

Impact of Loneliness & Social Isolation on Caregiver Well-Being

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Disclosures

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Objectives

- Overview of concepts and prevalence of age-related:
 - Loneliness
 - Social isolation
- Loneliness and social isolation in family caregivers
- Intervention strategies to address loneliness and social isolation with emphasis on strategies during the COVID-19 pandemic



Age-Related Loneliness and Social Isolation: Prevalence

“No one should be alone in old age he thought,
But it is unavoidable.”

--*The Old Man and the Sea*, Ernest Hemingway

What is loneliness? Social isolation?

► Loneliness:

- Discrepancy between actual and desired social relationships (Hawkley & Cacioppo, 2010)--differs from living alone, solitude, and social isolation but are inter-related.
- Subjective feelings of a lack of satisfying human relationships (Routasalo & Pitkala, 2003)

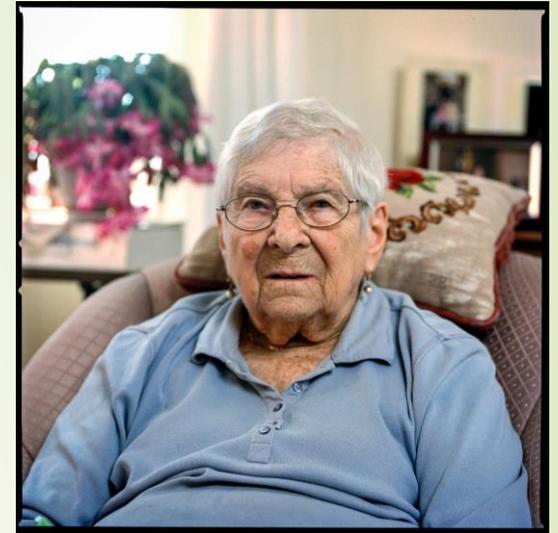
► Social Isolation:

- actual number of engagement/social contacts (Routasalo & Pitkala, 2004).

While these terms are used synonymously, but they are, in fact, different.

*While it's likely they can overlap, it is the perceived expectations that an older adult has for the **quality** of social relationships.*

Loneliness and social isolation can occur when expectations are not fulfilled.



What Do We Know About Loneliness?

First mentioned in the 1960s (Lowy, 1962), **loneliness and social isolation are:**

- **A global health epidemic** (Vivek Murthy, former US Surgeon General, 2017)
- **More prevalent than ever among all age groups**
 - (average network size decreased from 2.94 to 2.08 persons/individual (Brashears, 2006).
- **CIGNA 2018 study of 20,000 U.S. adults**
 - ~½ sometimes/always feel lonely (46%), left out (47%), or relationships are not meaningful/isolated (43%)
 - 27% rarely/never feel people understand them or feel close to people (20%), or have people to talk to (18%)
 - 53% have meaningful daily in-person interactions
 - Co-residers feel less lonely, while single parents feel more lonely
 - Gen Z (18-22 years old) and heavy social media users are the loneliest and least healthy

“Loneliness is the discrepancy between what you want from relationships and what you actually have”
(Cacioppo)

What Do We Know About Loneliness in Older Adults?

- U.S. prevalence: 17% - 57% and higher in people with mental and physical health concerns (e.g., heart disease, depression, anxiety, and dementia) (Musich et al., 2015)
- **Under-assessed**
- **Common in older adults**
 - 7% - 49% of older adults report feeling lonely (Victor et al., 2008; Holmén et al., 1994)
 - ~ 1/3 of older adults experience loneliness (Jansson et al., 2017; Savikko et al., 2005)
 - 5% are often or always lonely (Savikko et al., 2005)
 - ~1/3 of nursing home and assisted living residents report feeling lonely (Jansson et al., 2017)
- **Impact multiple areas of physical and psychological well-being**
- **Depression is linked to loneliness**

“YOU CAN FEEL LONELY EVEN SURROUNDED BY PEOPLE”

(Andersson, 1998)

What Do We Know About Social Isolation?

- ▶ **Linked to increased risk for dementia** (Crooks et al., 2008; Fratiglioni et al., 2000; Saczynski et al., 2006; Stoykova et al., 2011)
- ▶ **Socially isolated older adults more likely to experience daily stress and have a lack of social resources to use** (Boss et al., 2015) **and impaired sleep.**
- ▶ 24% of 65+-year-olds report being socially isolated, while 4% experience extreme social isolation **Risk factors for social isolation:**
 - ▶ Being unmarried and male
 - ▶ Low education
 - ▶ Low income
- ▶ **Costs ~\$7 billion/year (Medicare) due to increased hospital stays because community support at home is lacking** (AARP Public Policy Institute)

We Know Loneliness Impacts Older Adults in:

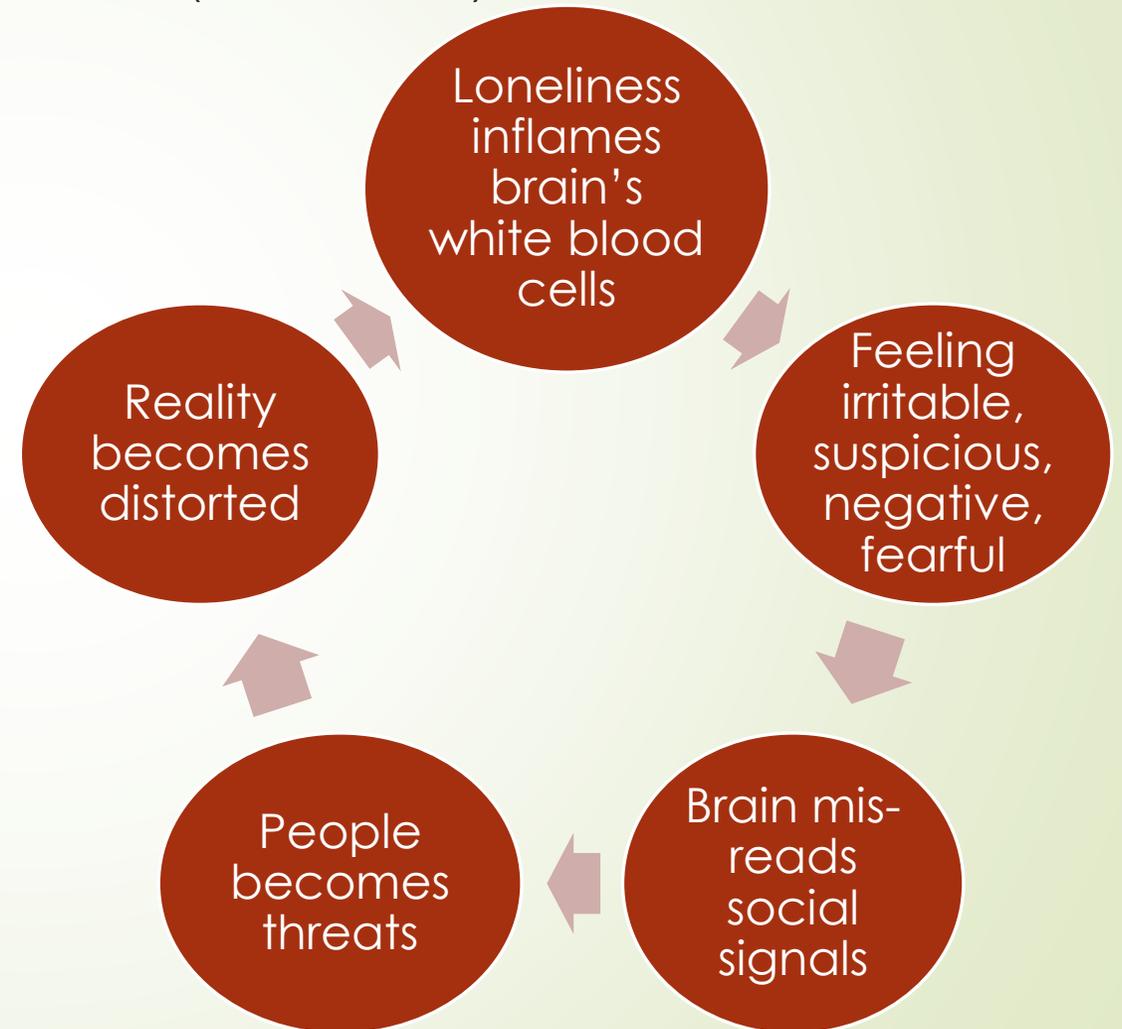
- Impaired quality of life (Jakobsson et al., 2005)
- Impaired cognition (Fragliglioni et al., 2004; Tilvis et al., 2000)
- Poor subjective health (Tighuis et al., 1999)
- Stress and depression (Courten & Knapp, 2015) and suicide
- Disability (Bisschopet et al., 2003; Ekwall et al., 2005)
- Increased use of health care services (Elaway et al., 1999; Geller et al., 1999; Russell et al., 1996; Tilvis et al., 2000)
 - 50% Emergency services, >12 PCP visits/year (Dreyer et al., 2018)
- Increased mortality (Herlitz et al., 1998; Pennix et al., 1997; Tilvis et al., 2000)
- Institutionalization (English Longitudinal Study of Ageing, 2018; Tilvis et al., 2000—10-year study)
- Long-term (> 4 years) (Tate, 2018)
 - Increased blood pressure, depression, weight gain, smoking, alcohol/drug use, and alone time
 - Decreased physical activity, cognition, heart health, and sleep, stroke and coronary heart disease, in particular (Valtorta et al., 2016)



“Is it loneliness specifically, or is it people becoming more socially disconnected?” (Holt-Lunstad)

Findings from landmark study (Holt-Lunstad et al, 2015) of 3.4 million persons over 7 years who self-reported being lonely, socially isolated, or lived alone indicate increased risk for death:

- 32% for those living alone
- 29% for those socially isolated
- 26% for those feeling lonely





What Do We Know About Caregiving?

“Loneliness and the feeling of being unwanted
is the most terrible poverty”

--Mother Theresa



Caregiver Profile

- **Female** (58%)
- **Primary/sole caregiver** (60%)
- **Related** to care-recipient (86%)
 - 55% parent/parent-in-law; 20% spouse; and 14% non-relative
- **Live nearby** (80% within one hour)
- **Married or partnered** (57%)
- **Age** (45% <45 years; 34% 45-64 years; 20.7% 65+ years)
- **Some College; middle class; and employed** (60% work 35 hrs/week)
- 1/4 provide 40+ hrs/week (average = 24 hrs/week)

Edwards et al., 2020



Caregiver Profile *continued*

- ▶ 60% help with at least one ADL
- ▶ 4.2 is the average # of IADLs
 - ▶ Transportation 78%; Shopping 76%; Housework 72%:
- ▶ Duration:
 - ▶ Average is 3.7 years
 - ▶ 24% have cared for 5+ years
- ▶ 29% have cared for 1-4 years one ADL
- ▶ 2/3 monitor care-recipient's care
- ▶ 51% advocate on behalf of older adult
- ▶ 60% provide medical/nursing care; 43% have formal training



Tasks of Caregiving

➤ Emotional

- Defining commitments
- Finding support and help
- Assessing personal sacrifice
- Accepting reality
- Fostering awareness and flexibility
- Protecting intimacy
- Sustaining the spirit

➤ Physical

- ADL/IADL help
- Administer/manage Rx
- Treatment compliance
- Behavioral symptom mgt
- Access/negotiate & monitor support services
- Liaison with health care system, families, etc.



Impact of Caregiving on Caregiver

- Negative reports often outweigh positive
 - Strain has been reported by up to 80% of caregivers
- Negative aspects of caregiving:
 - Emotional and physical health problems
 - Financial Security
 - Quality of life
 - Loss of self, powerlessness and loss of congruence or shared meaning



Impact on Caregiver Quality of Life

- 50% report lack of time for themselves
- 50% report negative impact on family (e.g., family conflicts, lack of privacy & intimacy)
- 50% report social isolation—greater for spouse caregivers

Positive Aspects of Caregiving



- ~1/2 report positive aspects of caregiving:
 - Inner Strength (70%)
 - Closer relationship with elder (50%)
 - Compassion (40%)
 - Love (30%)
 - Life Satisfaction (20%)
 - Renewed sense of family
 - Healing of broken relationships
 - Sense of reciprocity, returning what was given
 - Self-esteem due to unique gift or capacity
 - Development of new skills



Caregiver-Related Loneliness and Social Isolation

"You don't stop laughing when you grow old, you grow old when you stop laughing." - George Bernard Shaw

What Do We Know About Loneliness, Social Isolation, and Caregiving?

Caregiving-related stress leads to:



Chronic stress



Loneliness and social isolation



Neuroendocrine and neuroimmunological regulation and low-grade inflammation



Symptom cluster



Increased risk for physical and mental health illness (depression, sleep/appetite disturbance, cognition, morbidity, and mortality,

Social isolation can include loneliness and loneliness can include social isolation

Kovaleva et al., 2020



What Causes Lonely and Social Isolation for Caregivers?

- ▶ Non-caregiving activities becomes less of a priority
- ▶ There is no time for non-caregiving activities
- ▶ Scheduling becomes a challenge and it is sometimes easier just not to try to schedule time in other activities
- ▶ For dementia caregivers, they are losing the relationship they previously had with the person they are caring for
- ▶ Loneliness is linked to:
 - ▶ Being male
 - ▶ Being older
 - ▶ Living with the care-recipient
 - ▶ Caregivers who do not participate in support groups for caregivers

What Can Caregivers Do to Address Loneliness, Social Isolation and Caregiving?

- ▶ **Self-Care, Self-Care, Self-Care**

- ▶ **You cannot care for someone else if you don't take care of yourself!**

- ▶ Process caregiver experience, possible loss of self, and role engulfment

- ▶ Therapeutic writing, coping questions, support groups

- ▶ Ask yourself:

- ▶ What is the most stressful about caregiving?

- ▶ Am I lonely?

- ▶ What is contributing to my feeling lonely?

- ▶ When did I last have a physical exam? Am I fatigued, in pain, and/or having trouble sleeping?



ALONE Scale—new tool for assessment of loneliness

To assess an individual's perception of being lonely, ask each of the items below using the following rating scale:

Yes Sometimes No

- A** Are you **Attractive** to others as a friend? Yes _____ Sometimes _____ No _____
- L** Are you **Lonely**? Yes _____ Sometimes _____ No _____
- O** Are you **Outgoing/friendly**? Yes _____ Sometimes _____ No _____
- N** Do you feel you have **No friends**? Yes _____ Sometimes _____ No _____
- E** Are you **Emotionally upset** (sad)? Yes _____ Sometimes _____ No _____

Caregiver Well-being Scale: Basic Needs

1. Rarely 2. Occasionally 3. Sometimes 4. Frequently 5. Usually

1. Eating a well-balanced diet	1	2	3	4	5
2. Getting enough sleep	1	2	3	4	5
3. Receiving appropriate health care	1	2	3	4	5
4. Having adequate shelter	1	2	3	4	5
5. Feeling good about yourself	1	2	3	4	5
6. Feeling secure about your financial future	1	2	3	4	5

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Caregiver Well-being Scale: Activities of Daily Living

	1. Rarely	2. Occasionally	3. Sometimes	4. Frequently	5. Usually		
1. Buying food			1	2	3	4	5
2. Taking care of personal daily activities (meals, hygiene, laundry)			1	2	3	4	5
3. Attending to medical needs			1	2	3	4	5
4. Keeping up with home maintenance activities (lawn, cleaning, house repairs)			1	2	3	4	5
5. Participating in events at church and/or in the community			1	2	3	4	5
6. Taking time to have fun with friends and/or family			1	2	3	4	5
7. Treating or reward yourself			1	2	3	4	5
8. Making plans for your financial future			1	2	3	4	5

What Should Providers Be Doing?

- Adequately treat health issues that limit independent (e.g., chronic pain, sensory impairment, incontinence, foot health, malnutrition, and oral health)
- Identify depression and cognition
- Integrate such strategies as:
 - Comprehensive geriatric assessment which can increase by 25% the likelihood that older adult will still be living at home six months after assessment)
 - Regularly monitoring patient's needs
 - Promote clear and open communication with older adult and caregiver
 - Recognize and incorporate caregiver into the treatment process
 - Engage in “social prescribing” (i.e., making appropriate community referrals)

During the COVID-19 Pandemic, older adults can:

➤ STAY CONNECTED!

- Email, phone, videoconferencing, social media—if needed, learn the basics of technology. No need to be tech-savvy!
- Maintain daily routine as much as possible
 - Eat healthy, exercise, keep regular and adequate sleep
- Pay attention to needs and feelings
- Develop a plan for illness (including advance directives) and know resources
- Stay active
 - Engage in activities that are relaxing
 - Volunteer for organizations (faith, political, non-profit) to do calling
- Reach out to others
 - Develop a “buddy system” to check in with isolated friends, family, church members, etc.
- Go on a “news diet”
 - Limit access (e.g., check in the morning and evening for no more than 30-60 minutes)
 - There is so much information and so many resources available that it can be overwhelming—pace yourself!



During the COVID-19 Pandemic, caregivers can:

- **Take care of yourself!**
- Stay in touch with primary care providers, particularly if behavioral changes are noted—change can prompt increased impairment
- Provide extra reminders about preventive strategies (e.g., washing hands)
- Prepare for closures, changes, and illness
- Stay connected with family/friends and other caregivers
 - Email, phoning, social media, and videoconferencing
- Know resources in the community and on-line
 - Organizations that will shop/run errands (e.g., Nextdoor, Instacart)
 - MemoryCafe is going virtual (memorycafe.com)
- Pay attention to their own needs and feelings and engage in self-care

Sources: Alzheimer's Association; UK Campaign to End Loneliness, AARP



Take Home Messages

- Social isolation and loneliness were significant issues in our society before the pandemic but are particularly a concern now for people as they age.
- Caregivers can be lonely and socially isolated.
- We can know the signs of loneliness and social isolation and take action.

Thank You!



For more information:

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