Emotional effects of the COVID-19 Pandemic on Persons with Memory Loss and their Caregivers

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# Learning Objectives

- Identify COVID-19 factors which have contributed to emotional effects on persons with memory loss and their caregivers.
- State COVID-19 related emotional effects experienced by persons with memory loss and their caregivers.
- Identify interventions that are supported by the literature.



# It started when...

- She got sick with COVID.
- We couldn't go anywhere.
- We couldn't see anyone.
- His brother died of COVID.
- We couldn't have a funeral.

"I was the first one. They thought I had the virus and put me in a room by myself. I couldn't visit with anyone. It was the worst two weeks of my life. Then they found out the test was wrong. I was negative."...patient in nursing home.

"I've lost 19 of my friends over the past year to COVID."...patient in nursing home.

"We've really lost a year from our lives, and we don't know how many more years we have!"...wife/caregiver of patient living in a private residence. "I am taking my mom for a drive after this appointment. When she goes back, she has to stay in her room for two weeks."...daughter/caregiver of patient living at Assisted Living facility.

"I can't hear you with my mask on!"...patient living in private residence.

"I am afraid. They are so short- staffed and my husband can't get his medicine on time. I don't know what to do. Please help me."...wife/caregiver living in an Assisted Living facility. The mental health of caregivers and their patients with dementia during the COVID-19 pandemic: A systematic review

Carbone et al., 2021



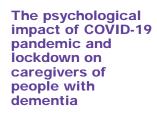
#### Results

• Studies completed in ten countries during 2020 COVID-19 lockdowns.

- 17 studies included in the systematic review
  - Social isolation triggered behavioral symptoms in persons with memory loss and higher levels of anxiety and depression in caregivers.
  - Disruptions in healthcare delivery and changes in social support availability was associated with higher levels of anxiety in persons with dementia and worsening of caregivers' mental health.

Carbone et al., 2021





Altieri & Santangelo, 2021



- Online survey of 84 caregivers of persons with dementia during the COVID-19 lockdown in Italy from April 21 – May 3, 2020.
- 79.8% of the persons with dementia were not aware of the COVID-19 situation.
- A rise in depressive symptoms in caregivers was associated with restriction and isolation of the lock-down.

Altieri & Santangelo, 2021

#### **Results**

- Caregivers who had *higher* levels of resilience experienced *higher* levels of anxiety.
- Caregivers with low levels of resilience paired with greater functional dependence by the person with dementia, led to higher levels of overall caregiver burden.

Altieri & Santangelo, 2021



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Impact of COVID-19 restrictions on behavioural and psychological symptoms in homedwelling people with dementia: A prospective cohort study

Gedde et al., 2022



- Participants included 104 dyads, living at home in Norway with assessment completed immediately before and 6-9 weeks after initiation of COVID-19 restrictions.
- Neuropsychiatric Inventory (NPI-12) scores got worse for 55% of the participants.
- There were higher scores to support psychosis subsyndrome and depression.

Gedde et al., 2022



#### **Results**

- Authors associated the increase in psychosis subsyndrome with insight into the COVID-19 pandemic and less contact with caregiver.
- Overall worsening of the NPI-12 was associated with reduced or delayed visits to the health care provider and due to greater impairment of cognition (as demonstrated on Mini Mental State Exam scores).

Gedde et al., 2022



Impact of COVID-19 on the health and well-being of informal caregivers of people with dementia: A rapid systematic review

Hughes et al., 2021



- 10 studies included in the systematic review all of which used telephone or online data collection methods. Participant numbers ranged from 31 to 4,913.
- Caregivers experienced an increase in anxiety that was associated to COVID-19 changes in life routines vs. level of cognitive impairment of their care receiver.
- Caregiver burden, however, was associated with advanced stages of dementia.

Hughes et al., 2021



#### **Results**

- 4,913 caregivers reported an increase in anxiety, depression, irritability and distress related to the quarantines associated with the pandemic.
- Loss of control, the "new normal", and uncertainty were expressed by additional caregivers.

Hughes et al., 2021



Minimal impact of COVID-19 pandemic on the mental health and wellbeing of people living with dementia: Analysis of matched longitudinal data from the IDEAL study

Sabatini et al., 2022



- 2 groups (Pandemic group, n=115, tested before and during the pandemic AND Pre-Pandemic group, n=230, assessed before the pandemic) were assessed for mood, sense of self, wellbeing, optimism, quality of life and life satisfaction.
- No significant difference between the groups in terms of sense of self, quality of life, and wellbeing.

Sabatini et al., 2022

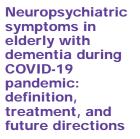


### **Results**

- Depression/anxiety reduced in the *pandemic* group comparing before-pandemic numbers to during-pandemic numbers.
- Pandemic group had a decrease of satisfaction of life from 91.3% to 85.8%. Pre-pandemic group expressed a slight improvement.

Sabatini et al., 2022





Simonetti et al., 2020



- 20 studies completed between March June 2020.
- Isolation/restricted family contact led to depression, hopelessness, and increased suicidal ideations in persons with dementia.
- Social isolation in nursing homes led to increase in apathy which increased over time.

Simonetti et al., 2020



# Results

- · Restricted social interaction increased anxiety.
- Increase in fear and agitation were associated with confinement.
- No increase in hallucination/delusions but noted increase in paranoia related to switch from in-person contact to virtual contact.

Simonetti et al., 2020



### **Recommendations**

- · Simplify daily routines; maintain consistency.
- Utilize technology for increased social interaction.
- Utilize Telehealth services, phone or audio/visual.
- Be cautious related to prescribing increased antipsychotics if unable to see the patient routinely.

Simonetti et al., 2020



A systematic review of home-setting psychoeducation interventions for behavioral changes in dementia: Some lessons for the COVID-19 pandemic and post-pandemic assistance



Alves et al., 2020

#### **Results**

- 43 studies included in this systematic review.
- Rural caregivers are more likely to experience burden due to lack of care accessibility. Thus, home-based interventions determining and addressing their needs is recommended.

 Home-based interventions providing cognitive and physical exercise are recommended.

Alves et al., 2020



#### **Results**

- Home-based programs which assist caregivers in adapting to their roles and provide individual and family counseling, encourage support group participation, and offer ad hoc phone counseling supports caregivers and reduces long-term placement. (NYU Caregiver Intervention)
- Telephone-based support with trained staff can reduce caregiver burden and is associated with fewer hospital stays for persons with dementia. (FITT-C)

Alves et al., 2020



"You don't understand. I have friends that are dying. The other ones have moved in with their kids. I have no one and no where to go."... patient living at Assisted Living facility.

## References

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