

Interprofessional Geriatrics Training Program

Caregiver Burden



Acknowledgements

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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

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

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

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

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

Family Challenges

Family Challenges

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

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

Assessment

Caregiver Strain Index (CSI)

- Screen for strains
- Robinson's "Caregiver Strain Index"
 - 13-question tool that measures strain related to care provision
 - Assesses major domains: employment, financial, physical, social, time
 - Quickly identifies families with potential caregiving concerns
 - A positive screen (7 or more items positive) indicates a need for more in depth assessment
 - http://www.npcrc.org/files/news/caregiver_strain_index.pdf

Caregiver Strain Index (CSI)

The Caregiver Strain Index: I am going to read a list of things that other people have found to be difficult. Would you tell me if any of these apply to you? (Give examples)

	Yes=1	No=0
Sleep is disturbed (e.g., because _____ is in and out of bed or wanders around at night)		
It is inconvenient (e.g., because helping takes so much time or it's a long drive over to help)		
It is a physical strain (e.g., because of lifting in and out of a chair; effort or concentration is required)		
It is confining (e.g., helping restricts free time or cannot go visiting)		
There have been family adjustments (e.g., because helping has disrupted routine; there has been no privacy)		
There have been changes in personal plans (e.g., had to turn down a job; could not go on vacation)		
There have been other demands on my time (e.g., from other family members)		
There have been emotional adjustments (e.g., because of severe arguments)		
Some behavior is upsetting (e.g., because of incontinence; _____ has trouble remembering things; or _____ accuses people of taking things)		
It is upsetting to find _____ has changed so much from his/her former self (e.g., he/she is a different person than he/she used to be)		
There have been work adjustments (e.g., because of having to take time off)		
It is a financial strain		
Feeling completely overwhelmed (e.g., because of worry about _____; concerns about how you will manage)		
TOTAL SCORE (Count yes responses. Any positive answer may indicate a need for intervention in that area. A score of 7 or higher indicates a high level of stress.)		

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>

Screening/Assessment: Zarit

The Zarit Burden Interview

- 0: NEVER
- 1: RARELY
- 2: SOMETIMES
- 3: QUITE FREQUENTLY
- 4: NEARLY ALWAYS

Please circle the response the best describes how you feel.

Question	Score
1 Do you feel that your relative asks for more help than he/she needs?	0 1 2 3 4
2 Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0 1 2 3 4
3 Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0 1 2 3 4
4 Do you feel embarrassed over your relative's behaviour?	0 1 2 3 4
5 Do you feel angry when you are around your relative?	0 1 2 3 4
6 Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?	0 1 2 3 4
7 Are you afraid what the future holds for your relative?	0 1 2 3 4
8 Do you feel your relative is dependent on you?	0 1 2 3 4
9 Do you feel strained when you are around your relative?	0 1 2 3 4
10 Do you feel your health has suffered because of your involvement with your relative?	0 1 2 3 4
11 Do you feel that you don't have as much privacy as you would like because of your relative?	0 1 2 3 4
12 Do you feel that your social life has suffered because you are caring for your relative?	0 1 2 3 4

Assessment Question 3

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

- a) Caregiver Stress Short Survey
- b) Zarit Burden Interview
- c) Mini-Mental Status Index
- d) 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

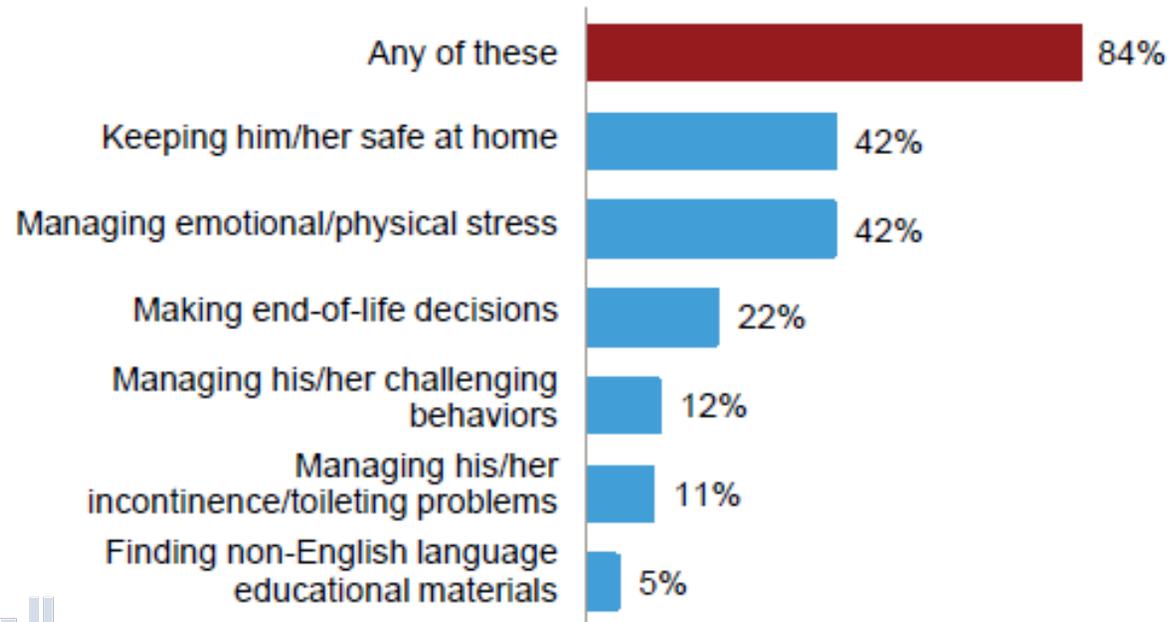
Interview: Louise Starmann, LCSW

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?

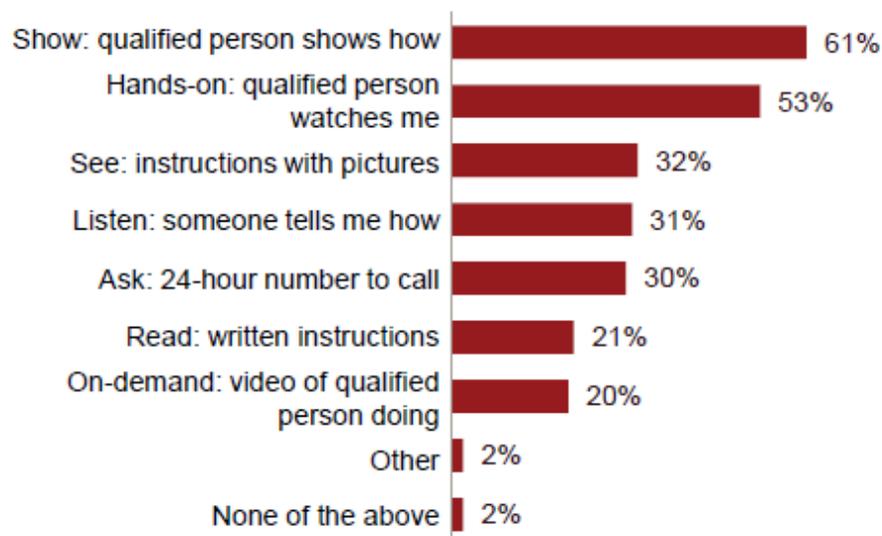


Dealing with Challenging Behavior

- 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

Teaching Caregivers

*If you had to learn how to do a medical/nursing task,
how would you prefer to learn?*



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

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)**

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

Clinicians Offer Resources

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

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, homecare, 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)

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

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

www.caregiver.org Accessed October 25, 2016

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

http://www.eldercare.gov/Eldercare.NET/Public/About/Aging_Network/Index.aspx Accessed October 25, 2016

<https://www.healthcare.uiowa.edu/igec/tools/caregivers/burdenInterview.pdf> Accessed October 25, 2016

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