Social Isolation and Loneliness Among Caregivers During the COVID-19 Pandemic

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Who We Are



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Research Questions

- 1. How do family caregivers compare with non-caregivers on indicators of social isolation, loneliness, and social participation during the early phase of the COVID-19 pandemic (April / May, 2020)
- 2. Among family caregivers, what sociodemographic and caregiving context sub-groups are at highest risk for social isolation, loneliness, and lack of social participation?

References

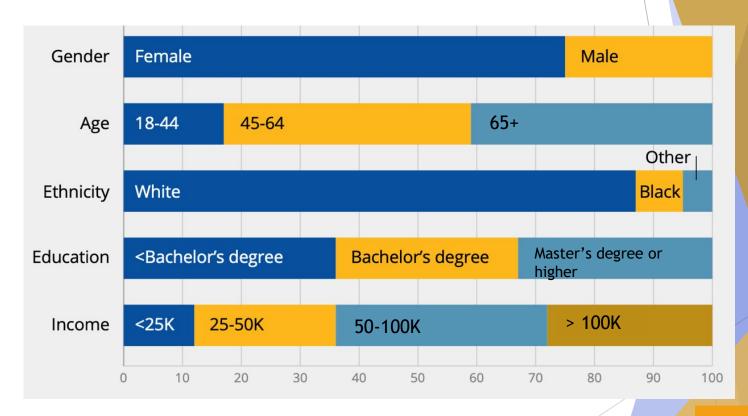
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Survey design & Participants

- Cross sectional community survey
- April 15 May 27, 2020
- Responses were received from
 - 619 family caregivers
 - 2,933 non-caregivers
- Assessment of COVID-19 impacts on employment, financial well-being, social interactions, health behaviors, and physical and mental health.





Social Isolation / Loneliness Measures

- Current
- How often do you feel lonely? [often / always / sometimes / occasionally / hardly ever / never]
- 2. How often do you feel that you are 'in tune' with the people around you? [never / rarely / sometimes / often]
- 3. How often do you feel that no one really knows you well? [never / rarely / sometimes / often]
- 4. How often do you feel you can find companionship when you want it? [never / rarely / sometimes / often]
- 5. How often do you feel that people are around you but not with you?
 [never / rarely / sometimes / often]
- Scoring: Simple count (0 5) of high risk (red) codes.
 [Collapsed to 0 / 1 / 2+ for analysis]



Social Isolation / Loneliness Measures cont.

► <u>COVID-19 Impact</u> (single item)

Compared to before the start of the coronavirus outbreak, would you say that feelings of social isolation or loneliness right now have:

[increased greatly / increased somewhat / stayed about the same / decreased somewhat / decreased greatly]

Scoring: As coded



Ability to Participate in Social Roles and Activities

- ► PROMI-29 4-item short form
- 1. I have trouble doing all of my regular leisure activities with others.
- 2. I have trouble doing all of the family activities that I want to do.
- 3. I have trouble doing all of my usual work (include work at home).
- 4. I have trouble doing all of the activities with friends that I want to do.

(Never / Rarely / Sometimes / Usually / Always)

<u>Scoring</u>: PROMIS algorithm. Higher scores mean greater ability to participate.

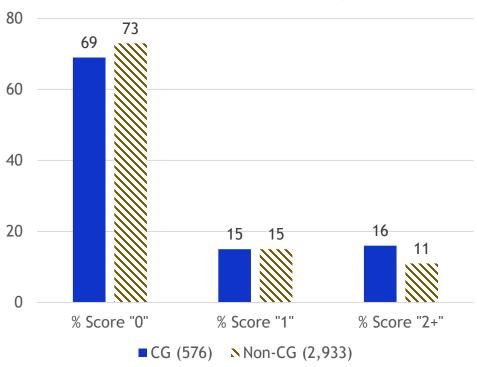
(National norm = 50)



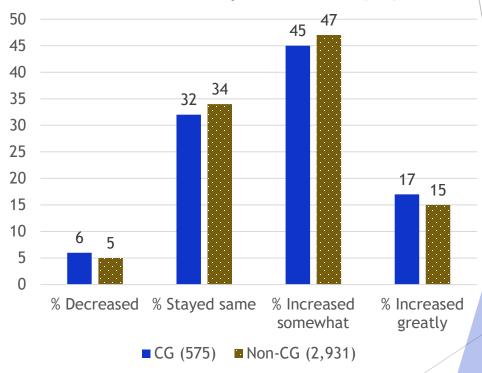
Family Caregivers vs. Non-caregivers

Family Caregivers vs. Non-caregivers: Social Isolation / Loneliness (SIL)





COVID-19 impact on SIL (ns)





Family Caregivers vs. Non-caregivers: Ability to Participate in Social Roles and Activities

PROMIS SCORE (Higher score, greater participation)	CG (576)	Non-CG (2,933)	National Norm (General Population)
Mean	46.1	47.3	50.0
(sd)	(9.3)	(9.5)	(10.0)

CG vs. Non-CG; *p* < .01



Family Caregivers at High Risk for Social Isolation / Loneliness / Lower Social Participation

Caregiver Sub-groups at higher risk for Social Isolation Loneliness / Lower Social Participation

Current Social Isolation / Loneliness (Index)	COVID-19 Impact on SIL	Lower Social Participation
 Younger CGs Lower income CGs CGs helping care recipient (CR) with medical / nursing tasks Adult child CGs of a parent CG assisting CR with Cognitive problems / Alzheimer's Disease CG assisting CR with emotional / behavioral / developmental disorder 	 Lower income CGs Female CGs CG lives with CR 	 Female CGs CGs helping CR with both personal care and medical / nursing tasks CG assisting CR with Cognitive problems / Alzheimer's Disease
Higher scores on COVID Caregiver Risk Index (CCRI)	Higher scores on COVID Caregiver Risk Index (CCRI)	Higher scores on COVID Caregiver Risk Index (CCRI)



COVID-19 Impacts on Caregiving: (COVID Caregiver Risk Index)

Has the coronavirus crisis had any of the following impacts on you and your care recipient	% CGs endorsing
Increased your caregiving efforts or duties	63%
Made providing care more emotionally difficult for you	56%
Led to increased worry, fear, depression, sleep problems, or other declines in CR's mental health	43%
Made it harder to get basics like food, household and medical supplies	41%
Interfered with doctors' appointments or treatment for CR	37%
Required changes in who is providing care	23%
Made providing care more physically difficult for you	22%
Interfered with your own health care	21%
Made providing care more financially difficult for you	20%
Led to family disagreements or conflict over caring for CR	17%
Made it harder to get prescription medications for CR	12%
Led to declines in CR's physical health (other than getting coronavirus)	10%
[Note: CCRI is simple sum (0 - 12) of items endorsed]	



Summary of Major Findings from Quantitative Analyses

- ► Family caregivers had slightly higher current (early in pandemic) social isolation / loneliness scores; and lower social participation scores than non-caregivers.
- ► There was no difference between caregivers and non-caregivers on the perceived impact of COVID-19 on social isolation / loneliness
- ► The following sub-groups of family caregivers were at highest risk for social isolation / loneliness / lower social participation:
 - Female CGs
 - Lower income CGs
 - CGs Helping CR with medical / nursing tasks
 - CGs assisting CR with cognitive problems / AD
 - CGs reporting greater overall impacts of coronavirus on CG and CR



"Isolated and lonely" - a qualitative analysis of **COVID** impacts on family caregivers and those receiving their care

Purpose

- Meaningful social contact is essential for health and wellbeing.
- ➤ COVID mitigation efforts and a taxed long-term care support systems put older adults and people with disabilities at risk for negative effects of social isolation.
- ➤ The purpose of this study was to explore caregiver's perceptions of how the pandemic had affected social participation/ isolation and loneliness for themselves and those receiving their care (care recipients).

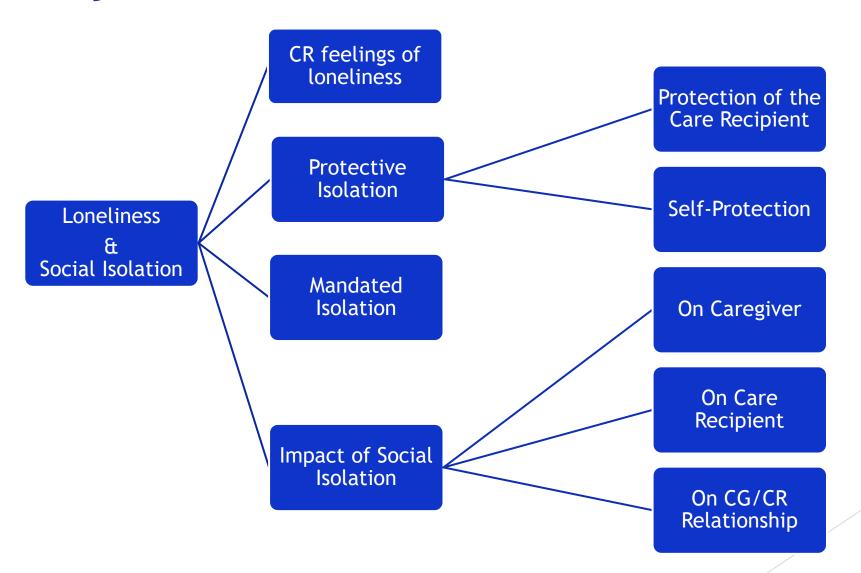


Methods

- ► Responses to open-ended questions in a survey of 576 family caregivers were reviewed to identify and extract statements related to social isolation feelings of loneliness.
- Content analysis was used to identify themes and subthemes within CG responses.
- ➤ Of 2365 responses to open-ended questions, 124 responses (5.24%) reflected loneliness and/or social isolation



Major Themes





Care Recipient Feelings of Loneliness (as reported by Caregiver)

"She has expressed increased loneliness despite best efforts."

Care Recipient Loneliness

"She's incredibly lonely and afraid all the time."

"We attempt to stay in touch for their mental well being by phone. They are lonely and feel isolated"

"Mom was happy in the assisted living, now wants to leave and move in with me. She is feeling very lonely."



Social Isolation: Protective

Protection of the Care Recipient

"I will stay isolated as long as I have to in order to ensure my mothers health and safety. "

Protective Isolation

"I used to be with my mother several days a week. I am now completely isolated with her to insure her safety during the pandemic."

Self-Protection "I have physically done little in person because I am at high risk. My husband has done most the in-person visits with significantly less time spent and social distancing."

"(I) had to cancel appts. For fear of being around people."



Mandated Isolation of Care Recipient

Mandated Isolation

One of his roommates tested positive, and he had to stay here for 10 days isolated from us.

I am concerned that he has to be isolated from family right now. I don't want him to feel deserted. I think he understands it, but he does feel alone.



Impact of Isolation on Care Recipient

Physical Health He loves to walk and pet all the dogs ... His physical health has declined due to lack of exercise and sitting in front of TV

Her ability to walk was declined after not seeing her for 1 month and her being inside apartment

Impact on Care Recipient

Mental Health Social isolation increases stress and decreases access to mental health resources. This has led to a marked increase in CR's mental health needs, and calls to crisis hotlines and in-patient treatment.

Her mental abilities seem to be declined; she is more distant, sleeping issues, seems depressed.

He has started becoming delusional and doesn't understand the situation. When I visit through the window he doesn't understand who is there. He constantly asks me to come in and help him. This has severely impacted his mental health

Cognitive Health

His mental clarity has declined due to lack of exercise, ability to go out and interact with people.



Impact of Isolation on Care Recipient

(cont'd)

Ability to remain independent

"Increased worry about her and how filthy her apartment is and how she's managing to do her laundry. Worry that I should remove her from her residence and bring her here."

"Family member became isolated, needed extra help with ADL and socialization to protect mental health."

"She calls me 2-3x per day or when needed, just to talk cause feels isolated and can't go to church daily.."

Lack of Social Participation

"(he's not exercising or going out everyday. And the gym is closed too. And all special Olympics have been cancelled. That's two days a week of activities that are not happening. Also his 3-week special needs summer camps was closed.."

Impact on Care Recipient



Impact of Isolation on Caregiver

Health & Wellbeing

It is harder to care for myself because unable to do hair appointments and visit friends

Well I had a problem, and I won't go to the hospital to get it taken care of...but I've been in contact with my doctor but I would've had to go to the hospital, and I'm not going.

Impact on Caregiver

Social Participation

Our children and grandchildren live nearby, so we are used to seeing them and doing things with them often. Not being able to see them in person is pretty difficult for both of us.

Inability to have social outlets to address my self-care

Because of the distancing (not) being able to meet and physically show him things it takes multiple extended phone calls to explain and clarify!

Increased Workload

I am now doing all their grocery shopping. I'm also watching my father whenever my mother leaves the house..



Impact of Isolation on the caregivercare recipient relationship

Impact on Relationship

"It's just that we're together too much. It's not because of the stroke or anything it's just cause we're here and we're not able to go places."

"Cabin fever causes irritability."



Conclusions

- ► Even early in the pandemic, family caregivers were acutely aware of the negative impacts on their loved ones physical and mental health.
- ▶ Deterioration of loved one's ability to care for themselves and get essential social interactions was a significant stressor for caregivers.
- ▶ Both protective and mandated isolation led to increased workload and reduced quality of life for caregivers.



Thank you!

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