Family and Care-giving Issues

PA Behavioral Health and Aging Coalition
Lynne Nessel, LCSW

Objectives

- Understand the impact of changes in medical and behavioral health of older adults on the family caregiver
- Assessment of the family in the context of their role of caregiving
Objectives (cont.)

- Understand the social, cultural and communication styles within family systems
- Identify the role of long-term planning in reducing stress for caregivers and family members

Experience of Aging

- 1970-Life expectancy was 70.8 years
- 2000-Life expectancy was 76.9
- 2030-the number of older adults age 85 and older will be 10million
- Rate of disability from physical decline has dramatically decreased over the past 20 years

*National Institutes of Aging (2009)*
Experience of Aging

- Approximately 80% of older adults have at least one chronic disease
- 50% have at least 2 chronic disease
- Can contribute to feelings of loss and decrease in well-being
- Education, treatment options and coping strategies for managing chronic health issues


Transitions in Later Life

- Living situations may change
- Financial changes
- Losses of family members and friends
Transitions in Later Life

- Retirement
- Health changes
- Cognitive changes (not apart of normal aging but may be a risk factor)

Effects of changes in medical and behavioral health on lifestyle

- Implications of chronic health problems
- Cognitive changes
- Changes in abilities for ADL and IADL
Effects of changes in medical and behavioral health on lifestyle

- Safety Issues-driving, medication management, cooking, falls
- Capacity/decision making
- Financial considerations

Experience of Aging

Most older adults successfully navigate through changes and challenges in their lives as they have done in the past
Experience of Aging

Recognizing changes and age-related themes will help the senior adult and their family members to effectively cope with changes and develop strategies to adjust to those changes.

Prevalence of Caregiving

Caregiving in the United States, 2009
(National Caregiver Alliance, AARP, MetLife Foundation 2009)
### Caregiving In The U.S.

<table>
<thead>
<tr>
<th>Type of Recipient</th>
<th>Prevalence</th>
<th>Estimated Number of Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>28.5%</td>
<td>65.7 million</td>
</tr>
<tr>
<td>Child</td>
<td>1.7%</td>
<td>3.9 million</td>
</tr>
<tr>
<td>Only Adult</td>
<td>21.2%</td>
<td>48.9 million</td>
</tr>
<tr>
<td>Both child and adult</td>
<td>5.6%</td>
<td>12.9 million</td>
</tr>
</tbody>
</table>

**Figure 1: Estimates of Individual Caregiving Prevalence by Age of Recipient**

### Key Findings

- Caregivers predominantly female (66%)
- Average of 48 years old
- One-third take care of two or more people
Key Findings

- One-third taking care of a parent

- Caregiving role averages 4.6 years and 31% for 5 or more
**Key Findings**

**Figure 4: Main Problem or Illness of Care Recipient Identified by Caregiver**

Q18. What would you say is the main problem or illness your relative/household for which health needs/wasted your care?

<table>
<thead>
<tr>
<th>Problem</th>
<th>2009 All Caregivers (n=1,600)</th>
<th>Caregivers of Recipient Age 18+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Old age</td>
<td>12%</td>
<td>12% 13%</td>
</tr>
<tr>
<td>Alzheimer's/Confusion</td>
<td>19%</td>
<td>6 12%</td>
</tr>
<tr>
<td>Cancer</td>
<td>7%</td>
<td>8 8</td>
</tr>
<tr>
<td>Mental/Emotional Illness</td>
<td>7%</td>
<td>7 7</td>
</tr>
<tr>
<td>Heart disease</td>
<td>5%</td>
<td>7 6</td>
</tr>
<tr>
<td>Stroke</td>
<td>5%</td>
<td>5 5</td>
</tr>
</tbody>
</table>

**Figure 17: Work Accommodations Due to Caregiving**

Q36. How has your work been affected by your caregiving role?

<table>
<thead>
<tr>
<th>Accommodation</th>
<th>2009 (n=553)</th>
<th>2010 (n=577)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any effect</td>
<td>69%</td>
<td>71%</td>
</tr>
<tr>
<td>Do it later, leave early, take time off</td>
<td>66%</td>
<td>70%</td>
</tr>
<tr>
<td>Leave of absence</td>
<td>17%</td>
<td>17%</td>
</tr>
<tr>
<td>Reduce work hours or take less demanding job</td>
<td>17%</td>
<td>17%</td>
</tr>
<tr>
<td>Give up working entirely</td>
<td>3%</td>
<td>3%</td>
</tr>
<tr>
<td>Turn down a promotion</td>
<td>5%</td>
<td>4%</td>
</tr>
<tr>
<td>Lose any job benefits</td>
<td>1%</td>
<td>2%</td>
</tr>
<tr>
<td>Change retirement age</td>
<td>3%</td>
<td>3%</td>
</tr>
</tbody>
</table>
Family Caregiving

- Almost 15 million Americans provide unpaid care for a person with Alzheimer's Disease (Family members, friends and neighbors)

- In 2010, they provided 17 billion hours of unpaid care = 202 billion dollars

Alzheimers Association (2011) Alzheimer’s Disease Facts and Figures

Family Caregiving

- It is a myth that most the elderly in the United States are cared for in nursing homes and health care institutions. Family and friends provide 80% of the long-term care of older adults in the United States.

National Alliance for Caregiving, 2004
Family Caregiving

- Family System
- Family Caregiving
- Cultural values, beliefs and practices

NASW Standards for Social Work Practice with Family Caregivers of Older Adults

- Ethics and Values
- Qualifications
- Knowledge
NASW Standards for Social Work Practice with Family Caregivers of Older Adults

- Cultural and Linguistic Competence
- Assessment
- Service, Planning and Delivery
- Advocacy

NASW Standards for Social Work Practice with Family Caregivers of Older Adults

- Collaboration
- Practice Evaluation and Improvement
- Documentation
NASW Standards for Social Work Practice with Family Caregivers of Older Adults

- Workload
- Professional Development and Competence

Caregiver Burden

Assessment for risk factors for caregiver burden
Causes of Caregiver Stress

- Pie of Life exercise
- Caregiver responsibilities
- Caregiver beliefs and expectations
- Family conflicts

Stress of Caregiving

- How stress affects us physically and psychologically
- When stress becomes distress
Health Effects of Caregiving

- Longitudinal Assessment of Informal Caregiving and Mental Health Status in the Nurses Health Study


Nurses Health Study: Informal Caregiving and Mental Health Status

<table>
<thead>
<tr>
<th>TABLE 1 — Characteristics of Married Women in the Nurses’ Health Study Population: Variation According to Care for a Disabled or Ill Spouse, 1992–1996</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<tr>
<td>————————————</td>
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<tr>
<td>n, before exclusion based on 1992 depressive or anxious symptoms</td>
</tr>
<tr>
<td>Excluded because of depressive or anxious symptoms in 1992, % (not adjusted)</td>
</tr>
<tr>
<td>No. included in analysis</td>
</tr>
<tr>
<td>Age, %</td>
</tr>
<tr>
<td>50–54</td>
</tr>
<tr>
<td>55–59</td>
</tr>
<tr>
<td>60–64</td>
</tr>
<tr>
<td>65–69</td>
</tr>
<tr>
<td>70–74</td>
</tr>
<tr>
<td>Mean MHI-5 score, 1992</td>
</tr>
<tr>
<td>Mean MHI-5 score, 1996</td>
</tr>
<tr>
<td>Mean change in MHI-5 score, 1992–1996 (change relative to that in non-caregivers)</td>
</tr>
<tr>
<td>Depressive or anxious symptoms, 1996, %</td>
</tr>
<tr>
<td>Working outside home, 1996, %</td>
</tr>
</tbody>
</table>
Caregiver Depression

Caregiver Depression: A Growing Mental Health Concern (Sept 2003) 
Policy Brief

*Family Caregiver Alliance and National Center on Caregiving* (2003)

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Symptoms of Depression

- Changes in appetite, sleep, motivation,
- Suicidal thoughts
- Anxiety or nervousness
- Alcohol use
Support for Families and Caregivers

Counseling and Support for Spouse Caregivers
- Reduced Depressive Symptoms
- Effectiveness of counseling was sustained for 3.1 years after baseline

Mittleman and Roth (2004) Sustained Benefit of Supportive Intervention for Depressive Symptoms in Caregivers of Patients with Alzheimer’s Disease

Support for Caregivers
- Healthy balance of self care and caregiving
- Recognizing that caregiving is an additional role (*Self-Awareness in Caregiving*)
- Identify other support through community resources, education, other family members and friends

National Alliance for Caregiving (2002) *Self-Awareness in Caregiving*
Promoting Positive Outcomes

Self Care Talk Intervention

Family Caregiver-Nurse Partnerships:
Improving health and well-being of older adult spouse caregivers

Parker and Teel-Self Care Talk intervention, Journal of Gerontological Nursing, 2011

Promoting Positive Outcomes

Caregiver Empowerment Model-
- assessing challenges
- finding meaning
- developing coping strategies

Jones and Winslow, Journal of Family Nursing (2011)
Caregiver Empowerment Model

Assuring Healthy Caregivers: A Public Health Approach to translating Research into Practice: The RE-AIM Framework

Centers for Disease Control and Prevention (2010)
Promoting Positive Outcomes

- Family caregiving at the end of Life- comprehensive review of published qualitative research (1998-2008)

  *Funk and Stajduhar, Palliative Medicine (2010)*

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Promoting Positive Outcomes

Interventions which improve positive outcomes of family caregiving:

- Psychoeducational
- Supportive
- Psychotherapy
- Multicomponent

*Alzheimer's Disease: Facts and Figures (2011)*)
Screening Tools:

Informal caregivers of Older Adults at Home: Let’s PREPARE (Atkins-VNA of New York)
Information to Improve Care and Outcomes:

Working With Families of Hospitalized Older Adults with Dementia (Hall and Maslow, Alzheimer’s Association)

Driving Safety

**Safety Risks**-

- The individual with a Dementia diagnosis may not be able to judge their loss of ability
- Caregivers/family members can help identify changes over time
- The decision to stop driving should involve advice from a specialist trained in working with people with dementia.
Driving Safety

- Caregiver Questionnaire
  1. I have concerns about the patient’s ability to drive safely.
  2. Others have concerns about his/her ability to drive safely.
  3. The patient has limited the amount of driving that he/she does.

*Academy of Neurology (2010) Evaluation and Management of driving risk in dementia*

Tips to Limit Driving

- Involve the person with Dementia in discussions/decisions about giving up driving
- Transition driving to others
- Support from family and friends

*Alzheimer's Association (2007)*
Planning for the Future

- Early discussions about long-term care planning
- Understanding the resources in the community
- Involvement of the older adult in the long-term planning before services are needed

Long-term Planning

- Early discussion about future care needs
- Financial Planning
- Advance directives
- Power of Attorney
- Options for Alternative living
Exploring Community Resources

- Area Agency on Aging
- Home Health and Home Care Services
- Hospice Services
- Respite Services

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Exploring Community Resources

- Assisted Living Facilities
- Nursing Home/Health Care Centers
- Independent Living Facilities
- Senior Housing/Apartments
Exploring Community Resources

- Transportation services
- Meals on Wheels
- Medical alert/response systems
- Adult Day Services
- Senior Centers

Caregiver Support

- Caregiver support groups
- Education
- Individual and family counseling
- Spiritual support
A local family physicians office contacted the ABC Home nursing service with the following referral:

Anna R, a 92 year old widowed female had missed several appointments with the family physician and seemed confused when the office called to confirm her appointment.

Mary B, (RN form ABC nursing) received the referral. She drove to Anna R’s home in a rural farming town in North Central PA. Mary noticed that Anna R lived in a three story farm house with 8 steps to get into the home.

It took about 10 minutes for Anna R to answer the door. She did not recall the reminder call that Mary had made about the visit. Anna R invited Mary into her home, and Mary noticed that Anna was disheveled and her home was not clean.

Mary started to ask Anna about her health problems and the medications she was taking. There were numerous bottles of medications; many did not match the medications that the doctor’s notes indicated. Anna stated that she had no medical problems despite a list of medical diagnosis, including Diabetes, COPD, recent history of CHF, s/p hip fracture and Depression history.
Case Study

Anna stated that she had no medical problems despite a list of medical diagnosis, including Diabetes, COPD, recent history of CHF, s/p hip fracture and Depression history. Mary noticed piles of bills on a table. She asked if she would check the refrigerator for her dietary questions, and there was some older cartons of milk, juice, some bread and cheese, some opened meals on wheels containers.

Case Study

Mary contacted Sally by phone to ask additional family history. Sally had visited her mother at the holidays and agreed her mother was a little more confused but she had showed her how to use a pill box planner and thought this would help with her medication management. Mary had noticed a car in the driveway and asked if her mother was still driving. Sally replied that she only drove locally to the hairdresser and to the local grocery store about 5 miles away.
Case Study

Sally stated her mother was always a good driver and only recently had some minor fender benders. Sally said her brother visits monthly and tried to help her with her bills but her mother does not want to share information about her finances. Sally has not talked with her brother in several months since they had an argument over the holidays because her brother wants their mother to move to an assisted living facility. Sally does not want to take away her mother’s independence.

Family and Caregiving Issues

References:
Alzheimer’s Association(2011) Facts and Figures

Atkins, B and Kowalsji, J (2010) Informal Caregivers of Older Adults at Home: Let’s Prepare! Best practices in nursing care to Older Adults, Hartford Institute of Geriatric Nursing, New York University

References


Funk, L and Stajduhar, K(2010) Home-based Caregiving at the end of life, Palliative Medicine, 24 (6)


References (cont.)

National Association of Social Workers (2010) family Caregivers of Older Adults, NASW Standards for Social Work Practice

National Alliance for Caregiving,(2009) Caregiving in the US