COVID-19 Caregiving: Older Adults, Adults with Disabilities, and Somali-Americans

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Caregiving during COVID-19

Limited testing in senior care facilities in Washington leaves them 'flying in the dark' against coronavirus

Caregiving in Times of Uncertainty: Helping Adult Children of Aging Parents Find Support during the COVID-19 Outbreak

Caregiving during COVID-19: A Qualitative Research Project

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

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?  
What are caregivers’ perceptions of restrictions?  
What particular caregiving challenges have been faced by Somali caregivers during COVID-19?
Caregiving during COVID-19
A Qualitative Research Project

Human Subjects Approval

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

Recruitment
Convenience Sample – online (rapid!)

Data Collection
Semi-Structured Interviews
Zoom with Recording

Caregiving during COVID-19
Research Project

Sample
64 total interviews
44 in English
10 in Somali
5 in Spanish
5 in Korean

Data Transformation and Analysis
Used Zoom Auto-Translate for English Interviews

Thematic Analysis
Open Coding
Develop Coding Structure
Recoding Data with Secondary Review
Final Review
Top Concerns of Caregivers

- Social Isolation
- Lack of caregiving support
- Keeping Relatives Safe
- Caregiving Stress
- Decline in Functioning
- Decline in Mental Health

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

- Technology for Entertainment
- Sending Activities

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

SILVER LININGS

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

Slower Pace
Increased Resilience
Quality of Relationships
Time to Spend Together
Innovation
Family Caregiving in the Somali-American Community

Somali American Context

- Primarily refugee community, hailing from Somalia in Eastern Africa; fleeing civil war and instability since 1991
- Primarily Sunni Muslim population, with a shared language and tribal social structure
- Resettled across the United States
  - Twin Cities, MN has become the largest hub
  - Other hubs include: Columbus, OH, Portland, ME, and San Diego, CA
Challenges of the Community

© Place Making
  ○ Community Building
  ○ Acculturation
  ○ Upholding cultural and religious values
  ○ Raising children and caring for elderly

© Intersectional Discrimination
  ○ Religious
  ○ Racial
  ○ Gender

Existing Literature on Somali Americans

© Focuses largely on discrimination (both inter and intra-community)
  ○ Experiences of racial and religious discrimination among adolescents and adults
  ○ Pre-eminence of gender discrimination within the community

© Generally sparse
© Some recent research investigates resilience and strengths within the community
  ○ Social support
  ○ Faith
  ○ Cultural roots
Somali Specific Sample

- Conducted phone interviews with Somali caregivers from Minnesota and Ohio
- Recruited participants through community channels including a private caregiver support agency
- Translated semi-structured interview scripts from the parent study into Somali, and conducted them in Somali language using a professional interpreter
- n = 10
  - 8 MN, 2 OH
  - 5 female, 5 male
  - 7 caring for elderly parents, 3 for relatives with disabilities

Primary Themes

- Visitation
- Hospital Accompaniment
- Self Sacrifice

Endured through God-consciousness, and utilizing family
Visitation

- Interviews revealed nearly ubiquitous concern that relatives and friends were unable to pay visits to their family member
- Linked with cultural expectations of visiting, particularly for elders
- Provided:
  - Emotional support
  - Social connection
  - Physical activity
  - Burden reduction for caregivers
Quotes

“Even the people who used to come visit her, since in the Somali culture people visit a lot, we had to tell them in a respectful way that there is a disease, so please don’t come visit.”

“No one is coming to visit you anymore, whether family or friends.”

“They used to visit for hours.”

“The relatives and friends who used to come see her, and the people she used to go out to visit, that used to relax her. It bothers here that she cannot talk and have conversations with those people.”

Participant #10

“She [mother] is a community elder, and everyone used to visit her, but we had to stop them because of the disease... sometimes she just asks ‘what happened to all the people who used to come to see me? What happened to my relatives and my other children?’ I tell her ‘people are worried because of the disease... and you are older so you are susceptible’ then she says, ‘this diseases created a big problem, it cut us off from our relatives.’”
2. Hospital Accompaniment

Caregivers reported acting as translators, guides, and advocates during hospital visits on behalf of their family member.

The inability to play this role during peak COVID restrictions led to a significant decrease in quality of care, and was a significant source of distress for both caregiver and care receiver.
Participant #4

“She [mother] had many doctor appointments that were all cancelled because the hospitals said that if someone has to go to the hospital they have to go alone, and she can’t manage that... even if she needed an interpreter, they said they would provide an interpreter.”

Participant #6

“We drove to the ER... a man came out and said no one except her [mother] could go inside. I told him “she doesn't even speak English, so can you let at least one of us go in with her?” And they refused. I said “she doesn't even know how to use the telephone.” They didn't accept that either... she was in the hospital for four days, and we didn't hear a peep from them. We kept waiting and saying 'we'll get a call'... they brought her outside on a wheelchair and we took her with us. That was the most heartbreaking experience for us. That kind of thing scares us, and I hope God doesn't make it happen again.”
Participant #7

“Before when we [caregivers] were with him [father] we were able to communicate with the doctors about his situation. The doctor would also find out that this person has a family and kids, and he’s an elder who they love so much. Even the doctor develops love for the person and it makes him take better care of him. But now, the situation is that when the person comes in alone he becomes just like the other people the doctor sees on a daily basis.”

Participant #7

“Since he [father] can’t get the one-to-one care we used to provide, he’s like the other people who can speak for themselves and say what they need… he goes into the hospital by himself three days a week and we don’t even know what’s happening to him during those hours… he says ‘the staff don’t take care of me very well. Today I said something to them and they didn’t give me attention, and I raised my hand and I was ignored.’”
3. Self-Sacrifice

Self-Sacrifice

© Despite myriad challenges (including those discussed previously), participants went to great lengths to avoid giving up the care of their relatives (particularly full time care facilities)

© Seemingly driven by moral values including intergenerational connection and religious values

© This self sacrifice appeared to be endured using two primary modes of coping:
  - God-consciousness
  - Utilizing family
“It’s easier because I asked my sister to move in with us, and she did. So that’s a big help because she’s there all the time. So that’s how we decided to care for my mother.”

“We don’t take her to elder care centers, we don’t get money assistance, or any of that. Since we are here for her care, we are taking care of her and we don’t want any of those things. She wouldn’t have accepted those things anyway, she doesn’t like them.”

“For me this is my mother. So I will keep doing things like I have been until the world is back to normal. I don’t want her to face difficulties, especially if she has to go to the hospital and we can’t go to see her. That’s our biggest fear, so we are going to remain cautious.”

3a. God-Consciousness
God-consciousness

◎ The challenges and sacrifices faced by the participants were met with firm reliance on religious values, particularly radical acceptance.

◎ This acted as both a tool for navigating challenges, and coping with distress.

Participant #9

“I can’t even get a few hours of rest, and if I want to do other things I can’t. But I still praise God.”
Participant #10

“I told her, “the disease is dangerous, you need to stop doing those things [i.e. meeting with relatives]. She said “Why are you trying to cut me off from my relatives?” I said “No, I'm not. This disease has been decreed by God, but you are required by God to protect yourself and be careful…” This was such a problem for us. Then she understood what happened and accepted it as God’s decree. So anything that is decreed by God, she doesn’t reject.”

Participant #8

“Since we are people of faith we accept when there are tests on people, and my mother also understands that this is God’s decree and she accepts that… I think our family has benefitted because we accepted the situation we are in. We are people who are grounded in religion, so if there is a difficult situation it doesn’t create as much distress for us.”
3b. Utilizing Family

Utilizing Family

- Family support was used to distribute caregiving burden, and motivate caregivers to endure through difficult times.
- Combination of cultural and religious values created a strong sense of responsibility and purpose for some participants.
“For me this is my mother. So I will keep doing things like I have been until the world is back to normal.”

“When someone, especially a mother, is taking care of her own child, they don’t see it as difficult. Even if it is, they don’t see it that way.”

“The children are assigned to spend at least one hour with their grandmother, and my husband spends time with her every evening… We called her siblings, and my siblings, and especially now with COVID-19 we have a special schedule where all my siblings call her at particular times.”

“Now everyone is staying home, so people talk more and spend more time together. The kids talk to each other, my mother tells them stories, they talk about different things, and they get to know each other.”

“People talk to each other, they tell stories, she tells us a lot of stories, we take pictures together, we do a lot of things together we didn’t do before. We cook together, and while we’re cooking people ask her “Grandma, what did you used to cook when you were young?” So people are asking each other more questions.”
Discussion and Future Directions

- This study highlights the voices of Somali caregivers, and describes their primary responsibilities, concerns, and motivations.

- Further qualitative and quantitative research is needed to develop a more clear picture of caregiving in the community, and what mediating role it plays in place making:
  - Intergenerational connection
  - Religious and cultural reliance
  - Social support and advocacy

Questions?
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Next Webinar: Wednesday, November 18, 12N-1PM

Lessons Learned in Long-Term Care During A Pandemic

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