

Interprofessional Geriatrics Training Program

Caregiver Burden



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Acknowledgements

Authors: Robert Rada, DDS, MBA

Susan Altfeld, PhD, MSW

Editors: Valerie Gruss, PhD, APN, CNP-BC

Memoona Hasnain, MD, MHPE, PhD

Expert Interviewees: Louise Starmann, LCSW

Esther Santana, PhD, Caregiver



Family Caregiving: The Facts

- An estimated 21% of households in the United States are impacted by caregiving responsibilities (National Alliance for Caregiving/AARP, 2004)
- Unpaid caregivers provide an estimated 90% of long-term care (Institute on Medicine, 2008)
- The typical caregiver is a 46-year-old woman with some college experience and provides more than 20 hours of care each week to her mother (National Alliance for Caregiving/AARP, 2004)
- The out-of-pocket costs for caregivers who are caring for someone who was aged 50 or older averaged \$5,531 in 2007 (Houser et al., 2008)
- About 37% of caregivers for someone aged 50 and older have reduced their work hours or quit their job in 2007 (Houser et al., 2008)



Opportunity to Support Caregivers

Providers Can Support Caregivers To:

- Become more confident and proficient in their caregiving capabilities
- Reduce their strain and avoid burnout
- Know they are not alone



Learning Objectives

Upon completion of this module, learners will be able to:

1. List common mental and physical health symptoms caregivers may experience related to caring for the older adult
2. Identify the risk factors associated with caregiver burden
3. Discuss assessment instruments for identifying caregiver burden
4. Employ resources and assist caregivers to develop coping skills to reduce the stress associated with caregiving



Caregiver Burden

- The emotional, physical, social, and financial responses to changes and demands that occur as an individual gives help and support to the older person
 - 41% report a relatively low burden
 - 18% report a moderate burden
 - 40% of caregivers report a high burden



(AARP Public Policy Institute and National Alliance for Caregiving, 2015)

Interview with Expert: Louise Starmann, LCSW



Interview: Louise Starmann, LCSW

Listen to Our Expert Discuss:

- Recognizing the different types of caregivers
- Define caregivers by their role
- Understand that most families/individuals will have responsibility for caring for an older adult



The Effect of Caregiving on One's Health

- Half of caregivers feel their health is *excellent* or *very good* (48%), while 17% say it is *fair* or *poor*; by comparison, 10% of the general adult population describe their health as *fair* or *poor*
- The longer a caregiver has been providing care, the more likely she or he is to report *fair* or *poor* health
- 22% of caregivers felt their health had gotten worse as a result of caregiving



(AARP Public Policy Institute and National Alliance for Caregiving, 2015)

Assessment Question 1

Caregivers will frequently:

- a) Find balancing the needs of the healthy and sick family members an easy task
- b) Experience minimal interpersonal conflicts as all family members are usually very understanding of the situation
- c) Experience conflicts at some point in time with their work/employment
- d) Enjoy financial benefits associated with generous government funding for caregivers



Assessment Question 1: Answer

Caregivers will frequently:

- a) Find balancing the needs of the healthy and sick family members an easy task
- b) Experience minimal interpersonal conflicts as all family members are usually very understanding of the situation
- c) Experience conflicts at some point in time with their work/employment (Correct Response)**
- d) Enjoy financial benefits associated with generous government funding for caregivers



Risk Factors for Caregiver Burden

- Female gender
- Low educational attainment
- Resides with the care recipient
- Higher number of hours spent caregiving
- Social isolation
- Financial stress
- Lack of choice in being a caregiver
- Behavioral challenges of the care recipient



Interview with Expert: Louise Starmann, LCSW



Interview: Louise Starmann, LCSW

Listen to Our Expert Discuss:

- Caregiver “breaking points”
 - Each caregiver has a different breaking point
 - Incontinence the most common breaking point
 - Behavior problems are another breaking point



Assessment Question 2

Which of the following has not been described as a risk factor for caregiver burnout?

- a) Social isolation
- b) Lack of choice in being a caregiver
- c) Residence in an assisted living facility
- d) Low educational attainment



Assessment Question 2: Answer

Which of the following has not been described as a risk factor for caregiver burnout?

- a) Social isolation
- b) Lack of choice in being a caregiver
- c) Residence in an assisted living facility (Correct Answer)**
- d) Low educational attainment



Caregiver Burden Symptoms



Interview with Expert: Esther Santana, PhD, Caregiver



Interview: Esther Santana, PhD, Caregiver

Listen to Our Expert Discuss:

- The impact of caregiving on her life:
 - Experience with identity and role changes and caregiver strain
- Many caregivers experience depression:
 - Depression is prevalent among caregivers
 - Depressed caregivers are more likely to report higher levels of burden
 - Studies estimate that between 18% and 47% of caregivers are depressed



(Lawton et al., 1993)

Other Caregiving Problems

Mental Health Concerns

- Ambivalence about care
- Anxiety
- Sadness
- Dread
- Caregiver guilt
- Worry

Physical Health Concerns

- Fatigue
- Injury
- Mortality
- Increased risk of illness
- Sleep problems



(American Psychological Association, 2016)

Secondary Strains



Common Caregiving Problems

Secondary Strains

- Conflicts with work/employment
- Financial strains
- Relationship stress
- Loss of time for self-care
- Reduced quality of life

 (American Psychological Association, 2016)

Family Challenges

Family Challenges

- Conflicts about care
- Lack of support for caregiver
- Balancing needs of healthy and sick family members
- Interpersonal conflicts

 (American Psychological Association, 2016)

Interview with Expert: Esther Santana, PhD, Caregiver



Interview: Esther Santana, PhD, Caregiver

Listen to Our Expert Discuss:

- The impact of caregiving on her life:
 - Family challenges, lack of support from family, feelings of isolation



Family Conflict

- Family conflict is a common stressor that can impact caregiver burden
- Conflict can exist between the caregiver and the care recipient (e.g., between spouses or mother and daughter) or between members of a caregiving network (e.g., adult children of a frail older adult)



Family Conflict

- Millie has moderate cognitive impairment but insists that she is able to drive safely; her daughter worries that she will cause an accident and wants to "take away the keys"
- Millie's son lives 700 miles away from his parents and sees them only occasionally but calls frequently; he feels that his sister should be more assertive with their parents and make plans for them to sell their home and move to assisted living



Zarit Burden Interview

- 22 items in which the caregiver is asked to respond using a 5-point scale
- Scores were unrelated to age, gender, locale, language, living situation, marital status, or employment status, indicating that the tool is appropriate for use with diverse populations
- Significant positive correlation with behavioral problems in the older adult patients and depression scores of the caregivers
 - <https://www.healthcare.uiowa.edu/igec/tools/caregivers/burdenInterview.pdf>



(Zarit et al., 1980; Hilbert et al., 2000)

Screening/Assessment: Zarit

The Zarit Burden Interview

- 0. NEVER
- 1. RARELY
- 2. SOMETIMES
- 3. USUALLY
- 4. ALWAYS

Please circle the response that best describes how you feel.

Question	Answer
1. Do you feel that your relative is shy for those help when he/she needs?	0 1 2 3 4
2. Do you feel that he/she is often alone and afraid with your relative that you don't know enough about his/her condition?	0 1 2 3 4
3. Do you feel worried because of caring for your relative and it may be stressful for you because of your condition?	0 1 2 3 4
4. Do you feel worried because of your relative's condition?	0 1 2 3 4
5. Do you feel angry because you are not getting your own things?	0 1 2 3 4
6. Do you feel that your relative is often angry or grumpy about his/her condition?	0 1 2 3 4
7. Do you feel that you are often angry or grumpy about his/her condition?	0 1 2 3 4
8. Do you feel that your relative is often sad or lonely?	0 1 2 3 4
9. Do you feel worried when you are around your relative?	0 1 2 3 4
10. Do you feel that your relative has suffered because of your condition?	0 1 2 3 4
11. Do you feel that your relative has not enjoyed life in your condition because of your condition?	0 1 2 3 4
12. Do you feel that your relative has suffered because of your condition because of your condition?	0 1 2 3 4



(Zarit et al., 1980; Hilbert et al., 2000)

Assessment Question 3

A more in-depth assessment tool for caregiver strain is the:

- Caregiver Stress Short Survey
- Zarit Burden Interview
- Mini-Mental Status Index
- Family Services Index



Assessment Question 3: Answer

A more in-depth assessment tool for caregiver strain is the:

- a) Caregiver Stress Short Survey
- b) Zarit Burden Interview (Correct Answer)**
- c) Mini-Mental Status Index
- d) Family Services Index



Management



Where Someone Provides Care is a Personal Decision
Interview with Expert: Louise Starmann, LCSW



Interview: Louise Starmann, LCSW

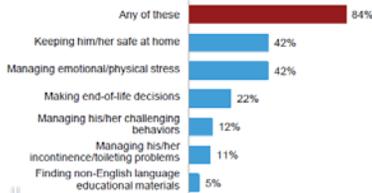
Listen to Our Expert Discuss:

- How the healthcare community can be helpful to caregivers
 - Recognize where someone provides care is a personal decision and validate their decision
 - Providers can't tell caregivers how they should provide care



Caregiver Knowledge Gaps

Which of the following topics do you feel you need/needed more help or information?



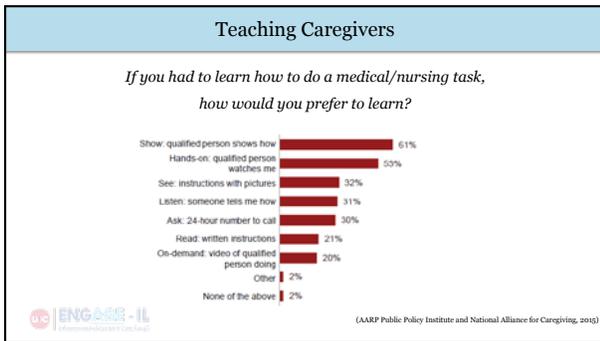
(AARP Public Policy Institute and National Alliance for Caregiving, 2019)

Dealing with Challenging Behavior

- Difficult behaviors in individuals with dementia can be especially challenging and closely linked with caregiver burden
 - For example, persons with dementia may experience: wandering, incontinence, combativeness, disrobing, and resistance to care
 - Understanding these behaviors as representing “unmet needs” is key to effectively dealing with them



(Maguire, 2016)



Assessment Question 4

Among the most requested information that caregivers want to know is:

- a) Estate planning
- b) Alternative sources of employment
- c) How to choose healthy foods
- d) How to keep their loved one safe at home

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Assessment Question 4: Answer

Among the most requested information that caregivers want to know is:

- a) Estate planning
- b) Alternative sources of employment
- c) How to choose healthy foods
- d) How to keep their loved one safe at home (Correct Answer)**

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Encourage Caregivers to Seek Support



Interviews: Esther Santana and Louise Starmann

Listen to Our Experts Discuss:

- The complexities in asking for help:
 - Esther
 - Cultural and personal expectations of herself
 - Negative connotations in asking for help
 - Louise
 - Health providers should let caregivers know that there is help available and it is ok to seek help
 - It is health care providers' job to ask questions and to know what caregivers confront in their daily lives
 - Clinicians should invite caregivers into a community of support



(American Psychological Association, 2016)

Clinicians Offer Resources

- Resources and eligibility for services for:
 - Residential placement
 - End of life care planning
 - Housing
 - Health care
 - Community services
 - Respite



(American Psychological Association, 2016)

Clinicians Provide Tips to Encourage Caregivers to Obtain Help

- Give each helper a specific responsibility
- Divide up the tasks
 - Medical visits
 - Grocery shopping
 - Paying bills
- Converse with other family members and express your concerns
- Don't be a control freak



Interview: Esther Santana, PhD, Caregiver

Listen to Our Expert Discuss:

- Important for clinicians to acknowledge the caregivers' needs
- Recognize that the caregiver is most likely not treating oneself as a priority
- *Referral Cue: Interprofessional teams, such as social workers, can provide psychosocial support*



Educate Caregivers about Hospice and Palliative Care

- Decisions for hospice and palliative care are often considered by families only long after they would be appropriate
 - There tends to be misinformation regarding eligibility for and/or goals of hospice and palliative care
- Patient and family education by primary care professionals is essential
 - Open and honest dialogue with caregivers
 - Home health services can provide needed support for caregivers



Educate Caregivers about Hospice and Palliative Care

- The **Eldercare Locator** is a useful resource for community-based services
 - http://www.eldercare.gov/Eldercare.NET/Public/About/Aging_Network/Index.aspx
- **Services** include meals, adult day care, homeware, transportation, and caregiver respite
- Eligibility criteria and service availability may vary by location
- **Programs** for older adults receiving Medicaid are also being modified and in many cases expanded under managed care programs



Family Caregiver Alliance

- A community-based nonprofit organization to address the needs of families and friends providing long-term care for loved ones at home
 - Policy and advocacy
 - Caregiver education
 - www.caregiver.org



Interview: Louise Starmann, LCSW

Listen to Our Expert Discuss:

- A case study example about a caregiver's challenge in deciding on clinical placement of their loved one
- The caregiver consulted with family members and social workers and made the difficult decision to place her loved one in a long-term care facility and is at peace with the decision



Assessment Question 5

Which of the following would be a good resource to find coping skills to reduce the stress associated with caregiving?

- a) The Eldercare Locator
- b) The Family Caregiver Alliance
- c) A Home Health Agency
- d) All of the above



Assessment Question 5: Answer

Which of the following would be a good resource to find coping skills to reduce the stress associated with caregiving?

- a) The Eldercare Locator
- b) The Family Caregiver Alliance
- c) A Home Health Agency
- d) All of the above (Correct Answer)**



Caregiver Rights and Authority

- Health professionals should empower caregivers to know their rights and their authorities
- Let caregivers know they have the right to
 - Get information about their family member's condition
 - Be involved in decision-making about their family member's care (authorized by cognitively intact patient or power of attorney for health care decisions)



(Minnick et al., 2010)

Caregiver Rights and Authority

- Let caregivers know that:
 - They are an essential partner in the health care team and have the right to be trained to provide care
 - In some states, being a caregiver can protect them from job discrimination
 - You can find support services that they might otherwise miss

 (Mink et al., 2010)

Interview with Expert: Esther Santana, PhD, Caregiver



What Drives Us to Be Better Caregivers
Interview: Esther Santana, PhD, Caregiver

Listen to Our Expert Discuss:

- What drives caregivers to provide better care:
 - Caregivers should be aware of what nourishes or drives them and to be self-aware of the traumas and triumphs that shaped their loved one
 - It is rewarding for her to continue a powerful relationship with her parents and she understands the loss was required for her to grow



Chronic Illness
Interview with Expert: Louise Starmann, LCSW



Interview: Louise Starmann, LCSW

Listen to Our Expert Discuss:

- Individuals are living longer and often with chronic illness
- Caregivers are an essential piece for older adults to be able to live independently in their communities
- Our goal is for older adults to age with dignity and we need the support of caregivers to achieve this goal



Resources

<http://www.caregiver.org>, Accessed October 25, 2016

<https://www.caregiver.org/finding-care-you-self-care-family-caregiver/>, Accessed July 6, 2016

<http://www.alzheimers.gov/Eldercare-NET/Public/About/Advisory-Network/index.aspx>, Accessed October 25, 2016

<https://www.healthcare-stigma.edu/you-look-caregivers.html#interview.pdf>, Accessed October 25, 2016

http://www.apornet.org/files/news/caregiver_strain_index.pdf, Accessed October 25, 2016



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