Family Caregiver Fatigue

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Rosalynn Carter
“There are only four kinds of people in the world:
• Those who have been caregivers,
• Those who are currently caregivers,
• Those who will be caregivers,
• And those who will need caregivers”

The Science of Caregiving
Yes it is a science
Hope

- “To help a person find hope you need to know them in real depth, within his past are the clues to where they can find hope”

- “Hope is constructed not just from rational deliberation, it arises as a mixture of thought and feeling.”

Fatigue

- Definitions lacking in the literature. Related concepts include:
  - Caregiver burden
  - Caregiver stress
  - Caregiver strain
  - CG burnout
  - CG role overload
  - Compassion fatigue

What do we know?

- Fatigue occurs when the role demand exceeds the Caregiver resources—especially if the Caregiver needs to work full time.

What do we know

- Average duration of caregiving role is 4 years; more for Alzheimer’s

- Fatigue occurs when the role demand exceeds the Caregiver resources—especially if the Caregiver needs to work full time.
Causes of Fatigue
- Role Strain
- Unreasonable demands
- Unrealistic expectations
- Lack of control

Symptoms of Fatigue
- Anxiety
- Depression
- Sleep disturbances
- Lack of motivation
- Resentment

What else do we know?
- Intensity and duration of caregiving experience are predictors of negative health effects
- CGs have higher incidence of chronic disease
- 30-40% moderate to severely clinically depressed and or anxious
- Closer death comes the more socially isolated
- If it were a disease Caregiving could be a diagnosis

Experience of Caregiving
42 Month Journey
Interactional Suffering

- Lack of Attention (Timely, Full attention)
- Lack of understanding (Thoughts and feelings)
- Lack of Communication (Empathy, hope)
- Lack of Competence (Pall Care; collaboration)
- Issues of Limitation (Med Science, technology)

How to ease interactional suffering

**Listen:** Hear the feelings - validate them “I know this is very scary and may feel very hopeless”

**Provide a sense of control** “While we are waiting to get things going here are some things you can talk about, think about, and some ways you can prepare yourself for the journey”

**Engage the caregiver as a partner** “Together, we can make sure your wife is safe and comfortable.”

**Reassure the caregiver** “I’m sure you know your mother better than anyone, I’m confident you will take excellent care of her”

What to do

- **Engage Caregivers** “This journey is going to be a long and challenging one. David is going to need you by his side. We want you to be our eyes and ears in your home - we need to hear from you as well as him how things are going - because sometimes patients can not remember?”

- **Provide reassurance:** “This is going to be difficult for you as well - please know we are here to assist you also. We realize that his care will depend on how well you can help him. Please feel free to not only talk about him, but also yourself, we need to know how you are doing.”

Facilitating collaborative and effective family involvement (TRIO Guidelines 1)

1. Consider caregivers in inpatient and outpatient procedures and set up: Chairs, meals, eye contact
2. Welcome caregiver attendance: Invite and encourage
3. Build rapport and show respect to family caregivers
4. Engage in careful communication of information when family are involved
5. Be observant of the patient and family relationship
6. Meet family caregivers’ informational and emotional needs
References

Thank you
- Legaciesfromthelivingroom.com
- Oliverdr@health.missouri.edu