Supporting Family Caregivers of Older Adults through Times of Stress and Isolation

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Supporting Family Caregivers of Older Adults through Times of Stress and Isolation
Overview

- This session will be interactive (e.g., polls), with 60 minutes of presenter-led discussion, followed by 30 minutes of presenter and participant discussion.

- Video replay and slide presentation are available after each session at: https://www.resourcesforintegratedcare.com
Support Statement

- This webinar is supported through the Medicare-Medicaid Coordination Office (MMCO) in the Centers for Medicare & Medicaid Services (CMS) to help beneficiaries dually eligible for Medicare and Medicaid have access to seamless, high-quality health care that includes the full range of covered services in both programs. To support providers in their efforts to deliver more integrated, coordinated care to dually eligible beneficiaries, MMCO is developing technical assistance and actionable tools based on successful innovations and care models, such as this webinar.

- To learn more about current efforts and resources, visit Resources for Integrated Care at https://www.resourcesforintegratedcare.com and follow us on Twitter @Integrate_Care
Introductions

■ Kathy Kelly, MPA
  Executive Director, Family Caregiver Alliance

■ Erin E. Emery-Tiburcio, PhD, ABPP
  Associate Professor of Geriatric and Rehabilitation Psychology and Geriatric Medicine and Co-Director of the Center for Excellence in Aging Rush University Medical Center

■ Bryan Godfrey, MA, MSW, LCSW
  Care Management Social Worker, UNC Geriatrics Specialty Clinic
Learning Objectives

- Describe the challenges facing caregivers of older adults, particularly those that may be present during the COVID-19 public health emergency.

- Identify strategies for assessing and addressing caregivers’ emotional health and the supports they may need to manage stress, isolation, and new responsibilities.

- Describe practical tips for effectively linking caregivers to support services provided by health care and community-based organizations (e.g., telehealth, online classes, and webinars).
Webinar Outline

- Polls
- Supporting Family and Friend Caregivers
- Caregiver Mental and Emotional Health
- Caregiver Assessment and Resources for Caregivers
- Panel Discussion
- Audience Q&A
- Resources
- Evaluation
Supporting Family and Friend Caregivers

Kathy Kelly, MPA
Executive Director
Family Caregiver Alliance
Family Caregivers of Older Adults

- Over 34 million individuals in the U.S. provide unpaid assistance and support to an older adult (50+),\(^1\) including many individuals dually eligible for Medicare and Medicaid
  - 60% of caregivers of older adults are female; over half are 50 years and older\(^1\)
  - 14% are friends, neighbors, or other non-relatives of the care recipient\(^1\)
Family Caregivers of Older Adults (cont.)

- Complex caregiving tasks, including medical tasks, can have negative emotional, mental, and physical health effects on caregivers\(^2,3\)
  - 50% of all family caregivers perform complex medical/nursing tasks (e.g., administering multiple medications, changing dressings, handling medical equipment) in the home for individuals with physical, cognitive, or behavioral health needs\(^3\)
- Many caregivers, however, also report positive experiences from caregiving, including feeling a sense of giving back to a loved one and personal meaning and purpose\(^4\)
- Support services, caregiver education, and respite can all help alleviate potential negative effects of caregiving on health\(^2\)
Impact of Caregiving on Caregiver Mental and Emotional Health

- **Stress**: Caregivers have higher levels of stress than non-caregivers and caregivers with chronic stress may be at greater risk of cognitive decline\(^5\).

- **Isolation**: Caregivers who provide complex care, have fewer social connections, and are less satisfied with their social supports are at higher risk of strain, depression, sleep disturbance, and poor health\(^6\).

- **Depression and Anxiety**: Caregivers report higher levels of depressive symptoms and anxiety than non-caregivers; 40 to 70% of caregivers have clinically significant symptoms of depression\(^7\).
  - Caregivers of individuals with dementia have higher levels of depression and emotional stress\(^8,9\).
Caregiving in the COVID-19 Pandemic

- In addition to their typical caregiving responsibilities, caregivers may now have other concerns, including:
  - Added financial difficulties
  - Extra measures for cleaning and disinfecting
  - Limited social interaction
  - Direct care precautions (e.g., personal protective equipment (PPE))
  - Disruptions in in-home support services, routine doctor’s appointments, and respite care
- Caregivers who have older relatives living in residential care facilities or assisted living may not be able to visit their loved one in person
- Older adults may have moved in with loved ones for the duration of the COVID-19 pandemic; these individuals may be taking on new caregiving responsibilities
Caregiving in the COVID-19 Pandemic (cont.)

During the COVID-19 pandemic, caregivers may need additional supports and services, and virtual options for accessing such supports. Services and supports that may be the most helpful include:

- Wellness check-in calls
- COVID-19-related care protocols, education, and supplies
- Strategies for managing behaviors associated with dementia
- Stress reduction techniques
- Vouchers/gift cards for food, consumable supplies, transportation
- Short-term counseling
- Direct care skills training
- Support groups
- Strategies for adapting to new living situations, as relevant
- Guidance around care (and changes in care) unrelated to COVID-19
Connecting Family and Friend Caregivers to Resources during COVID-19

- Health plans and providers can take the following steps to connect caregivers to resources:
  - Locate the local resource clearinghouse (e.g., Area Agency on Aging, Aging and Disability Resource Center, 211 or 311 information services) to refer for assistance with specific needs or services during this time
  - Connect with or start a resource sharing roundtable with your services network
  - Gather lists of resources for family/friend caregiver services and information and disseminate widely to caregivers (*included in this presentation, slides 14 and 41*)
  - Convert existing support groups to telephone or online
  - Seek alternative ways to provide caregiver education or training classes virtually, or contract with organizations or individuals who can do so
# Select Caregiver Resources

<table>
<thead>
<tr>
<th>Organization Name</th>
<th>Resource Name and Link</th>
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<tbody>
<tr>
<td>Family Caregiver Alliance</td>
<td><a href="https://www.ResourcesForIntegratedCare.com">Curated COVID-19 Resources and Articles for Family Caregivers</a></td>
</tr>
<tr>
<td>Family Caregiver Alliance</td>
<td><a href="https://www.ResourcesForIntegratedCare.com">Family Caregiver Alliance YouTube Videos and Webinars</a></td>
</tr>
<tr>
<td>AARP</td>
<td><a href="https://www.ResourcesForIntegratedCare.com">Home Alone Alliance Medical Tasks Videos for Caregivers</a></td>
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<tr>
<td>Center to Advance Palliative Care</td>
<td><a href="https://www.ResourcesForIntegratedCare.com">Palliative Care COVID-19 Resources</a></td>
</tr>
<tr>
<td>UCLA Health</td>
<td><a href="https://www.ResourcesForIntegratedCare.com">Coping Skills for Caregivers of Persons with Dementia</a></td>
</tr>
<tr>
<td>Collaborative Action Team training for Community Health — Older Adult Network (CATCH-ON)</td>
<td><a href="https://www.ResourcesForIntegratedCare.com">CATCH-ON: A HRSA Geriatric Workforce Enhancement Program: Caregiver Section</a></td>
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Caregiver Mental and Emotional Health

Erin E. Emery-Tiburcio, PhD, ABPP
Associate Professor of Geriatric and Rehabilitation Psychology and Geriatric Medicine
Co-Director of the Center for Excellence in Aging
Rush University Medical Center
Caregivers Confront Complexity and Differing Circumstances

The context of caregiving differs for each family; care recipients have a range of needs and each family has different social, economic, and psychological factors.

Social Stressors

- Anxiety
- Medical Illness
- Depression
- Cognitive Impairment
- Economic Insecurity

Social Stressors
Sources of Caregiver Stress

- Lack of control and predictability
  - Disease progression, unusual and unpredictable behaviors (e.g., severe mood swings, wandering, paranoia)

- Loss of sources of support
  - Social support
  - Economic insecurity

- Perception of things getting worse
  - As disease and aging progresses, new symptoms emerge

- Feelings of not having what it takes to meet the next obstacle
  - Helplessness
Sources of Caregiver Stress: During the COVID-19 Pandemic

- Lack of control and predictability
  - Virus spread, community closed – when will life get back to normal?
- Loss of sources of support
  - Social isolation due to physical distancing & shelter-in-place
- Perception of things getting worse
  - Virus spread, economy – will we ever recover?
- Feelings of not having what it takes to meet the next obstacle
  - Helplessness, fears about what happens if the caregiver gets sick and is no longer able to provide care
Social Isolation in Caregivers

- Caregiving duties allow for less personal space and social interaction\(^{10}\)
  - Often sharing a home
  - Work and community roles decrease
  - COVID-19 shelter-in-place compounds these issues

- Loneliness among caregivers is associated with powerlessness, helplessness, and a sense of sole responsibility; it also predicts depression in caregivers\(^ {11,12}\)
Experiencing Loss as a Caregiver

- Caregivers’ lives change when they become caregivers
  - For some, this is a welcome role change
  - Some may experience grief, as they give up aspects of their lives to become caregivers (e.g., jobs, hobbies, financial security)

- During the COVID-19 pandemic, more individuals are taking on caregiver roles, and people already in caregiving roles may be taking on additional responsibilities
  - This may bring up additional feelings, including grief
  - Some may lose the person they are caring for to COVID-19
Assessing Caregiver Mental Health

- Assessment tools: critical to screen caregivers
  - Anxiety: What if?
    - Worry, chest tightness, shortness of breath, cold hands and feet
    - Generalized Anxiety Disorder Screening (GAD-7) free online
  - Depression: Would’ve, Could’ve, Should’ve
    - Sad/flat mood, loss of interest, appetite change, excess guilt, low energy, poor concentration
    - Patient Health Questionnaire (PHQ-9) free online
  - Grief: Ask about losses the caregiver has experienced since COVID-19 began
    - Social connection, job, death
Interventions for Caregiver Mental Health

- Routine
  - Physical activity
  - Healthy food
  - Sleep
  - Limit alcohol

- Connection to others
  - Friends and family via video chat
  - Support groups

- Skill building: Family Caregiver Alliance

- Referral for psychotherapy
  - Many telehealth options during COVID-19
Example Resource for Caregivers: FACE COVID

- F = Focus on what is in your control
- A = Acknowledge your thoughts and feelings
- C = Come back into your body
- E = Engage in what you are doing

For people who want to learn more, watch this 5 minute video

- C = Committed action
- O = Opening up
- V = Values
- I = Identify resources
- D = Disinfect and distance
Caregiver Assessment and Resources for Caregivers

Bryan Godfrey, MA, MSW, LCSW
Care Management Social Worker
UNC Geriatrics Specialty Clinic
Case Study: Relearning the World

Care Recipient: Mrs. B, age 72
- Lives with husband Bob
- Daughter, Patricia, 20 minutes away
- Generally healthy and active
- Used to attend day program (now closed)
- Bored and depressed at home
- Increasing conflict with husband

Caregiver: daughter Patricia, age 53
- Single mother of two children, ages 14 and 19
- Works as Certified Nursing Assistant (CNA)
- Wants to help but worried about intervening and risk of COVID-19 exposure
- Increasing stress, trouble sleeping
Assessing Family and Caregiver Needs

**Care Recipient: Mrs. B.**
- Something to do during the day
- Time away from her husband
- Mental health support
- COVID-19 education?

**Caregiver: Patricia**
- Reduced stress, improved sleep
- Ongoing caregiver support
- Mental health support
- COVID-19 education?

**Mrs. B.’s husband, Bob**
- Time away from wife
- Healthcare
- Mental health support
- Something to do during the day?
- COVID-19 education?

**Patricia’s Kids**
- Childcare support
- Activities to do during the day
- Mental health support
- COVID-19 education?
Addressing Caregiver Needs

- **Priorities**
  - What issues must be addressed now?
  - What issues can wait, or not be addressed at all?
  - What might change? When should problems/decisions be revisited?

- **Resources**
  - What resources are present? Financial, social, community, etc.
  - What strengths does each person possess?
  - What has worked in the past?

- **Values, Motivation, and Goals**
  - **What does each person want?**
    - What are parties interested in or willing to try?
    - What is required by your agency or the law?
Addressing Family/Caregiver Needs

Care Recipient: Mrs. B.
- Find day activity
- Time away from her husband
- Mental health support
- Care for her husband?

Caregiver: Patricia
- Lower stress, improve sleep
- Caregiver support
- Mental health support
- COVID-19 education?

Mrs. B.’s husband, Bob
- Time away from wife
- Healthcare
- Mental health support
- Day activity?

Patricia’s Kids
- Childcare support
- Activities to do during the day
- Mental health support?
- COVID-19 education?
# Learning About Local Resources

## Contact...
- Local Senior Center
- Department on Aging
- Department of Social Services
- Veteran’s support organization (va.gov or nvf.org)
- Disease-specific support organization
  - Alzheimer’s Association (alz.org)
  - Parkinson’s (parkinson.org)
  - Cancer (cancer.org)
- Health plan (if relevant)
- Work supports / EAP
- Local 211 and 311 Helplines

## And ask about...
- Aging-in-place supports
- In-home services (companion, aide, etc.)
- Caregiver education and respite (support groups, home care, virtual options)
- Meals and socialization (Meals on Wheels, phone support lines, etc.)
- Exercise/fitness programs (virtual options)
- Mental Health supports (virtual options)
- Home medical care and telehealth options
- Supports for finances, childcare, etc.
Resources for Use during COVID-19

- **Free Physical Activity Resources:** NIA Go4Life, Home Strong Arthritis Foundation Exercises, YMCA Exercise Classes, Planet Fitness Facebook page, Core Power Yoga website, Nike Training Club (mobile app), Walk at Home (YouTube)

- **Mental Health:** Coordinate with the caregiver or care recipient’s health plan, search online, or call NAMI (800-950-6264) to identify psychotherapy or psychiatry options
  - Cognitive behavioral therapy (CBT) is available from sites such as This Way Up and Free CBT-I
  - Try free mindfulness mobile apps such as Headspace, Calm, or Simple Habit

- **Hotlines:** Disaster Distress Helpline 1-800-985-5990; National Domestic Violence Hotline 1-800-799-7233
Panel Discussion

Erin E. Emery-Tiburcio, PhD, ABPP
Associate Professor of Geriatric and Rehabilitation Psychology and Geriatric Medicine and Co-Director of the Center for Excellence in Aging Rush University Medical Center

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UNC Geriatrics Specialty Clinic
How can providers support individuals who are new to the caregiving role or taking on new responsibilities?
What recommendations might you have for providers to support caregivers who may be feeling isolated?
How can supervisors and managers help staff who are supporting caregivers during times of stress and isolation?
Daniela has been caring for her father, Mr. Ramirez, a 75-year-old who has dementia, in their home with added support from an adult day program, which is now closed. Daniela is still employed, working from home, but now has responsibility for daily caregiving tasks along with paid work.

How can you help Daniela, and caregivers in general, cope with the stress of additional responsibilities?

Are there specific recommendations for caregivers of individuals with dementia with behavior challenges?
Mrs. Young has multiple chronic conditions and recently had a fall. She currently lives at home and receives support from a part-time home care aide and her sister, Miri. Miri recently moved in with her sister to help care for her. Mrs. Young now needs a new care plan to address her changing needs.

How would you approach developing a care plan for Mrs. Young, which also addresses Miri’s needs? And how would this differ from in-person approaches?

What are the additional considerations for virtual approaches to supporting caregivers?
Questions and Answers

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Additional Resources

- You can download our resource guide for caregivers related to stress and isolation here:
  https://www.resourcesforintegratedcare.com/Older_Adults/Resource_Guide/Supporting_Family_Caregivers_Stress_and_Isolation

- For resources for providers, health care leaders, and caregivers on emotional support, coping, and managing stress during COVID-19:
  https://www.resourcesforintegratedcare.com/COVID-19/Emotional_Support_Coping_Stress_Resources_for_Providers_Health_Care_Leaders_Caregivers
Thank You for Attending!

- The video replay and slide presentation will be available at: https://www.resourcesforintegratedcare.com
- Questions? Please email RIC@lewin.com
- Follow us on Twitter at @Integrate_Care to learn about upcoming webinars and new products!
Webinar Evaluation Form

- Your feedback is very important! Please take a moment to complete a brief evaluation on the quality of the webinar. The survey will automatically appear on the screen approximately a minute after the conclusion of the presentation.

- We would also like to invite you to provide feedback on other RIC products as well as suggestions to inform the development of potential new resources: https://www.research.net/r/MVGNWVJ
Resources

- AARP Family Caregiving How-To Video Series (medical/nursing tasks)
- COVID-19 – Tips for Dementia Caregivers
- FACE COVID – How To Respond Effectively To The Coronavirus Crisis video
- Generalized Anxiety Disorder (GAD-7) Screening
- Patient Health Questionnaire (PHQ-9)
- SAMHSA – Tips for Social Distancing, Quarantine, and Isolation During an Infectious Disease Outbreak
- Taking Care of YOU – Self-Care for Family Caregivers
Sources


Sources


