Part 2: COVID-19 Challenges to Caregiving and Caregivers in Minnesota

Elizabeth Lightfoot

Caregiving during COVID-19
Caregiving during COVID-19 Research Project

- All Volunteer Team of Researchers at UMN
  - 1 Professor at SSW
  - 1 Faculty Director/Administrator
  - 3 PhD Students
  - 1 MSW Student
  - 1 Undergraduate Student

- Study Population
  - Caregivers of Older Adults and Adults with Disabilities (in the community or long-term care facility)

- Data Collection
  - Semi-Structured Interviews over Zoom

- Current Sample
  - 55 total interviews
    - 5 in Somali
    - 5 in Spanish
    - 5 in Korean

Research Questions
- How has COVID-19 changed caregiving tasks?
- What are their biggest concerns about caregiving (including restrictions, etc.)?
- What are the benefits of caregiving during COVID-19?
- Where are caregivers getting supports?

Preliminary Findings

- Top Concerns
- Caregiving Changes
- Coping with Changes
- Silver Linings?
- Attitudes Regarding Lifting Restrictions
- Specifics Regarding Facilities
Top Concerns of Caregivers

Social Isolation

“I have teenagers. And so in the summers, like last summer when they didn’t have school, they would go over there and have lunch with them, four times a week to keep them company. But then now... my parents haven’t left their apartment. And no one has gone into their apartment.“

--Caregiver of parents (70s) living in community

“Just the isolation, probably, like, the fact they’re pretty much in their rooms, they can’t do much else... and just the impact isolation has on a person

--Caregiver of 75 y.o. dad in LTC
Decline in Mental Health

“He has enough awareness to where this is . . . a source of anxiety and depression for him. And every time I talked to him he brings it up.”
--Caregiver of 85 y.o. dad in LTC

“That [social isolation] really affected her behavior, and her personality became more difficult. She sometimes feels that we are the ones doing this to her, and it’s not happening to other people. She felt a lot of pressure, feeling that we are creating the pressure for her.”
--Caregiver to 81 y.o. mom in her home

Decline in Physical & Cognitive Functioning

“I don't think she's getting the exercise that she was getting before because they're not taking her and we would take her own walks.”
--Caregiver of 84 y.o. mom in LTC

“By the time we end this COVID isolation, he would have gotten to the point where he can't look forward to those sorts of things.”
--Caregiver to 76 y.o. dad in her LTC
Keeping Relatives Safe from COVID-19

"The biggest one is that we worry that she will get the disease. If the person contracts the disease, you can’t even go with the to the hospital and see them, you can’t even sit with them to help them drink water. You can’t stand next to your parent, and that creates a lot of worry for us.”
--Caregiver of 84 y.o. mom in home

"I would just never forgive myself because of asymptomatic nature of the virus if I walked in there and gave it to her … or if I gave it to somebody else."--Caregiver to 88 y.o. mom in LTC

Lack of Caregiving Support

"I would really hesitate to have someone come in here because they might do more harm than good.”
--Caregiver of 73 y.o. husband in home
Caregiver Stress

“The big challenge on my part is staying emotionally, um, distant enough that I can support my mom without, I mean she is my mom she reads when I'm upset she reads when I'm sad. So being able to support her and give her the strength and courage to say this is okay. It's not right but it's OK.”
--Caregiver to 98 y.o. mom in LTC

“But I just realized that it's really takes a toll on me that probably the effects, you know, other areas of my family and my life and how good I can be for myself and for others?”
--Caregiver to parents (70s) in their own home

Poll #1!

Which of the following have you done for the FIRST TIME since March 15? (check all that apply)
- Went on a socially distanced walk
- Attended a party over Zoom
- Attended an OUTDOOR concert, play, or religious services
- Had groceries delivered to your home
- Took up a new hobby
What has changed?

- Limited Social and Physical Interactions
  - No in-person contact
  - No physical contact
  - Smaller social networks for assistance
  - Changed social interactions

- Can't Do Caregiving Tasks
  - Provide social stimulation or exercise
  - Monitor
  - Get supplies and medicine
  - Take to appointments
  - Changed schedules

- Reduction of Supports and Therapies
  - Health care and rehabilitation
  - Formal caregiving supports
  - Activities
  - Hard to find staff

- Vigilance about Covid-19
  - Masks and distancing
  - Keeping home safe
  - Advocating for safety
  - Worry

Coping with Caregiving Changes

- Keeping Connected Through Technology
- Alternative In-Person Visits
- Sending Letters/Gifts
- Enlisting Staff
- Connecting More Often

- Technology for Support
- Sharing caregiving
- Hiring Staff
- Advocating/Monitoring
- Seeking Formal Resources
- Telehealth

- Helping Loved Ones Stay Occupied
- Technology for Entertainment
- Sending Activities

- Self-Care
- Dealing with Guilt
- Enjoying Free Time
- Adapting to New Routines
- COVID-Relief Activities

- Getting Support & Services in New Ways
- Reducing Caregiver Stress

- Keeping Connected
- Keeping Connected Through Technology
- Keeping Connected Through Technology
- Keeping Connected Through Technology

- Getting Support & Services in New Ways
- Technology for Support
- Technology for Support
- Technology for Support
- Technology for Support
Technology

“I started thinking that if the apocalypse happens... cockroaches, Keith Richards and my mom (will survive it)”

SILVER LININGS

Slower Pace
Increased Resilience
Quality of Relationships
Time to Spend Together
Innovation
Poll #2

When did the CDC first recommend that people wear masks when they were out in the community?

A. March 19, 2020
B. April 3, 2020
C. May 8, 2020
D. June 29, 2020

Loosening Restrictions
Reaction #1: Too Early

"I think the decision was hasty, they shouldn’t open things up until the disease is completely contained or almost contained." Caregiver of 78 y.o. mom in home
Loosening Restrictions
Reaction #2: Mixed Feelings

| Risk of Getting Covid-19 | Risks of Social Isolation |

"I think my mom would rather have us visit with the option that something might happen [than] not be with us."
--Caregiver of 84 y.o. mom in LTC

Facilities

THANK YOU HEROE$
Local Resources for Caregiving

https://elderCare.acl.gov/

Sources of COVID-19 Information

Minnesota Department of Health
https://www.health.state.mn.us/diseases/coronavirus/index.html
https://www.health.state.mn.us/diseases/coronavirus/situation.html

Minnesota Department of Health Long-Term Care – Covid-19
https://www.health.state.mn.us/diseases/coronavirus/hcp/ltc.html

Centers for Disease Control

Centers for Medicare and Medicaid
Questions?

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Next Webinar: October 27, noon
Understanding Historical and Contemporary Trauma in African American Communities: Navigating Supports so Elders Thrive

Co-Hosts:
• Rajean Moone, UMN
• Alana Wright, Minnesota Leadership Council on Aging

Presenters:
• Jonathan Palmer, Hallie Q. Brown
• Robbin Frazier, Alzheimer’s Association MN/ND
• Suzanne Madison, Metropolitan Area Agency on Aging