Trends in Caregiving: Where Are We Going? What Are We Doing?

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Definition – Caregiver

Wide range of unpaid care that is given to a chronically ill or impaired adult (most often older adult) family member, partner, friend or neighbor that exceeds the usual level of support.

- Direct self-care
- Instrumental Activities of Daily Living
- Recognition of paid professional caregivers
What’s Trending Now?

• Growing # of caregivers
  • Medical advances are allowing us to live longer
    • Average age and number of caregivers will continue to rise. Currently 15% of population is over 65. By 2060, it will be 25%.
    • Living longer with more chronic illnesses. But, are living longer better? Living more depending on others for basic needs.
    • Bias toward prolonging life vs. having a meaningful discussion about dying well.
  • 20 year effort of successfully lowering healthcare costs have worked to shift care responsibility from professions to families
    • More seniors providing care when they should be receiving care themselves.
    • More retirees and young adults providing care
    • More employed caregivers with increased absenteeism, unpaid leave or show up late/leave early.
    • Caregivers provide $450 billion worth of care each year. Double spent on home health and nursing home care combined.
What’s Trending Now?

• Families pulled in multiple directions
  • More two income families
    • Greater demands on the family unit due to activities for children and work-related demands.

• We are more mobile and transient
  • More families living out-of-state or farther away from the dependent adult
What’s Trending Now?

• Societal values
  • Puritan work ethic
    • We value the element of hard work, independence and upward mobility
    • We want what we want and feel entitled to do so. It’s the American Way.
  • But, family caregiving and interdependence is the antithesis of this concept
    • Caregivers feel out of step with society which breeds isolation and loneliness
    • Can we learn to become comfortable or accept the concept of interdependence?
What’s Trending Now?

- Older adults will have fewer family members available for support at home.
- Most will be unmarried or divorced and living alone who are geographically more distant from their children.
  - 60% female
  - 85% of older adults are cared for by relatives
  - 50% are cared for by children
  - 1 in 10 caregivers are caring for a spouse.
• Let’s face it…caregiving is stressful
The Many “Faces” of Caregiving

Anger
Anxiety
Irritability
Depression/Sadness
Disgust
Embarrassment
Fear
Frustration
Grief
Guilt
Impatience
Jealousy
Lack of Appreciation
Loneliness
Loss
Resentment
Tiredness
Caregiving is manageable in the short term, but the longer care is required, the more damaging is the cumulative effect.

- Severely depressed
- Less energy and creativity
- Rigid in your care routines
- Unable to see new possibilities for solving problems or soliciting help
- Feeling trapped in an unending nightmare
- End up most vulnerable to eventually giving up.
What Does This Mean?

- Long term caregiving is not only potentially depressing but consuming.
  - The longer you give your all for a loved one, the less you may seem able to make time for your own needs
- Self neglect breeds social isolation when you stop responding to friends' overtures.
- Elderly caregiving spouses who have their own chronic illnesses are 63% more likely to die than their non-caregiving peers.
Caregivers need to consider their level of commitment.

- What do you want to do?
- What are you realistically capable of doing?
- What’s emotions are you experiencing in relation to your loved one’s problem?
- Does it scare you to think that he/she is declining?
- What does this mean for him/her?
- What does it mean for you?
What Is Our Response?

• Is there such a thing as Minor Surgery?
What Is Our Response?

• We are in a Crisis
  • Definition – “A perception or experiencing of an event or situation as an intolerable difficulty that exceeds the person’s current resources and coping mechanisms.”
    • Unless the individual receives “relief, the crisis has potential to result in severe affective, behavioral and cognitive malfunctioning.”
      • Financial, medical, spiritual, cultural

• A crisis tends to expose existing dysfunctional dynamics (*personal or familial*)
# What Is Our Response?

Overwhelming and challenging to address each individual emotional state.

<table>
<thead>
<tr>
<th>Caregiver Emotion</th>
<th>Coping Skill</th>
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<tbody>
<tr>
<td>Anger</td>
<td>Forgive yourself</td>
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<tr>
<td>Anxiety</td>
<td>Pay attention</td>
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<tr>
<td>Irritability</td>
<td>Take a break</td>
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<tr>
<td>Depression/Sadness</td>
<td>Seek support</td>
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<tr>
<td>Disgust</td>
<td>Seek help</td>
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<tr>
<td>Embarrassment</td>
<td>Be creative</td>
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<tr>
<td>Fear</td>
<td>Plan and prepare</td>
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<tr>
<td>Frustration</td>
<td>Acknowledge</td>
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<td>Grief</td>
<td>Accept it</td>
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<tr>
<td>Guilt</td>
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<td>Impatient</td>
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<tr>
<td>Jealousy</td>
<td>Admit it</td>
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<td>Lack of appreciation</td>
<td>Express it</td>
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<td>Loneliness</td>
<td>Get out</td>
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<td>Loss</td>
<td>Recognize it</td>
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<td>Resentment</td>
<td>Seek help</td>
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</tbody>
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Powerlessness

• Typical characteristics
  • Other people have power over us.
  • Trapped by the demands of others.
  • Feel stuck and frustrated with no way out or control.
  • We escape thru maladaptive behaviors.
  • Be refusing to admit our powerlessness we deceive ourselves.
  • Humbling and difficult to accept
  • Life can be good. Relief is available. Hope exists.
Powerlessness

• **Step 1 of the Twelve Steps Program**
  • I admit that I am powerless over my problems and that my life has become unmanageable.

• **The Serenity Prayer** *(theologian-philosopher Reinhold Niebuhr)*
  • God, grant me the serenity *(peace, calm)* to accept the things I cannot change, the courage *(strength in the face of pain or grief)* to change the things I can, and the wisdom to know the difference.  Amen.
What Is Our Response?

• Define the problem
  • State the top one or two from caregivers perspective

• Ensure the safety of the caregiver
  • What is the level of risk to the caregiver and/or care recipient?

• Provide support
  • Communicate thru listening, attending (eye contact, sit forward) and check your own feelings and emotions.
  • Reflect and reframe observed emotions and statements
What Is Our Response?

- Ask caregiver who or what is available to provide them the support they need
  - People in past or present, formal and informal

- How have they coped in the past?

- What is it they understand about their situation?
  - Helps to look at the caregivers thinking patterns, perspective and possible need for education.
  - Reframe situation which can lessen anxiety

- Ask for possible solutions and implement a plan

- Obtain a commitment and follow-up
What Is Our Response?

• **Goals of Intervention**
  • Therapeutic approach
  • Improve caregiver knowledge
  • Combined approach maximizes benefit

• **Areas to address**
  • Overwhelmed with physical demands
  • Feeling isolated
  • No time for self
  • Difficulty with recipient’s behavior
  • Caregiver’s negative responses
• References & Bibliography
1. NICHE Geriatric Resource Module 5: Caregiving