

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

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# Who We Are



**NATIONAL CENTER  
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*The contents of this presentation were developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90RTGE0002). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this presentation do not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the Federal Government.*



# 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

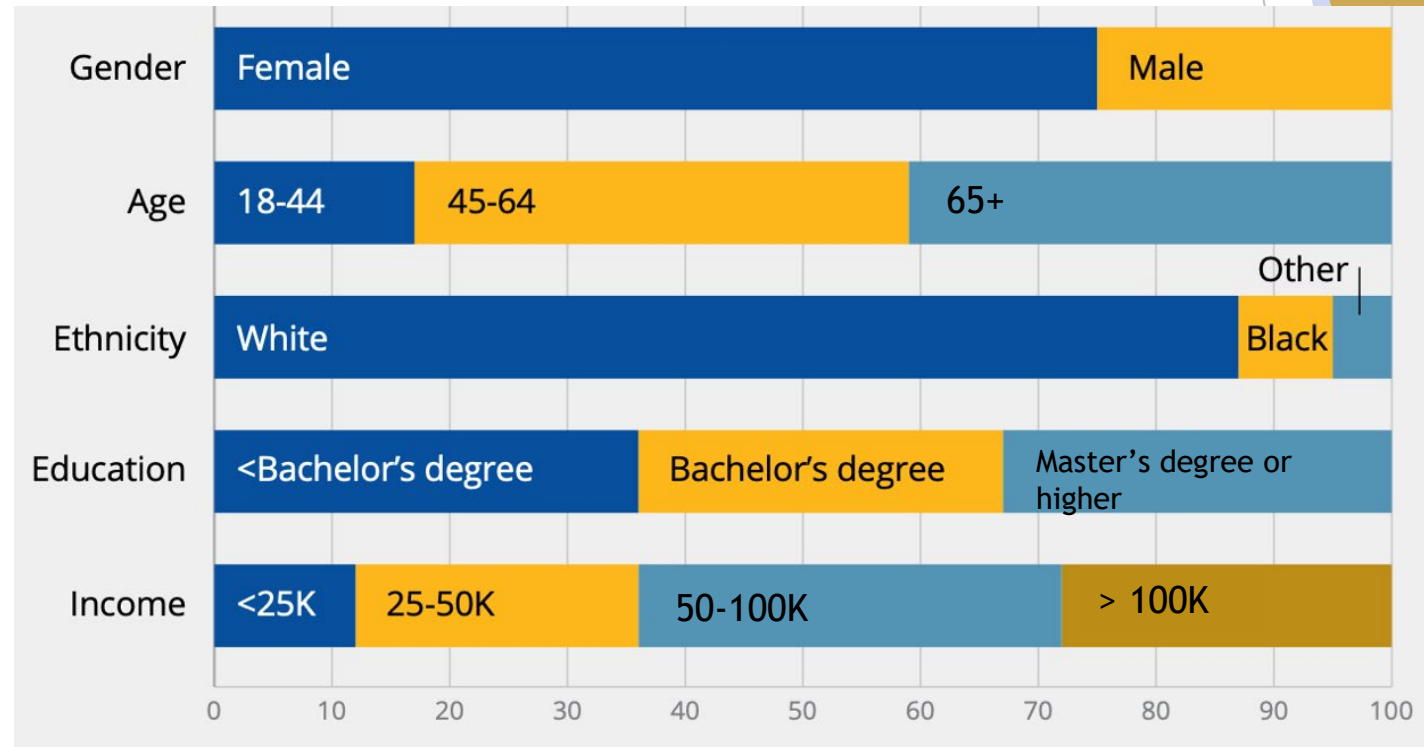
National Rehabilitation Research and Training Center on family Support (NRRTC). (2020, July). *Effects of COVID-19 on family caregivers: A community survey from the University of Pittsburgh*. University of Pittsburgh.

Beach, S.R., Schulz, R., Donovan, H., & Rosland, A. (2021). Family caregiving during the COVID-19 pandemic. The Gerontologist, *61*(5), 650-660. PMID: 33847355 PMCID: PMC8083337. doi:10.1093/geront/gnab049.



# 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

1. *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.

## ▶ COVID-19 Impact (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)

Scoring: PROMIS algorithm. Higher scores mean greater ability to participate.

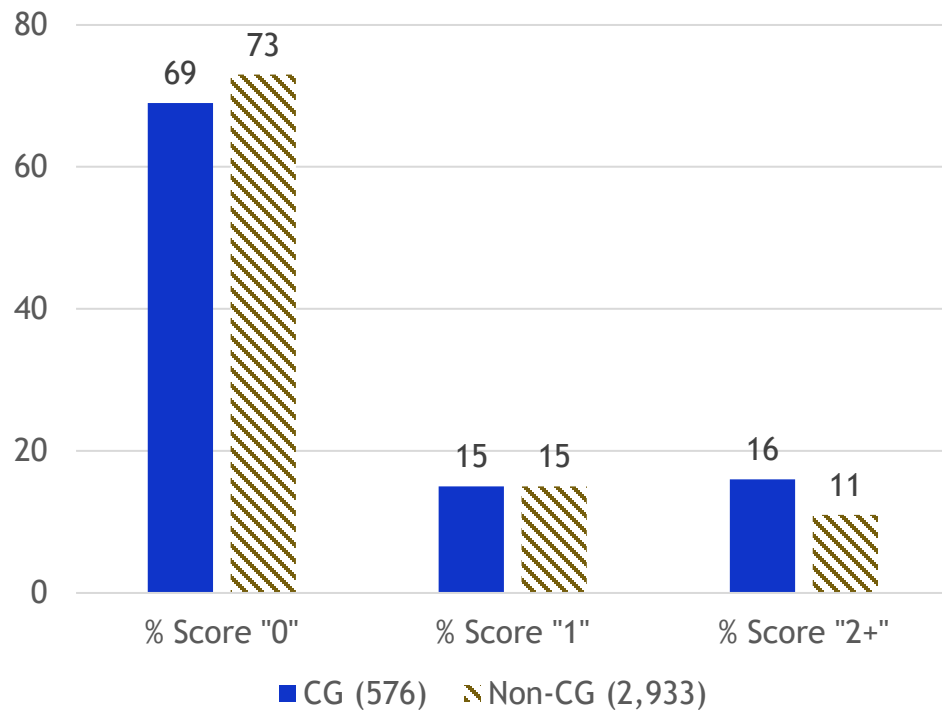
(National norm = 50)

# Family Caregivers vs. Non-caregivers

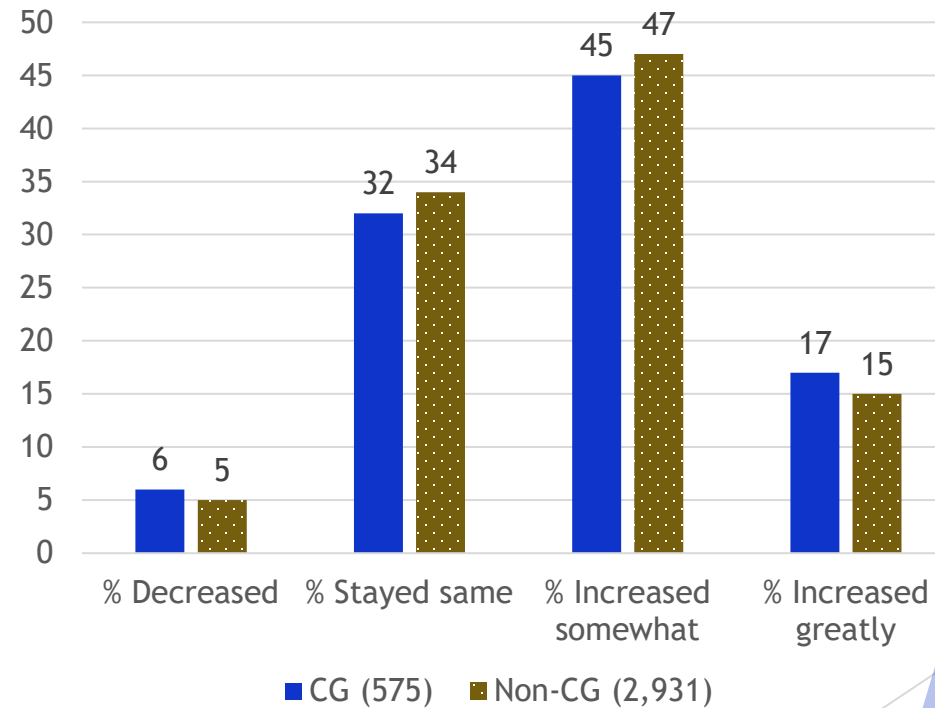


# Family Caregivers vs. Non-caregivers: Social Isolation / Loneliness (SIL)

Current SIL: Index score ( $p < .01$ )



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
<ul style="list-style-type: none"> <li>• Younger CGs</li> <li>• Lower income CGs</li> <li>• CGs helping care recipient (CR) with medical / nursing tasks</li> <li>• Adult child CGs of a parent</li> <li>• CG assisting CR with Cognitive problems / Alzheimer's Disease</li> <li>• CG assisting CR with emotional / behavioral / developmental disorder</li> <li>• Higher scores on COVID Caregiver Risk Index (CCRI)</li> </ul>	<ul style="list-style-type: none"> <li>• Lower income CGs</li> <li>• Female CGs</li> <li>• CG lives with CR</li> <li>• Higher scores on COVID Caregiver Risk Index (CCRI)</li> </ul>	<ul style="list-style-type: none"> <li>• Female CGs</li> <li>• CGs helping CR with both personal care and medical / nursing tasks</li> <li>• CG assisting CR with Cognitive problems / Alzheimer's Disease</li> <li>• Higher scores on COVID Caregiver Risk Index (CCRI)</li> </ul>

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

<i>Has the coronavirus crisis had any of the following impacts on you and your care recipient</i>	<i>% CGs endorsing</i>
Increased your caregiving efforts or duties	63%
Made providing care more <i>emotionally</i> 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 <i>physically</i> difficult for you	22%
Interfered with your own health care	21%
Made providing care more <i>financially</i> 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%
<i>[Note: CCRI is simple sum (0 - 12) of items endorsed]</i>	

# 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

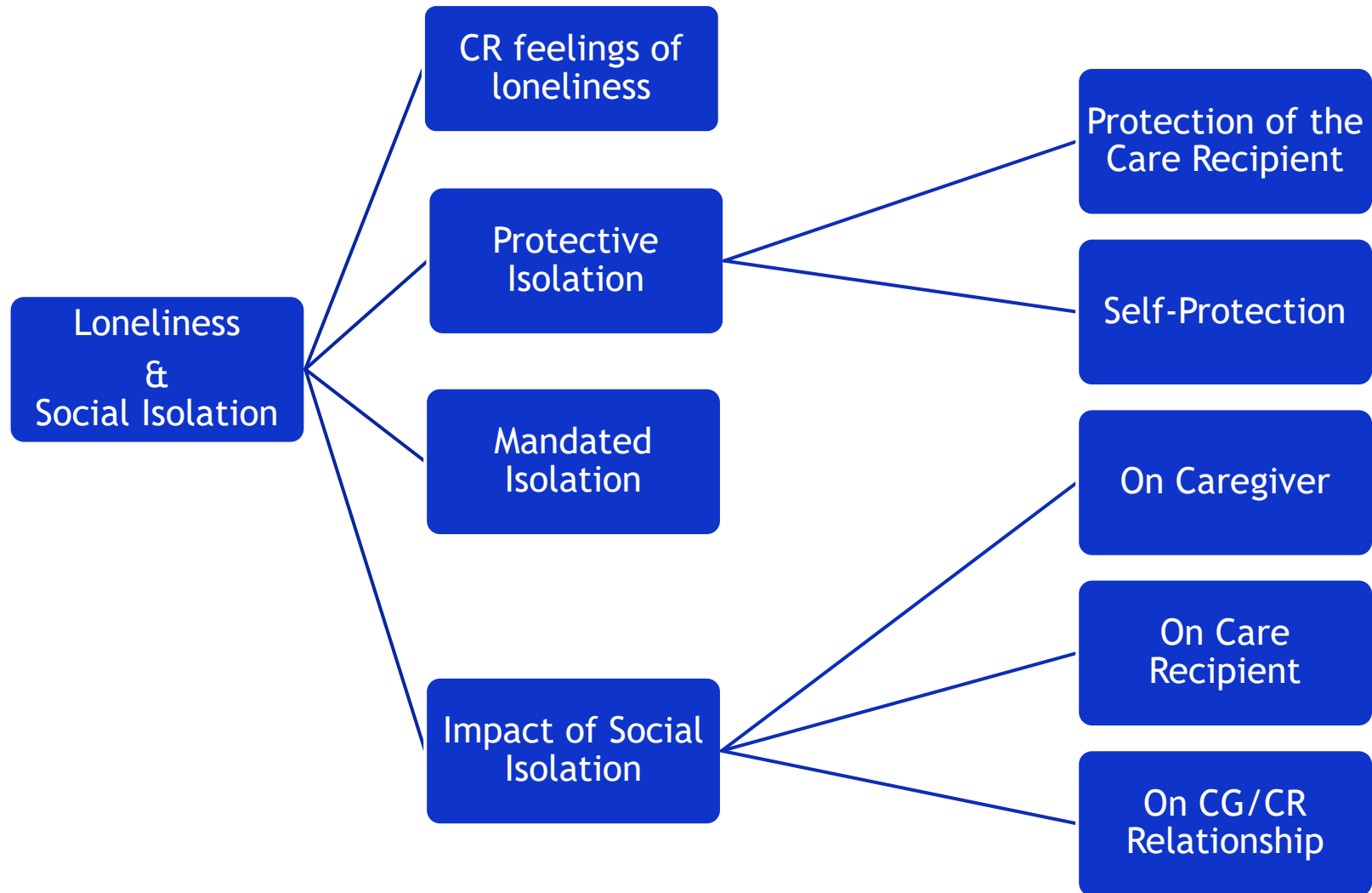
- ▶ Meaningful social contact is essential for health and well-being.
- ▶ COVID mitigation efforts and a taxed long-term care support systems put older adults and people with disabilities at risk for negative effects of social isolation.
- ▶ The purpose of this study was to explore caregiver's perceptions 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)

Care Recipient Loneliness

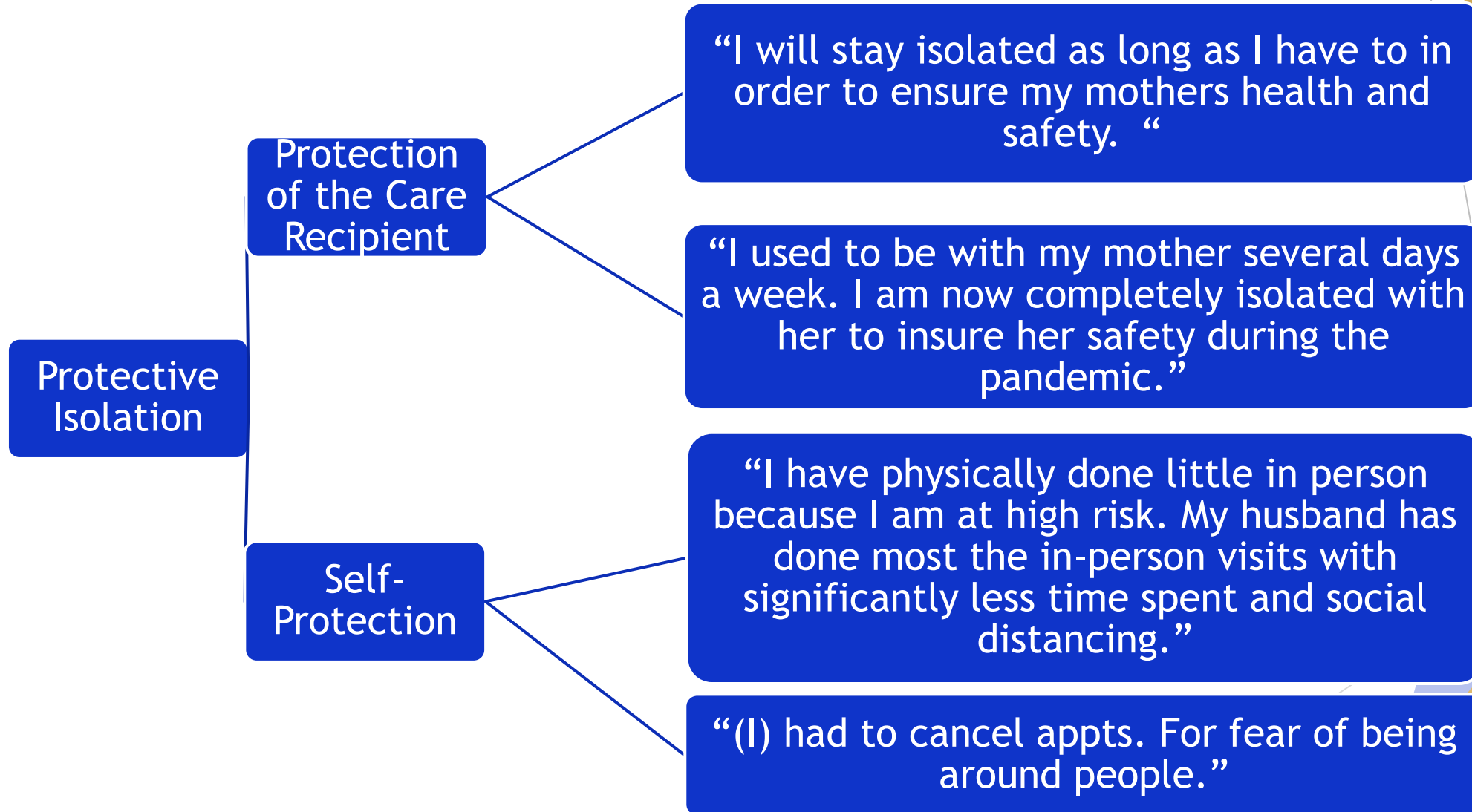
“She has expressed increased loneliness despite best efforts.”

“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



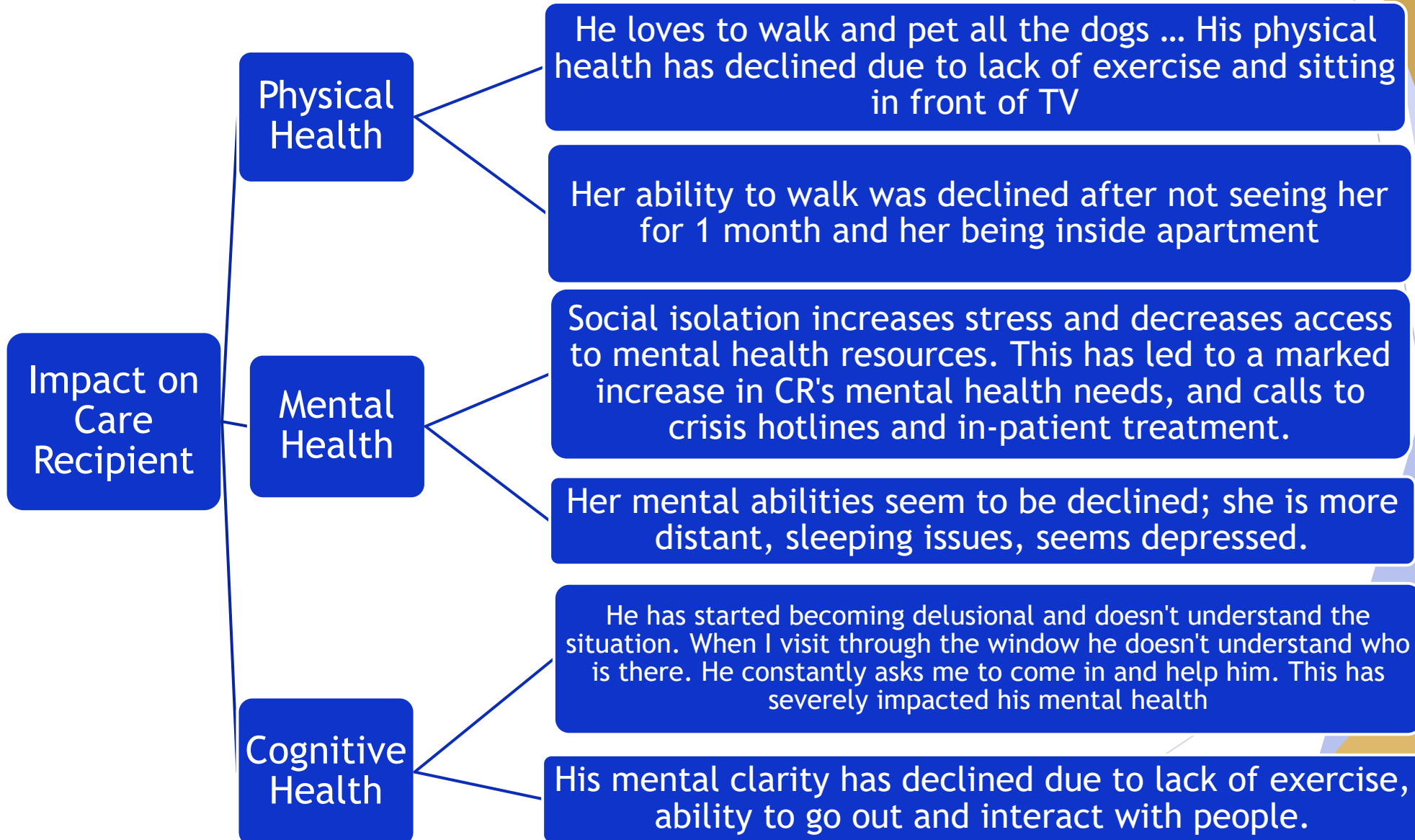
# Mandated Isolation of Care Recipient

Mandated  
Isolation

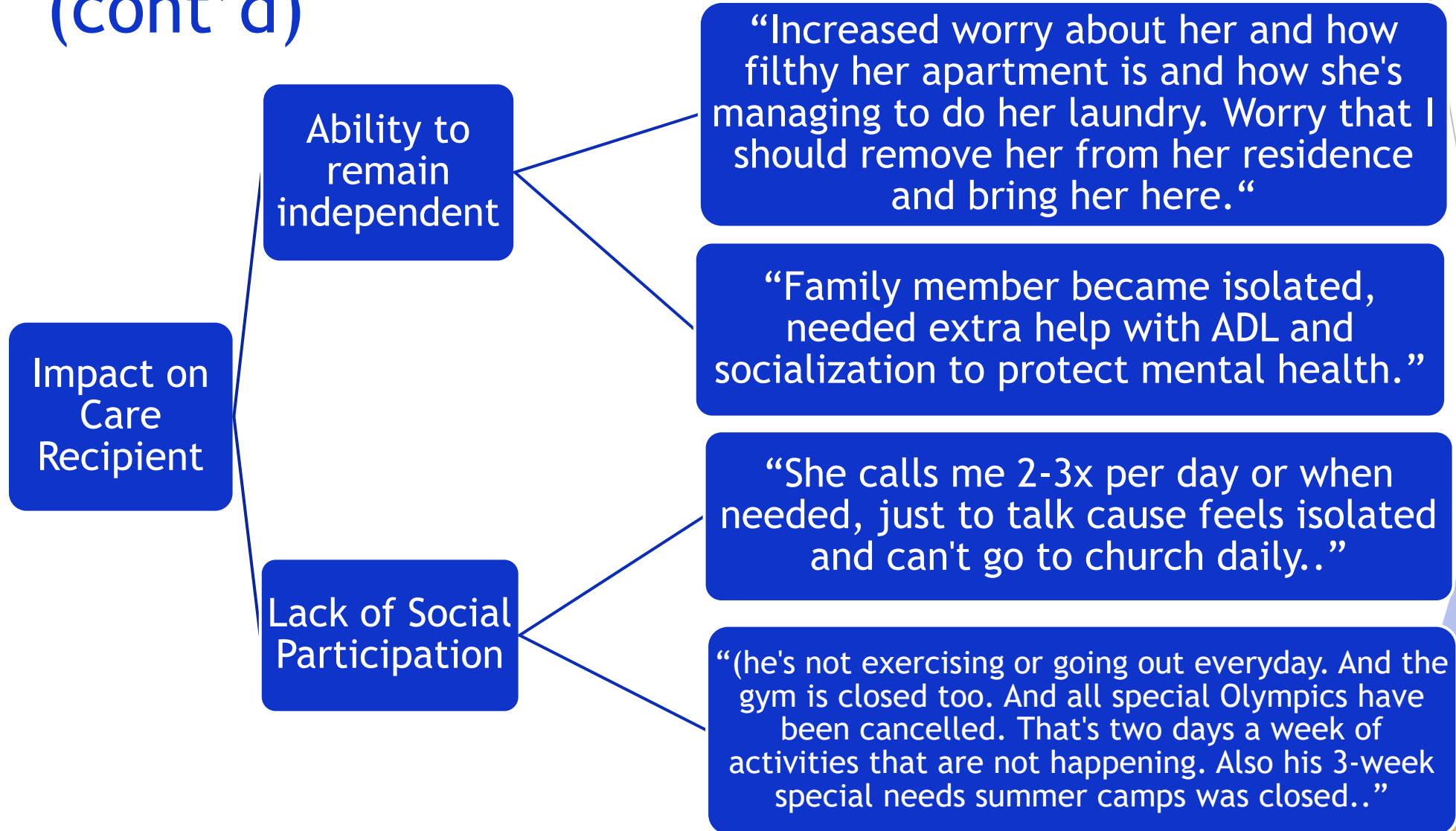
One of his roommates tested positive, and he had to stay here for 10 days isolated from us.

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.

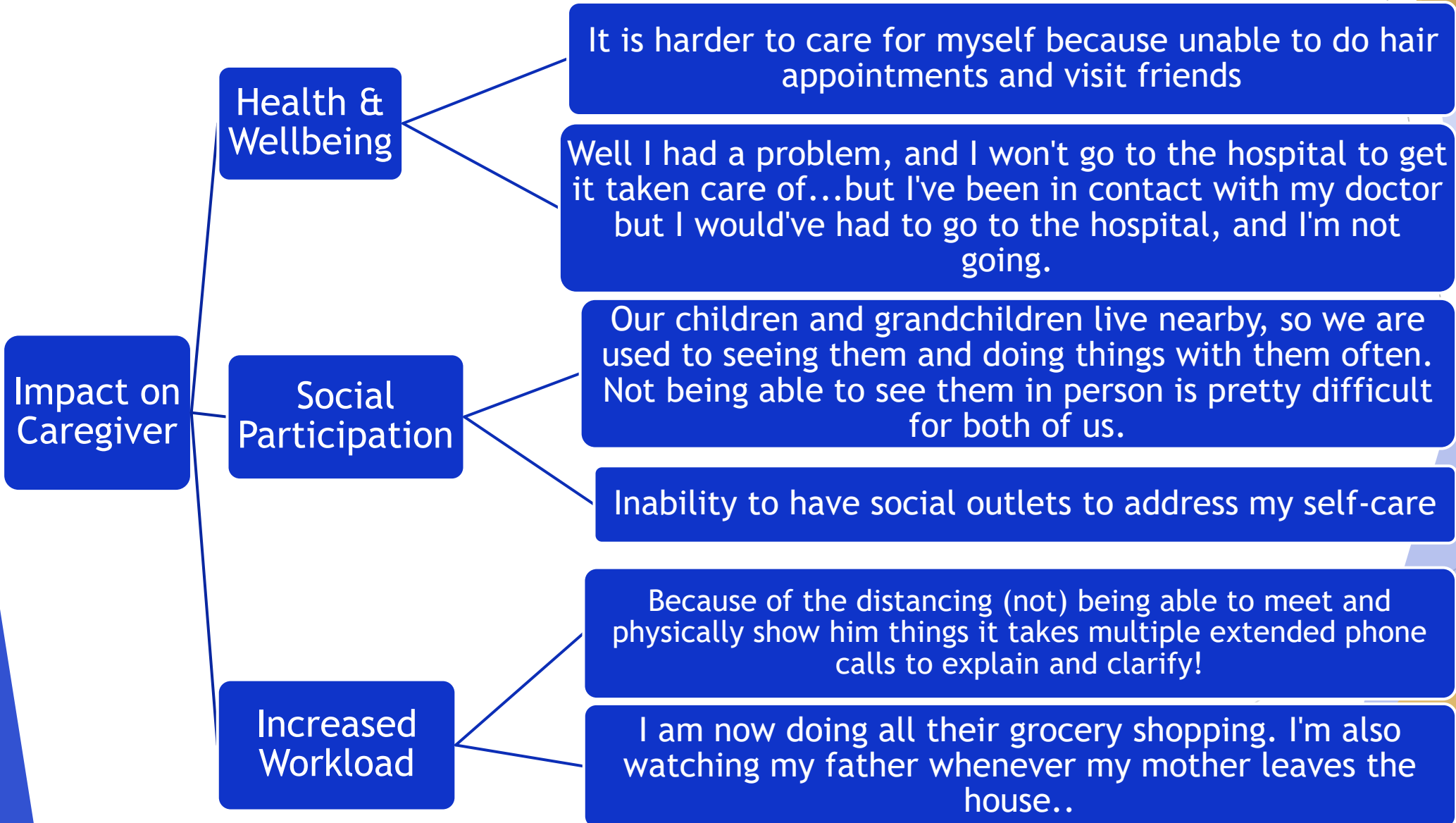
# Impact of Isolation on Care Recipient



# Impact of Isolation on Care Recipient (cont'd)



# Impact of Isolation on Caregiver





# Impact of Isolation on the caregiver-care 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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