational programs
- Skills training
- Technology
- Several websites listed in text p 299
- Research studies
- Support groups
- Respite services

Educational Programs
- Benefit of caregiver education programs
- Educational not only regarding disease but also:
  - Controlling stress and tension
  - Strategies for handling behavioral problems
  - Strategies to increase life satisfaction
- Average time in medical care for both caregiver and patient decreased over time..lasted at least 6 mos post intervention
- Results supported effectiveness in psychoed for reduction in burden, improved QOL in both health and psychiatric morbidity of caregivers.

How to manage stress
10 ways to be a healthier caregiver

- Understand what's going on as early as possible
- Know community resources available
- Become an educated caregiver
- Get help
- Take Care of Yourself

- Manage your level of stress
- Accept changes as they occur
- Make legal and financial plans
- Give yourself credit, not guilt
- Visit your doctor regularly

Referral to Support Groups
- An Alzheimer’s Support is a small discussion group of caregivers, family, and friends of individuals with Alzheimer’s disease and related dementias
- Go to Alzheimer’s Association website for a complete list of support groups anywhere in the country
- Check with the LTC facilities or Senior Centers in your area to see if they offer any type of caregivers support groups that are open to caregivers of any type of long term problems

Support Groups Are.......
- A place:
  - that is non-threatening and non-judgmental
  - to express feelings
  - to talk about needs and concerns
- A forum for:
  - exchanging information
  - getting practical ideas
  - learning about local resources
  - developing new friendships
- A refuge with:
  - emotional support
  - people who will listen and understand
  - a feeling of belonging

Other Help
- Lotsa Helping Hands
- Online calendar helps caregivers organize helpers
- Lotsa Helping Hands is a free, personalized online calendar to organize family and friends who want to help. It finds tasks and other family roles, and then assigns them to interested people. It even reminds you of upcoming events through emails and text messages.
- Go to the site: lotsa-helping-hands.org
Helpful Websites

- www.alz.org
- www.alz.org/midlands
- http://www.helpguide.org/elder/altzheimers-disease-dementia-support-caregiver.htm#protecting
- Helpline number, 1.800.272.3900, is available 24 hours a day, seven days a week, and 365 days a year.
- For support group information from Midlands Chapter, please contact betty.chin@midlandsalz.org or 402.502.4300.
- For Safe Return, respite, speakers, health fairs, grant information please contact clayton.freeman@midlandsalz.org or 402.502.4300

Resources for Caregivers

- American Association of Homes and Services for the Aging
  - http://www.aahsa.org
- Family Caregiver Alliance
  - http://www.caregiver.org
- National Caregivers Library
  - http://www.caregiverslibrary.org
- Strength for Caring
  - http://www.strengthforcaring.com
- Well Spouse Association
  - http://www.wellspouse.org/home.html

Reference Books

- Measure of the Heart, Mary Ellen Geist, 2008. Springboard Press (forward by Dr. Oliver Sacks)

Prayer for Laughter

Dear Lord,
The day can be challenging, often our problems overwhelm our joy.
Today, help me to see the moments that lighten my heart.
Help me to laugh more and fret less.
May the radiance and joy of your love shine in me.
Amen