

FAMILY CAREGIVING FOR OLDER ADULTS: CAREGIVER SUPPORT NEEDED



Objectives

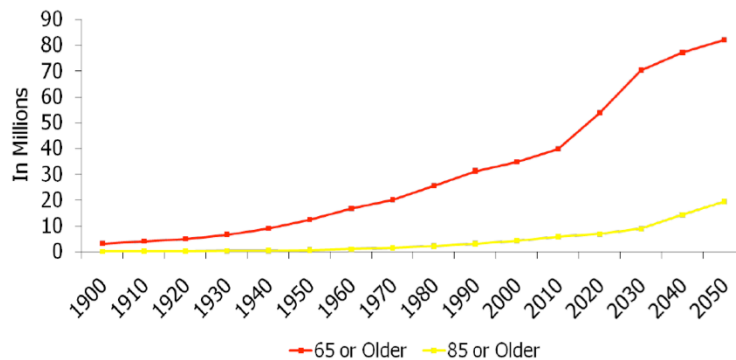


- Provide prevalence rates for family caregiving
- Describe the tasks associated with caregiving in long-term care
- Discuss the consequences of caregiving and associated risk factors
- Describe the benefits of family caregiving
- Identify the challenges and issues with caregiving
- Locate resources to support family caregivers

Caregivers Needed as the Population of Older Adults Increases



Total Number of Persons Age 65 or Older by Age Group, 1900 - 2050



(Federal Interagency Forum on Aging Related Statistics, 2012)

- The number of older adults (≥ 65 years) is expected to rise by 101% by 2030, a rate of 2.3% yearly. However, the number of family members available to provide care for them is expected to increase by only 25%, a rate of only 0.8% per year (Mack & Thompson, 2001).
- Unpaid caregivers provide an estimated 90% of long-term care (IOM, 2008).
 - For people living with Alzheimer's disease almost 75% of home care is provided by family/friends.
- Family caregivers represent the largest source of long-term care for older adults and as people live longer the need for family caregivers is even greater.

Becoming a Caregiver



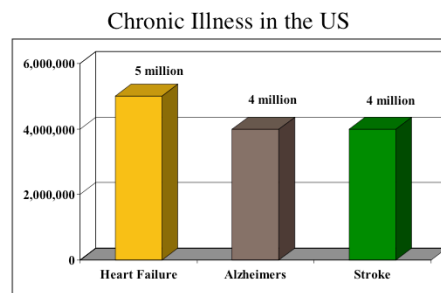
- May happen
 - ▣ Slowly over time as older adult's needs increase
 - ▣ Suddenly with illness (e.g. stroke)
 - ▣ Without choice – spouse or women (e.g. daughter, daughter-in-law) often expected to assume the role
- Regardless of how one becomes a caregiver, people are often unprepared for the long trajectory of chronic illness.

- If one were writing an advertisement for a family caregiver, it might say things like, willing to work long hours WITHOUT pay, no vacation, unqualified applicants chosen at random.
- Family members often are unprepared for the challenges of being a family caregiver. Generally, during the early life of many families there may be episodes of acute illness where there is a short-term need for families to help and they do....however this is very different from the long trajectory of chronic illness.

Diseases Requiring Long-Term Care



- Researchers have examined the experiences of family caregivers caring for older adults with:
 - Alzheimer's Disease
 - Dementia
 - Heart Failure
 - Stroke
 - Parkinson's Disease
 - Depression
 - Cancer
 - Medically ill



- The path of Chronic Illness can be challenging for caregivers because it can be unpredictable, slow and progressive, associated with repeat hospitalizations and procedures, and self-management of symptoms.
- Alzheimer's disease, Stroke, and heart failure are major health problems in the US and expected to increase significantly in the coming years as the population ages.
- The trajectory of Alzheimer's is long, from 10-15 years or more, recovery from stroke is often slow and heart failure is the most common diagnosis for hospitalization for those 65 y/o and older.
- While the specific disease may guide some of the caregiving. There are often common life decisions that need to be made related to limitations older adults experience.

Caregiving Tasks

(Tasks from Oberst Caregiver Burden Scale, 2004)



- Medical/nursing treatments
- Personal Care
- Household task
- Assistance with mobility
- Emotional support
- Surveillance of symptoms and progress
- Transportation
- Structuring/planning activities
- Managing behavior problems
- Finding and arranging care while away
- Communication
- Coordinating, arranging, and managing services and resources
- Seeking information and talking with healthcare providers



- Family caregivers provide an array of services for their older adult family members, assisting them with medical, physical, emotional, and cognitive/communication needs.
- Many task may be invisible to others
- Task include - Medical/nursing treatments (medications, skin care, dressings)
 - Personal Care (bathing, toileting, getting dressed, feeding)
 - Additional household task (laundry, cooking, cleaning, yard work, home repairs)
 - Assistance with walking, getting in and out of bed, exercises
 - Emotional support, “being there”
 - Watching for and reporting symptoms, watching how he/she is doing, and monitoring progress
 - Providing transportation or “company” (driving, riding along going to appointments, running errands)
 - Structuring/planning activities (recreation, rest, meals, things for him/her to do)
 - Managing behavior problems (moodiness, irritability, confusion, memory loss)

Consequences of Caregiving



- Burden, stress, physical and psychological strain
- Poor health habits (i.e. neglecting health care, eating a poor-quality diet)
- Impact on work – (e.g. late arrival, leaving early, taking time off or leave of absence, retire early.
- Financial burdens
- Difficulty in finding time for themselves
- Family conflict

- Depression is one of the most common negative effects of caregiving.
- In workforce, caregiving has been called the silent killer of productivity

"Caring for a sick child is an acceptable reason to be off (from work), caring for a sick older relative is not given the same priority." The MetLife Study of Sons at Work, 2003.

MetLife The effect of caregiving for employers is huge related to lost productivity, hiring replacements for employees who quit due to caregiving responsibilities, work lost from employees being absent or partially absent.
- Caregiver out-of-pocket expenses are, on average, \$2,400 per year to help care recipients and a loss in wages and other work related benefits are due to changes in work patterns (AARP, 2007).
- Female caregivers fare worse than their male counterparts on the negative effects of caregiving (Pinquart & Sorensen, 2006).

Factors Associated with Increased Caregiver Stress



- Caregivers health problems
- Working outside the home
- Negative attitudes towards caregiving
- Greater functional needs of the family member
- Higher frequency and time spent caregiving
- Limited informal and formal support

- The challenges of caregiving become more difficult to resolve when caregivers face personal health issues, resulting in increased depression and lower quality of life
- Role strain and role overload are associated with caregivers who work, however, some caregivers use employment as an escape.
- Caregivers often feel trapped in their role and don't have time for themselves which may result in negative attitudes towards caregiving.
- The stress level of caregivers increases in proportion to the physical needs of the care recipient
- The greater the intensity of caregiving the greater the stress
- Having a support system (ie. family members and friends to assist with caregiving task, community resources) can ease the strain of caregiving

Benefits of Caregiving



- Get to know family member better, develop closeness
- Opportunity to resolve past conflicts/hurt
- Payback for care the family member (e.g. parent) provided
- Satisfaction in providing comfort to someone
- Family humor and working together
- Gift of time

- We should be clear and acknowledge that there are benefits to caring for an older family member.
- A caregiver who cared for her mother in law with Alzheimer's disease and had teenage sons and a 2 year old talked about the stress of being pulled between the mother-in-law and child. However, she said she didn't think her sons would have learned as much about patience and compassion if her mother-in-law weren't living with them.
- The time that caregivers spend is often a priceless gift of love. There are families where providing care is handled and not perceived as stressful for the caregiver. However, even in the best of circumstances, family members often find the stress associated with caring for a family member overwhelming.
- Healthcare providers can assist caregivers by identifying the benefits and rewards of caregiving and coaching them about how to conduct a mindful life review.

Caregiving Case Study



- Phyllis is a 78-year-old, widowed woman living independently in her own home in a small town. She has four adult children, all married who live at a distance. The closest adult child is her daughter who lives 1½ hours away. The other adult children live several states away.
- In talking to one of her sons one day, Phyllis mentions that she has “done it again”. She has had another small accident hitting a guard rail. She says her car is not damaged that much and the policeman did not give her a ticket. As her son thinks about it, this is the fifth accident that his mother has mentioned in the previous year. She has hit guard rails before, almost pulled her car door off at a gas pump, and once fell asleep while driving. Luckily, she has not had any major injuries or caused injury to others. Phyllis always has a reason that she explains about why the accident happened.

Caregiving Case Study cont.

- Although she lives in a small town, his mother does not have a lot of close friends, which has been typical throughout her life, and her daughter does not get down to visit that often as she has two teenage children. Generally, she can get to where she wants to go without getting on major highways, but she does have to take a major interstate to get to the large shopping mall or if she drives up to see her daughter.
- She also has made recent comments about how much work needs to be done on her house and how she does not know who to call to make repairs. Her son becomes concerned and talks with his siblings. One brother thinks something might be wrong as well, but another brother thinks she's fine and that the brothers worry too much.

Caregiving Case Study Questions


- Is there cause for concern?
- How should the family approach the mother?
- What options do they have?

Challenges for Family Members



- ☐ Managing the medical condition
- ☐ Dealing with family issues
- ☐ Communicating effectively
- ☐ Identifying community services
- ☐ Long-term planning

DEAR ABBY



JEANNE PHILLIPS

Siblings in denial about Alzheimer's


DEAR ABBY: For years now, my dad's health has slowly deteriorated. He has good days when he kind of knows what's going on, and bad days when his whole world is off balance. Recently he suffered some mini-strokes, and last September the doctor diagnosed him with Alzheimer's.

I was there when Dad was diagnosed. You could see the look of relief on his face to finally have a name for what was going on inside him. He told the doctor, "Well, at least now I know I'm not going crazy" because it was a medical condition he could comprehend.

The problem is his siblings. They get angry at Mom when she tells the doctor how Dad is at home and accuse her of exaggerating. They get upset with us for not letting Dad drive, even though he doesn't see well and has been known to get lost. They have even gone behind our backs and told Dad he does not have Alzheimer's, which only compounds the problem.

Some of Dad's siblings see him

Problematic Interactions with Family Members



"The problem is his siblings. They get angry at Mom when she tells the doctor how Dad is at home and accuse her of exaggerating...they have even gone behind our backs and told Dad he does not have Alzheimer's... they all insist he is "fine" and blame Mom for his lack of spirit."

(UExpress, 2004)

- In families some members may not understand the illness and what it means. This may be especially true of family members who live at a distance. If one member assumes most of the caregiving responsibility and do it well, other family members may not think there is a need for assistance to help the caregiver.

Common Late Life Family Issues - Starting the Conversation about...



- ☐ Living arrangements
- ☐ Issue of Driving
- ☐ Financial and legal concerns
- ☐ End-of-life health care decisions

- Regardless of the illness, there are common issues that often need to be addressed. Family members and caregivers need to have these conversations early on with the care recipient. Having these conversations are difficult and uncomfortable for some family members. Sometimes in the need to assist and help the older adult, family caregivers may not think through all the consequences of some of these decisions. Some considerations that need to be given to these major life decisions are addressed later.

Living Arrangements



ARGEO

- Home
 - ▣ Coordination of services
- Living with children
 - ▣ Who will provide the social interaction for older adults?
- Other settings (independent living, assisted living, adult day care etc.)
 - ▣ Cost, variety of services, turnover of staff

- As an older adult becomes less able to perform activities of daily living either due to physical or mental impairments, the issue of whether the older adult should remain in his/her home is often a concern. Depending on how disabled the older adult is, family members/caregivers may be able to arrange for in home services. This assistance can be helpful, but can be costly.
- Sometimes family members want the older adult to move in with them. However, they need to recognize that they may be moving the older adult out of their support network and have little to do to occupy their day. Also, having the older adult live in their home may present challenges with making it work for everyone involved.
- Other settings may provide options, but may be costly. For example assisted living costs can vary greatly depending on services needed. For example, the Assisted Living may or may not be able to provide transportation to medical appointments, they may or may not be equipped to care for those with moderate cognitive impairment.

Resources about Living Options



- Click on or copy and paste the weblink below to access Eldercare.gov's Housing Options for Older Adults brochure:

- ▣ http://www.eldercare.gov/Eldercare.NET/Public/Resources/Brochures/docs/Housing_Options_Booklet.pdf

- Click on or copy and paste the weblink below to access the AARP's "Which Housing is Best for You?" guide:

- ▣ http://www.aarp.org/home-garden/housing/info-08-2009/ginzler_housing_choices.html

Issues of Driving



- Extremely important to one's independence
- Safety has to take priority
- AARP 55 Alive Driving Program
- Independent Driving Evaluation
 - ▣ Not covered by insurance, expensive, simulated in lab and road tests



Resources for Older Drivers



- Click on or copy and paste the weblink below to access this article: Carr, D. B., & Ott, B. R. (2010). The older adult driver with cognitive impairment. *JAMA*, 303(16), 1632-1640.
 - ▣ <http://jama.jamanetwork.com/article.aspx?articleid=185732>
- Click on or copy and paste the weblink below to access the NHTSA's older drivers education resources: <http://www.nhtsa.gov/Senior-Drivers>
 - ▣ Adapting motor vehicles for older drivers
 - ▣ How to understand and influence older drivers
 - ▣ Driving safely while aging gracefully

- These resources may be helpful to health care providers and families.
- The three booklets from the National Highway Traffic Safety Administration may be helpful for families and caregivers. The one on *How to Understand and Influence Older Drivers* can help caregivers start the conversation with older adults, what to observe, and how to develop a plan of action. The booklet even points out that families can be wrong as it isn't the age of the driver, but driving performance that is important.
- This site also has several specific booklets about driving and medications along with a "Drive Well Toolkit" that may be helpful to Health care providers.

Financial And Legal Concerns



- Families
 - ▣ Often are unaware of benefits associated with Medicare (<http://www.medicare.gov/>)
 - ▣ Have different “rules” about discussing finances/money
 - ▣ Often do not understand the difference between wills, living wills, and health care power of attorney
- Click on or copy and paste the weblink below to access a case study from the New York Times about what can happen when families do not have “the talk”
 - ▣ <http://www.nytimes.com/2013/05/25/your-money/aging-parents-and-children-should-talk-about-finances.html?pagewanted=all&r=0>

- Approximately ¼ of families of persons with CHF had spent all of their life savings during the course of the illness. Families have different comfort levels about discussing money and finances in general. However, it is important for families to know if older adults have adequate resources for their needs. For example, one woman who was not taking her medication for osteoporosis said it was too expensive and her son had done so much for her she did not want to have to ask for anything else.
- As the NY times article points out that an unexpected death may make it difficult for adult children to resolve an estate when there is not a will and they do not know where important papers are.

End of Life Decisions



ARGEO

- Living wills
- Health Care Power of Attorney
- How much treatment a person wants relative to the risks
- Extending life with little quality

RESOURCES:

- Click on or copy and paste the weblink below to access the Family Caregiver Alliance website:
 - ▣ http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=401
- Click on or copy and paste the weblink below to access the National Hospice and Palliative Care Organization website:
 - ▣ http://www.caringinfo.org/files/public/brochures/End-of-Life_Decisions.pdf

- The resources provide definitions and information about advance directives — living wills and healthcare powers of attorney, including frequently asked questions.
- The resources also provide tips on how to begin the conversation about end of life decision making.

A Discussion about Family Caregiving



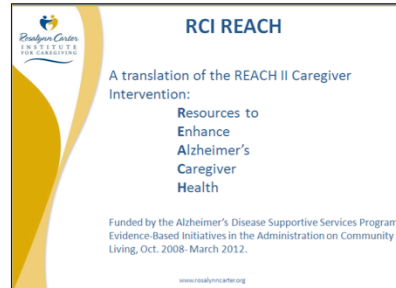
- Laura J. Bauer is the Director of National Initiatives at Rosalynn Carter Institute (RCI) for Caregiving. She is a co-author of the Institute's signature training program, *Caring for You, Caring for Me – Education and Support for Family and Professional Caregivers, 2nd Edition*
- Laura will talk about the challenges family caregivers face, evidence based programs to support family caregivers, and the role of the RCI.
- Click on or copy and paste the weblink below to listen to the podcast
 - <https://gsu.sharestream.net/ssdcms/i.do?u=4fb8fd52d79545b>

Resources Mentioned in Podcast



- A report entitled “**State of the Science: Professional Partners Supporting Family Caregivers**” was published through the *American Journal of Nursing* and the *Journal of Social Work Education* and includes 17 articles on assessment and support of caregivers. Click on or copy and paste the weblink below to access the above:

- <http://www.nursingcenter.com/lnc/static?pageid=809507>



- Click on or copy and paste the weblink below to access the REACH II:

- <http://www.edc.gsph.pitt.edu/Reach2/>

Tools for Assessing Caregiver Burnout



- Click on or copy and paste the weblink below to access the Caregiver Self Assessment Questionnaire
 - ▣ http://www.amaassn.org/ama1/pub/upload/mm/433/caregiver_english.pdf
- Click on or copy and paste the weblink below to access the Zarit Caregiver Stress Self Assessment Tool
 - ▣ http://www.aging.emory.edu/documents/caregiver_stress_self_assessment.pdf
- Click on or copy and paste the weblink below to access the Montgomery-Gorgotta Caregiver Burden Scale
 - ▣ <http://www.aging.emory.edu/documents/MontgomeryGorgottaCaregiverBurdenScale.pdf>

- These evidence based tools can assist providers in identifying caregivers experiencing stress/burden related to their caregiving roles.

Caregiver Support Resources



- Click on or copy and paste the weblink below to access the ARCEC Transitions in Care Toolkit
 - ▣ <http://www.aging.emory.edu/arcec/toolkit/index.html>
- Click on or copy and paste the weblink below to access the Rosalynn Carter Institute for Caregiving – Caregiver Intervention Database
 - ▣ http://www.rosalynncarter.org/caregiver_intervention_database/
- Click on or copy and paste the weblink below to access the Family Caregiver Alliance Tools and Multimedia
 - ▣ http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=2324&chcategory=52

Caregiver Support Resources con't

- Click on or copy and paste the weblink below to access the HELPGUIDE.org Tips for Making Family Caregiving Easier.
 - ▣ http://www.helpguide.org/elder/caring_for_caregivers.htm
- Click on or copy and paste the weblink below to access the Atlanta Area Agency on Aging AgeWise Connection – Services for Caregivers
 - ▣ <http://www.agewiseconnection.com/services/svcsforcaregivers>

Planning Ahead & Asking for Help



- Have a family meeting and develop a plan
- Conference calls can be used to include family members at a distance
- Recognize that some family members may not be comfortable in some aspects of caregiving
- Acknowledge the individual's right to set limits on what he/she can do
- Use a calendar to schedule activities

- These are some additional tips for supporting family caregivers.

Planning Ahead & Asking for Help

(continued)



- Make environmental changes that may facilitate providing care (safety bars, raised toilet seat, raising chairs)
- Get to know your resources – especially for those in you local community
- Seek support of church groups or friends
- Ask for specific types of help (respite time, help with household chores, help with paperwork, help with transportation, emotional support, etc.)

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