



Promoting Positive Caregiving (in Tough Times)

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Today's Talk

- Caregiving in America
- Negative, positive effects
- Minimizing strains, maximizing gains
- Keys to caregiving
- Covid coping

















Family Caregiving in America

- 53 M Americans engage in some form of caregiving activity in a year (NAC/AARP, 2020)
- Prevalence: 21.3% (18.2% in 2015)



- 60% women/40% men
- ¼ Millennials; ¼ Gen-Xers
- Average family caregiver: A 49-year-old woman still working at least part-time and also caring for children—“sandwich generation”



Family Caregivers' Healthcare Roles (Wolff, Jacobs, 2015)

- Attendant
- Administrator
- Companion
- Driver
- Navigator
- Technical Interpreter
- Patient Ombudsman
- Coach
- Advocate
- Case Manager
- Healthcare Provider



- NAC/AARP 2020: 21% of caregivers said their health was fair or poor (17% in 2015; 12% in US pop in 2020)
- **Most stressed caregivers:**
- Spouses, military, dementia

From Wife of Alzheimer's Patient

- *"I don't think anyone can understand the intense, crushing isolation and loneliness of caregiving unless they have 'walked a mile in our shoes.' I miss the intimacy we've had for more than 50 years, and I'm not talking about physical intimacy, although I miss that, too. I miss having someone to talk to or share a chuckle or one of our little 'inside' jokes. It's all gone! I'm not ready to ditch my marriage vows and dash out and have an affair, but I long to have a companion again--even someone to just stand and hold me while I cry the tears I've had to squelch and swallow for so long."*

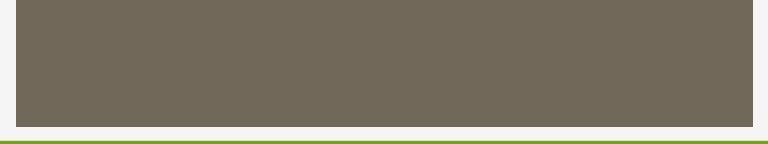
- **Schulz:** dementia caregiving associated with insomnia, depression, musculoskeletal problems, increased mortality



- **Roth:** caregiving associated with increased lifespan, enhanced sense of purpose



- *"The majority of caregivers...readily endorse caregiving gains or positive aspects of caregiving [including] having the opportunity to serve as a role model, having the chance to give back to care recipients..., experiencing an enhanced sense of purpose..., feeling appreciated, and helping to maintain the identity and well-being of the family (Coon, 2012, p. 233)*

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- *Caregiving brings “strains and gains”*
 - *How do we minimize its strains and maximize its gains to make this a more positive and caring experience?*

Keys to Caregiving

- Believe in the value of **caring for yourself**
- Accept negative and positive **feelings**
- Define **commitments** realistically
- Utilize **support**
- Selectively separate **past/present**
- Find **positive** meanings in the sacrifices that you are making

- *Believe in the value of caring for yourself*

Marathon Metaphor

Caregiving as marathon, not sprint:



- Learn the up-hills and down-hills of the course
- Maintain sustainable pace
- Take any and all replenishment
- Run alongside others

- Protected time
- Respite
- Physical exercise
- Spiritual practices
- Mindfulness/relaxation exercises



Mindfulness

- Daily reflection—journaling
- Meditation
- Present engagement; staying in the moment through caregiving tasks
- Positive self-talk
- Gaining larger perspective of limits of time → gratitude

- *Accept negative and positive feelings*

Normalizing Ambivalence

- *“Is it okay if I don’t always enjoy being a caregiver?”*
- Many caregivers have mixed feelings about their caregiving tasks
- They feel guilty about their negative feelings
- They then try to compensate for their negative feelings by working even harder

- It is normal and expectable to have negative feelings
- Hating caregiving tasks is not hating care recipient
- Give yourself permission to set limits on the caregiving tasks you hate

- *Define commitments realistically*

Defining Commitments

- *“I feel I have to do this. But what’s the right way to do it? How much should I do?”*
- Take stock of individual and family development, resources
- Choose consciously to define commitments and limitations/necessary balance

“Everyone has limits about what they are willing and able to do. What part of caregiving will be especially hard for you? What are your limits?”

- Delegating isn't shirking duties
- Accepting compromise; “good enough” caregiver



○ *Utilize support*

“Our family takes care of its own. Besides, no one can take care of her as well as I can”



- Accepting help almost feels shameful, disempowering
- Use supports not to avoid care but to empower you to give care for as long as you choose



- *“Our friends don’t come around anymore. Who can I talk to?”*

- Social isolation increases duress
- Social support increases resilience
- 3 circles of social support—
 - Immediate family
 - Extended family/neighbors/religious community
 - Professionals

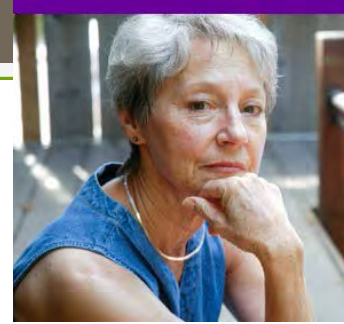
- *Find positive meanings in the sacrifices that you are making*

Finding Positive Meanings

- ***“What’s the purpose of this caregiving? Why am I making all of these sacrifices?”***
- Lack of purpose leads to greater likelihood of resentment and burnout

- *“Why do you do what you do for you loved one?”*
- *What are the values underlying your choice to give care?*

Karen



- *"Shortly after I was pregnant, I left my husband. And then after the child was born, I decided I was going to go back with him. And my parents knew it wasn't going to work. And my mother kept saying, 'You'll go back and have another baby.' And my father said to me, 'You can always come home. I don't care if you have 10 babies. You can always come home.' He left that door open for me. And I did just that. I went back and had another baby and came back with two babies. And, I'll never forget that. I always knew I could go home."*

Prospective Retrospection

- Aka pre-hindsight
- **“How do you think you will look back at this time in your life 5 years from now?”**
- “What do you think will be important to you in the future about the choices you are making now?”

- *How has the pandemic affected family caregivers?*

Isolation

- 71 y.o. woman whose husband with FTD is home with her all the time now since adult day care is closed and she decided to not use aides at this time



Decreased services
Loneliness --> shame
Increased exposure to loved ones' deficits
Increased despair



- *Lower your standards and expectations.*
- *Take regular self-care breaks, even if you must be in the same room.*
- *Find simple ways to connect.*
- *Give meditation a try.*
- *Connect with other relatives and friends.*



Coping with Distance

34 y.o. daughter whose mother has moderate dementia

Mother is in a nursing home where some residents have had Covid

Guilt that she isn't there with mother
Fear for mother's life
Growing sense of anger and helplessness





*Accept realistic limits that
you cannot change*

*Use all available
technology*

*Journal your thoughts and
feelings*

*Connections are in the
heart, if not in the room*



When is It Safe to Go Out?

46 y.o man caring for his 77 y.o father with Parkinson's disease

Unsure what to do now that stay-at-home order has been lifted

- Doesn't want to put father or himself at any risk
- But father is tired of being cooped up and other family members want to see him





- *Start with medical advice*
- *Weigh risks and benefits*
- *Use family as sounding board*
- *Reserve the right to change your mind*

Summary

- Caregiving brings strains and gains
- We meet the challenges with flexibility and determination and seek the positive and transformative



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