



WEBINAR SERIES

Caregiver Burnout

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Disclosures

- Tiffany Channing, PsyD – Nothing to disclose
- Megan Samples, MS - Nothing to disclose

Following this session:



- Participants will be able to define what the general components of burnout are
- Participants will be able to define specifically what caregiver burnout is
- Participants will be able to understand what risk factors may make one more likely to experience caregiver burnout
- Participants will be able to identify why caregiver burden is important to assess
- Participants will be able to identify what instruments are used to measure burnout
- Participants will be able to elicit conversation regarding burnout and make appropriate recommendations

What is burnout?

- ▶ According to Maslach and Jackson (1981)
 - Emotional exhaustion
 - Depersonalization
 - Reduced sense of accomplishment
- ▶ ICD-11
 - “Burn-out is a syndrome conceptualized as resulting from chronic workplace stress that has not been successfully managed”
 - Feelings of energy depletion or exhaustion
 - Increased mental distance from one’s job, negativism, cynicism
 - Reduced professional efficiency

What is caregiver burnout?

- ▶ Cleveland Clinic (2019)
 - A state of physical, emotional, and mental exhaustion
 - Changes in attitude toward their role
- ▶ Llanque et al. (2015)
 - The “unequal exchange” of assistance among individuals who are in close relationship to another, resulting in perceived tension and fatigue on the caregiver
- ▶ Turner et al. (2012)
 - “Caregiver Burden” is the strain or change in mental/physical status for a person who cares for an elderly, chronically ill, or disabled family member or other person.

Why does caregiver burnout occur?

- ▶ Pearlman et al (1990)
 - A process comprising a number of interrelated conditions (e.g. socioeconomic characteristics, resources of caregivers, primary and secondary stressors)
- ▶ Different risk factors for different types of diseases and disease progression
- ▶ Unrealistic expectations, lack of control, unreasonable demands, role confusion
- ▶ Perceived stress resulting from caregiving
- ▶ Is it an occupation?

Risk factors related to caregiver burnout

► Wellbeing of the caregiver

- Advancing age of individual
- High levels of anxiety or depression
- Greater level of patient dependency
- Lack of family support
- Changes in life plans

(Baharudin et al, 2019; Hvaldsten et al., 2019; Kim et al., 2011; McCullagh et al., 2005; Tooth et al., 2005; Truzzi et al., 2012)



Risk Factors for caregiver burnout

➤ Characters of the individual

- Level of disability
- Type of presentation (behavioral and psychiatric symptoms)
- Burden at baseline
- Age
- Gender

Baharudin et al, 2019; Hvdsten et al., 2019; Kim et al., 2011; McCullagh et al., 2005; Tooth et al., 2005; Truzzi et al., 2012

What does caregiver burnout “look like”?

▶ Physical

- Changes in appetite or weight
- Changes in sleep patterns
- Getting sick more frequently
- More Frequent prescription medication use and need for healthcare services

▶ Emotional

- Feeling depressed, anxious, or irritable
- Withdrawal from friends, family, and other loved ones
- Loss of interest in activities previously enjoyed
- Feelings of wanting to hurt yourself or the person for whom you are caring

▶ Psychosocial

- Reduced quality of life
- Decreased family functioning
- Relationship breakdown

Is it Stress or is it Burnout?

Stress

- ▶ Anxiety, depression, irritability
- ▶ Feeling tired and run down
- ▶ Difficulty sleeping
- ▶ Overreacting to minor nuisances
- ▶ New or worsening health problems
- ▶ Trouble concentrating
- ▶ Feeling increasingly resentful
- ▶ Drinking, smoking, or eating more
- ▶ Neglecting responsibilities
- ▶ Cutting back on leisure activities

Burnout

- ▶ Less energy than before
- ▶ It seems like the individual caught every cold or bout of flu that's going around
- ▶ Constantly feeling exhausted, even after sleeping or taking a break
- ▶ Neglecting own needs, either because they are too busy or don't care anymore
- ▶ Life revolves around caregiving, but it gives little satisfaction
- ▶ Trouble relaxing, even when help is available
- ▶ Feeling increasingly impatient and irritable with the person being cared for
- ▶ Feeling helpless and hopeless

▶ Caregiver Stress and Burnout



Stages of Caregiver Burnout

Stage One - Frustration

“The primary caregiver expresses continuing frustration and disappointment over the care recipient’s deteriorating condition or lack of progress. The primary caregiver has difficulty accepting that the quality of care and effort has nothing to do with the actual health-related decline or mood of the care recipient.”

Stage Two - Isolation

“The primary caregiver struggles to maintain a sense of purpose in working so hard to provide care. He or she may express feelings of loneliness, being unappreciated, second-guessed or criticized by other family members and the care recipient. Reality of the care recipient’s condition and the limitations of caregiving are not accepted. The primary caregiver is reluctant, unable or unwilling to reach out for help from others.”

Stage Three - Despair

“The primary caregiver feels helpless and adrift. The primary caregiver is unable to concentrate and loses effectiveness as a caregiver. He or she is no longer excited about the progress or response of the care recipient to quality care. As a consequence, the primary caregiver neglects personal care and well-being, loses interest in the community, social contact and respite activities, such as reading books, watching movies or other stimulating activities.”

Adapted with permission from Preventing Caregiver Burnout by James R. Sherman, Ph.D., Pathway Book, 1994, pp. 8 - 10.



Why is caregiver burden important to assess?

- ▶ Quality of life & health for the caregiver
- ▶ The impact on the quality of care given to your patient
- ▶ Bidirectional relationship between the caregiver and the caregivee
 - Caregiver stress impacts the anxiety and depression in cancer patients (Bhattacharjee & Banerjee, 2018)
 - High expressed emotion found to be a predictor of rehospitalization (Wang et al., 2017)
- ▶ Perceived social support as a protective factor

Ways to Measure Caregiver Burnout

Zarit Burden Interview

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

Question	Score
13 Do you feel uncomfortable about having friends over because of your relative?	0 1 2 3 4
14 Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0 1 2 3 4
15 Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0 1 2 3 4
16 Do you feel that you will be unable to take care of your relative much longer?	0 1 2 3 4
17 Do you feel you have lost control of your life since your relative's illness?	0 1 2 3 4
18 Do you wish you could leave the care of your relative to someone else?	0 1 2 3 4
19 Do you feel uncertain about what to do about your relative?	0 1 2 3 4
20 Do you feel you should be doing more for your relative?	0 1 2 3 4
21 Do you feel you could do a better job in caring for your relative?	0 1 2 3 4
22 Overall, how burdened do you feel in caring for your relative?	0 1 2 3 4

Interpretation of Score:

- 0 - 21 little or no burden
- 21 - 40 mild to moderate burden
- 41 - 60 moderate to severe burden
- 61 - 88 severe burden



Ways to Measure Caregiver Burnout

Caregiver Self Assessment Questionnaire

Caregiver Self-Assessment Questionnaire

How are YOU?

Caregivers are often so concerned with caring for the relative's needs that they lose sight of their own well being. Please take just a moment to answer the following questions. Once you have answered the questions, turn the page to do a self evaluation.

During the past week or so, I have ...

- | | |
|--|---|
| 1. Had trouble keeping my mind on what I was doing ... <input type="checkbox"/> Yes <input type="checkbox"/> No | 13. Had back pain ... <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 2. Felt that I couldn't leave my relative alone ... <input type="checkbox"/> Yes <input type="checkbox"/> No | 14. Felt ill (headaches, stomach problems or common cold) ... <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 3. Had difficulty making decisions ... <input type="checkbox"/> Yes <input type="checkbox"/> No | 15. Been satisfied with the support my family has given me ... <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 4. Felt completely overwhelmed ... <input type="checkbox"/> Yes <input type="checkbox"/> No | 16. Found my relative's living situation to be inconvenient or a barrier to care ... <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 5. Felt useful and needed ... <input type="checkbox"/> Yes <input type="checkbox"/> No | 17. On a scale of 1 to 10, with 1 being "not stressful" to 10 being "not overly stressful," please rate your current level of stress. _____ |
| 6. Felt lonely ... <input type="checkbox"/> Yes <input type="checkbox"/> No | 18. On a scale of 1 to 10, with 1 being "very healthy" to 10 being "very ill," please rate your current health compared to what it was this time last year. _____ |
| 7. Been upset that my relative has changed so much from his/her former self ... <input type="checkbox"/> Yes <input type="checkbox"/> No | |
| 8. Felt a loss of privacy and/or personal time ... <input type="checkbox"/> Yes <input type="checkbox"/> No | |
| 9. Been angry or irritable ... <input type="checkbox"/> Yes <input type="checkbox"/> No | |
| 10. Had sleep disturbed because of caring for my relative ... <input type="checkbox"/> Yes <input type="checkbox"/> No | |
| 11. Had a crying spell(s) ... <input type="checkbox"/> Yes <input type="checkbox"/> No | |
| 12. Felt strained between work and family responsibilities ... <input type="checkbox"/> Yes <input type="checkbox"/> No | |

Comments:

(Please feel free to comment or provide feedback.)

Self-Evaluation

To determine the score:

- Reverse score questions 3 and 15. For example, a "No" response should be counted as a "Yes" and a "Yes" response should be counted as a "No."
- Total the number of "yes" responses.

To interpret the score:

Chances are that you are experiencing a high degree of distress if any of the below is true:

- if you answered "Yes" to either or both questions 4 and 11
- if your total "Yes" scores = 10 or more
- if your score on question 17 is 6 or higher
- if your score on question 18 is 6 or higher

Next Steps

- Consider seeing a doctor for a check-up for yourself
- Consider having some relief from caregiving (Discuss with your healthcare provider or a social worker the resources available in your community.)
- Consider joining a support group.

Valuable resources for caregivers

HealthAging.org
 (800) 343-8116 | www.healthaging.org

Caregiver Action Network
 (302) 454-0970 | www.caregiveraction.org

Bilcare Locator
 (a national directory of community services)
 (800) 477-1116 | www.bilcare.com

Family Caregiver Alliance
 (800) 443-8108 | www.caregiver.org

Medicare Helpline
 (800) 633-4227 | www.medicare.gov

National Alliance for Caregiving
 (202) 719-8444 | www.caregivers.org

Local resources and contacts:



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How to start the conversation and provide care to the caregiver

- If there are no noticeable symptoms:
 - “It looks like you are doing a great job caregiving for ____, I wanted to check in and see how you were doing as caregiving is a job in and of itself.”
- If there are noticeable symptoms:
 - “I noticed that you have been ___ (e.g. sick a lot lately, feeling down, etc.), I am wondering how you have been coping with being Mr. X’s primary caregiver?”
- Administer measure of burnout which can elicit further conversation
- Provide psychoeducation and validation on caregiver burnout
- Provide recommendations

Caregiver Support and Recommendations

- ▶ [Caregiver Stress and Burnout](#)
- ▶ [Caregiver Resources, Articles & Videos](#)
- ▶ [Family Care Navigator](#) – Including eldercare services. (Family Caregiver Alliance)
- ▶ [Resources for Caregivers](#) – Support for caregivers of adults, children, individuals with disabilities and mental disorders, veterans, and more. (American Psychological Association)
- ▶ [Elder Care Services Search](#) – Services for older adults and their carers. (The U.S. Department of Aging)
- ▶ [Respite Locator](#) – Services in both the U.S. and Canada. (Arch National Respite Network)



Case Example

Mrs. X is a 68 year old woman who has presented to your office with her husband, who is your patient. Mrs. X's husband was diagnosed with Frontotemporal Dementia (FTD) approximately one year ago and has been in your care during this time. You notice that since Mr. X's last office visit, Mrs. X has lost a significant amount of weight and has indicated that she has been physically ill more recently. When you ask how she has been doing, she states "Oh you know, things are busy right now but I'm keeping it together. We just have to keep it moving."

Do you think that Mrs. X is at risk for caregiver burnout? Why?

When considering your occupational role, how would you best approach this situation and speak with Mrs. X about your concerns? What tools would you use during this conversation and would be most appropriate within this case?



Take Home Messages



- Caregiver burnout is an important factor to assess with the patients and clients that you work with
- Caregiver burnout may present as a variety of symptoms and may not be evident on the surface
- Caregiver burnout may be assessed informally or formally through measures
- If you notice that caregiver burnout is occurring, do not hesitate to start the conversation and provide appropriate recommendations and support



Questions?



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