Home Caregiving Strategies for Health Professionals and Home Caregivers

Valerie Alsbrook, BSN, RN
Objectives

- Identify the primary providers of long term care
- Identify aspects of family caregiving that influence patient outcomes
- Discuss ways to be a caregiver advocate
There are only four kinds of people in the world:

1. Those who have been caregivers
2. Those who currently are caregivers
3. Those who will be caregivers
4. Those who will need a caregiver

First Lady Rosalyn Carter
What is Caregiving?

Helping someone out, assisting someone, nurturing them...

Providing assistance to a person who is ill, disabled, or needs help with daily activities

The provision of healthcare services
Who are the Caregivers?

FORMAL CAREGIVER

INFORMAL CAREGIVER
The Primary Family Caregiver:
(Informal, not paid)

Does not think of self as a “caregiver”
Thinks in terms of relationships
The Invisible Caregiver

The Primary Family Caregiver:

Typically is not recognized by the formal healthcare system as part of the care team
Family Caregiver Stats

- 29% of households in the U.S. provide care to a chronically ill, disabled or elderly person in any 12-month period
  National Alliance for Caregiving, AARP 2009

- Spend an average of 20 hours/week providing care for their loved one
  13% of family caregivers spend 40 hours +
  National Alliance for Caregiving, AARP 2009

- 62% rearrange work schedules, decrease their hours or take leave
  MetLife, 2010
Aging in America

Population 65+ by Age: 1900-2050
Source: U.S. Bureau of the Census

Number of Persons 65+

<table>
<thead>
<tr>
<th>Year</th>
<th>65-74</th>
<th>75-84</th>
<th>85+</th>
</tr>
</thead>
<tbody>
<tr>
<td>1900</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1910</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1920</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1930</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1940</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1950</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1960</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1970</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1980</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1990</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2000</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2010</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2020</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2030</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2040</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2050</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Value of “free” care

(in billions)

- Services Provided by Family Caregiver: $375
- Services Provided by Government: $158
Cost to the Family Caregiver

Financial:
- Personal loss of about $659,139 over a lifetime
- Spend an average of $5,531 a year on caregiving expenses

Family Caregiver Alliance: 2009 National Policy Statement
## Government Assistance

<table>
<thead>
<tr>
<th>Services Provided</th>
<th>Medicaid</th>
<th>Medicare</th>
</tr>
</thead>
<tbody>
<tr>
<td>Homemaker-laundry, shopping, errands</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>Home delivered meals</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>Electronic Personal Emergency Response System</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>Adult Day Health Care</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>Respite-temporary relief for the primary caregiver</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>Nursing Home care</td>
<td>YES</td>
<td>LIMITED</td>
</tr>
</tbody>
</table>
Becoming a Caregiver

“The Call”

Sudden

Gradual-chronic
Tag, You’re It

1. The spouse/partner
2. The adult child
   - Caregiver by choice
   - Caregiver by default
3. Other relative or friend
Caregiver Profile

49 year old woman, married, employed
Cares for her widowed mother
37% have children or grandchildren under 18 years old living with them

Caregiving in the U.S.: National Alliance for Caregiving in Collaboration with AARP 11/09
The Care Recipient

An adult with a chronic illness or disabling condition

An older person who needs ongoing assistance with everyday tasks to function on a daily basis (frail elder)

3/4 have one chronic illness
1/2 have at least two chronic illness

Thompson, L. Long-term care: support for family caregivers. 2004
Care Recipient Residence

- **52%** Personal Home
- **29%** Family Caregiver's Home
- **8%** Someone Else's Home
- **3%** Nursing Home
- **4%** Assisted Living
- **4%** Independent Living or Retirement Home
Family Caregiving

Early Stage:

Responsibilities are often assumed gradually, especially if the illness is chronic.
Family Caregiver Strategies

Early Strategies:

- Ask the professionals questions
- Seek information
- Prepare
Health Professional Support

Early Stage:

Help the primary family caregiver recognize he/she is a caregiver!

Awareness: diagnosis + interaction with the health care system

Over 90% become more proactive after they self-identify

Health Professional Support

Early Stage:

- Address the concerns of both the client and the primary caregiver
- Provide disease/condition specific resources
- Be informed of local and internet resources for education and caregiver support
Family Caregiving

**Middle Stage:**
Responsibilities increase
- Buy groceries
- Prepare meals
- Clean house
- Do laundry; mow yard
- Talk to doctors, care managers and others to understand what to do
- Become the financial manager
Family Caregiver Strategies

Middle Stage:
- Learn caregiving skills
- Practice self-care!
- Attend a support group
- Identify ways for others to help and
  Let Them!!
Health Professional Support

Middle Stage:

- Suggest a family meeting facilitated by a neutral party to create a long term care plan
- *Listen* and validate the caregiver’s concerns
- Be sure the caregiver understands all home care instructions; use lay language
- Continue to provide resources for education and support
- Promote caregiver respite and self-care
Late Stage:

Family member quits working to become a full time caregiver and patient advocate

Typically one family member is on call 24/7
Late Stage: Assists with ADL’s

- Transfers
- Bathing and dressing
- Toileting; incontinence care
- Feeding, including tube feeding
- Med administration including injections
Impact

Health Challenges:

Mental Health - High rate of mental health problems

Physical Health –
- 72% of family caregivers report not going to the doctor as often as they should
- 55% say they skip doctor appointments for themselves
Impact

- Financial Challenges:
  - Six in 10 family caregivers are employed
    *MetLife Study of Working Caregivers and Employer Health Costs; National Alliance for Caregiving and MetLife Mature Market Institute. February 2010*
  - 66% make adjustments to their work life
  - 1 in 5 family caregivers take a leave of absence
    *Caregiving in the United States; National Alliance for Caregiving in collaboration with AARP. November 2009*
Cost to Businesses

American businesses can lose as much as $34 billion each year

Family Caregiver Strategies

- Self-care!
- Respite
- Support group
  - understanding
  - safe environment
  - creative solutions
Family Caregiver Advocate

- Assess for caregiver burnout or depression
- Inquire about the caregivers health, coping, assistance from others
- Continue to provide education to the caregiver as well as the client
Challenges

- One out of five Medicare patients are readmitted within 30 days
  Re-hospitalizations among Patients in the Medicare Fee-for-Service Program
  Stephen F. Jencks, M.D., M.P.H., Mark V. Williams, M.D., and Eric A. Coleman, M.D., M.P.H.

- MedPAC estimated that in 2005 readmissions cost the Medicare program $15 billion, $12 billion of which could have been avoided
Strategies - Project Red

Project Re-Engineered Discharge

- *Educating the patient about his or her diagnosis throughout the hospital stay*
- Asking the patient to explain in their own words the details of the discharge plan
- Making appointments for follow-up and testing
- Confirming the medication plan and making sure the patient understands changes in the routine and side effects to watch for
- Phoning the patient 2 to 3 days after discharge to identify and resolve any problems
Transitions of Care

*Improve communication during transitions between providers, patients, and caregivers*

Establish points of accountability for sending and receiving care, particularly for hospitalists, physicians practicing in skilled nursing facilities, primary care physicians, and specialists.
Transitions of Care

- Increase the use of case management and professional care coordination
- Expand the role of the pharmacist in transitions of care
Consumers Advancing Patient Safety

“At the heart of safe discharge is clear communication and education for patients and families”

- Importance of prompt follow-up care
- What to expect and what to do when they leave the hospital
- How to plan for their immediate and longer-term needs
New York University Caregiver Intervention

Provides counseling and support interventions for rural elder spousal caregivers of Alzheimer’s disease patients

Caregivers reported:
- Better physical health
- Fewer depressive symptoms
- Higher satisfaction with social support network
- Less troubled by spouses memory and behavior changes
- Delay nursing home placement and as-needed telephone counseling sessions to family caregivers
Evidence-Based Programs

Environmental Skill Building Program

Occupational Therapists instruct caregivers of persons with dementia to:

- Manage functional decline
- Manage challenging behaviors
- Enhance home safety
- Enhance caregiving efficacy
Caregiver Advocacy

Discussion
Valerie Alsbrook, BSN, RN
Coordinator of Home Caregiver Training
valsbrook@uams.edu
479-751-3043 Ext. 231