

What's New 2019-2020: Research on Caregiving

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A 3-Item Screening Scale for Caregiver Burden in Dementia Caregiving: Scale Development and Score Mapping to the 22-Item Zarit Burden Interview

- The 22-item Zarit Burden Interview(ZBI) is widely accepted to distinguish significant burden.
- A brief screening scale for caregiver burden is needed in routine dementia services to identify those needing further interventions.

Liew, T. M., & Yap, P. (2019). A 3-Item Screening Scale for Caregiver Burden in Dementia Caregiving: Scale Development and Score Mapping to the 22-Item Zarit Burden Interview. *Journal of the American Medical Directors Association*, 20(5), 629–633.e12.
<https://doi.org/10.1016/j.jamda.2018.11.005>



Results:

- Rigorous methods were used to determine that 3 items can give reliable and valid results consistent with the ZBI.
- The 3 items are:
 - Are you afraid what the future holds for your relative?
 - Your health has suffered because of your involvement with your relative?
 - You have lost control of your life since your relative's illness?
- Implication: This accessible tool can quickly screen for caregiver burden and help focus caregiver interventions.



Multifactorial Examination of Caregiver Burden in a National Sample of Family and Unpaid Caregivers

- Multivariable regression model used National Health and Aging Trends Study and National Study of Caregiving data
- More than half of the caregivers reported burden related to caregiving
- Burden = physical, emotional, & financial hardship

Riffin, C., Van Ness, P. H., Wolff, J. L., & Fried, T. (2019). Multifactorial Examination of Caregiver Burden in a National Sample of Family and Unpaid Caregivers. *Journal of the American Geriatrics Society*, 67(2), 277–283.
<https://doi.org/10.1111/jgs.15664>



Who is most likely to experience caregiver burden?

- Caregiver characteristics:
 - Caregivers assisting with more ADLs and instrumental ADLs, health management task, and health system logistics
 - Female caregivers
 - Adult child caregivers
 - Caregivers in poor health
 - Caregivers with anxiety symptoms
 - Caregivers using respite were more likely to experience burden
- Recipient characteristic:
 - Dementia
- Results reinforce that various types of assistance to support caregivers is needed.



Caregiving Not as Bad for Your Health as Once Thought, Study Says

Is Family Caregiving Associated With Inflammation or Compromised Immunity? A Meta-Analysis

- Previous research articles have told us that caregiving “takes a toll on a person's health, boosting levels of inflammation and weakening the function of the immune system.”

Roth, D. L., Sheehan, O. C., Haley, W. E., Jenny, N. S., Cushman, M., & Walston, J. D. (2019). Is Family Caregiving Associated With Inflammation or Compromised Immunity? A Meta-Analysis. *The Gerontologist*, 59(5), e521–e534. <https://doi.org/10.1093/geront/gnz015>



Johns Hopkins Medicine. "Caregiving not as bad for your health as once thought, study says." *ScienceDaily*, 10 April 2019. www.sciencedaily.com/releases/2019/04/190410112747.htm

Caregiving not as bad for your health as once thought:

- The notion that caregiving is so stressful it causes deteriorating health and increased mortality leads to fear and reluctance to care for loved ones
- 30 paper meta-analysis by Johns Hopkins researchers
- Link is overstated and association is extremely small
- Caregiver stress explains less than 1% of the variability in immune and inflammation biomarkers
- Caregiving is stressful, but if “done right, can actually be an extremely beneficial, healthy activity that enhances your life because you’re engaged in pro-social behavior.”



Informal Caregiving and Mortality – Who Is Protected and Who Is Not? A Prospective Cohort Study from Japan

- Informal caregiving has been linked to psychological stress.
- Some studies have suggested a protective association between informal caregiving and mortality among caregivers.
- Prospective cohort study designed to test the association between caregiving and survival.

Miyawaki, A., Tanaka, H., Kobayashi, Y., & Kawachi, I. (2019). Informal caregiving and mortality-Who is protected and who is not? A prospective cohort study from Japan. *Social science & medicine* (1982), 223, 24–30.
<https://doi.org/10.1016/j.socscimed.2019.01.034>



Results:

- Found no statistically significant overall association between informal caregiving and all-cause mortality (using multivariate Cox proportional hazards model)
- Only group with increased mortality was female caregivers in the lowest income group.
- This implies that impact on informal caregiving on mortality may differ by societal contexts.
- Policy-makers and health care providers need to pay attention to vulnerable caregivers and ensure access to formal care.



Influence of Positive Aspects of Dementia Caregiving on Caregivers' Well-Being: A Systematic Review

- Explore how positive aspects of caregiving (PAC) affects well-being of caregivers of people with dementia.
- 53 studies were included in the narrative synthesis- 20 different PAC measures were employed

Quinn, C., & Toms, G. (2019). Influence of Positive Aspects of Dementia Caregiving on Caregivers' Well-Being: A Systematic Review. *The Gerontologist*, 59(5), e584–e596.
<https://doi.org/10.1093/geront/gny168>



Results:

- PAC associated with lower depression symptoms and burden; better mental health, quality of life, satisfaction with life, and competence/self-efficacy.
 - PAC was not associated with self-rated health or personal strain/stress.
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Implications:

- Identifying PAC is associated with better caregiver well-being.
- Interventions that enable caregivers to gain a more positive caregiving experience could be beneficial to their well-being.



Association Between Sleep Disturbance in Alzheimer's Disease Patients and Burden on and Health Status of Their Caregivers

- Investigation of the association between sleep disturbance in AD patients and the burden on and health status of caregivers
- Studied 496 caregivers of AD patients with insomnia
- Used a cross-sectional web-based questionnaire
- Collected demographic data, Sleep Disorders Inventory (SDI) scores, Burden Index of Caregivers-11 (BIC-11), health status (including Pittsburg Sleep Quality Index, PHQ-9, 12-Item Short Form Health Survey).

Okuda, S., Tetsuka, J., Takahashi, K., Toda, Y., Kubo, T., & Tokita, S. (2019). Association between sleep disturbance in Alzheimer's disease patients and burden on and health status of their caregivers. *Journal of neurology*, 266(6), 1490–1500. <https://doi.org/10.1007/s00415-019-09286-0>



Findings:

- The BIC-11 total score increased as the SDI score increased---a significant positive association.
- There was an association between sleep disturbances of AD and health of caregivers (sleep quality, depression, physical/mental quality of life)
- Sleep disturbances with AD patients was associated with increased burden and poorer health status of caregivers.

Implication:

- Sleep management in AD patients is important₄₃



Caregivers in Crisis: Caregiving in the Time of COVID-19

- Study by Rosalynn Carter Institute for Caregiving with support of Bristol Myers Squibb Foundation
- Between June 2 and August 1, 2020, 422 caregivers completed an online survey about changes in their lives since the pandemic

Rosalynn Carter Institute for Caregiving. (2020, October). *Caregivers in Crisis: Caregiving in the Time of COVID-19*.
<https://www.rosalynncarter.org/wp-content/uploads/2020/10/Caregivers-in-Crisis-Report-October-2020.pdf>

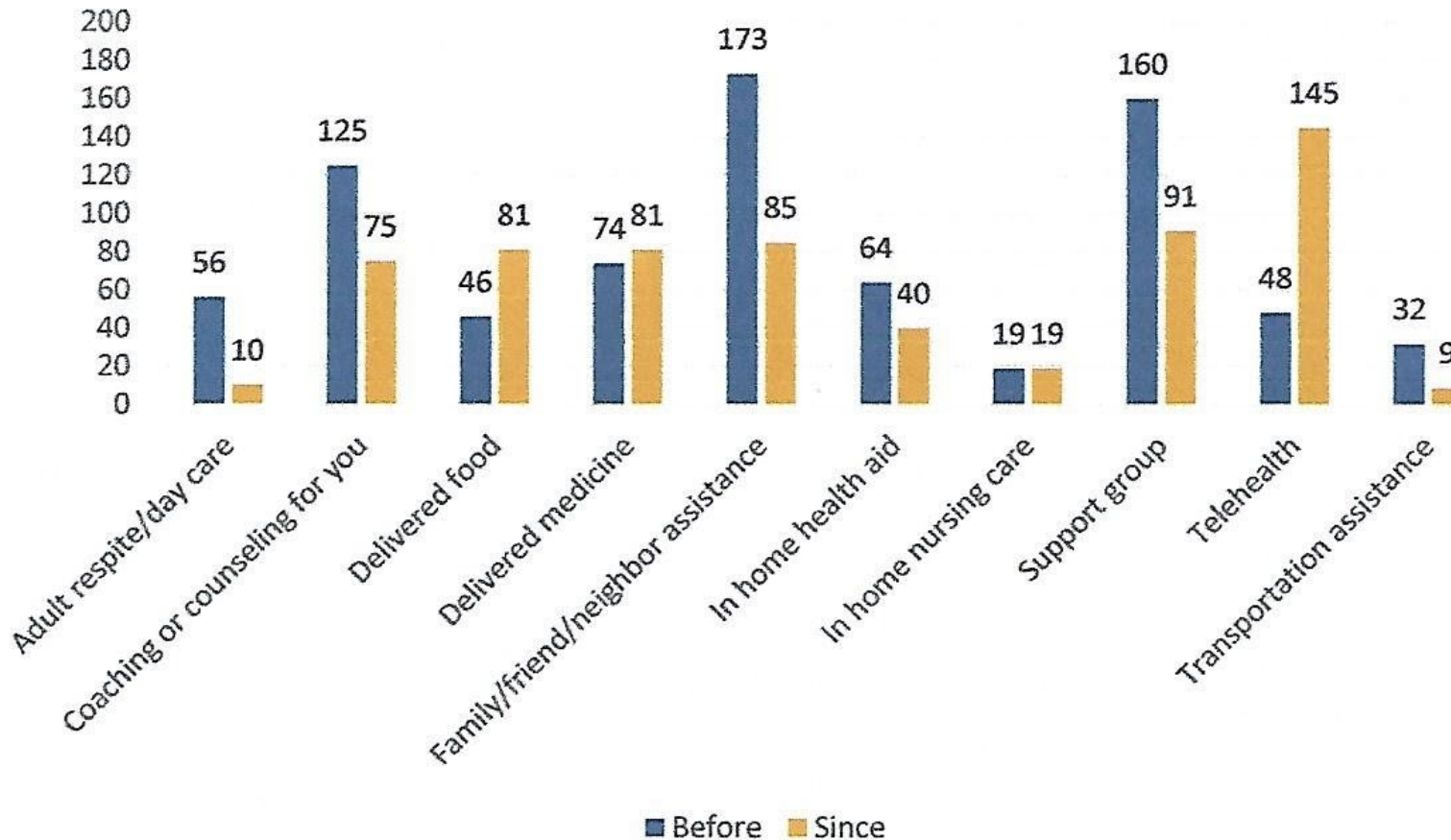


Findings:

- 83% reported increased stress related to caregiving
- 42% noted that the number of other caregivers available to help had declined
- Key sources of stress: isolation, increased burden from additional responsibilities, & worry about getting infected
- Other sources of stress: financial concerns, instability, & resource insecurity
- Caregiver burden and stress impacts caregiver's overall health and wellness & leads to increased depression and anxiety
- Burden and stress are taking their toll on relationships
- The need for support is greater, yet caregivers have received less support



Support Received Before and Since the Outbreak



Caregivers had a statistically significant decline in support from family/friends, respite/day care, coaching/counseling, support groups, & transportation, but a statistically significant increase in support from telehealth & delivery of food.



- Caregivers expressed a need for more formal and informal support:
 - Respite & daycare
 - Social interaction
 - Peer support and self-care
 - Financial assistance
 - Clinical and in-home care services
- Primary source of stress was fear of getting infected or of placing a family member at risk



Recommendations

- Increase access to peer support through remote caregiver support groups, support services, & programs that train peer specialist counselors
- Create online forums to build communities to combat isolation and empower caregivers
- Build awareness & availability of respite options
- Increase access to formal, remote mental health services for caregivers

- Provide caregiver psychoeducational programs

- Strengthen support for basic needs:



food assistance, childcare, educational support, home health
worker, home cleaning services---consider access/cost

Please complete the GWEP demographic survey:

<https://www.aheconnect.com/ncahec/evaluation.n.aspx?a=0&s=21&o=0&p=0&e=200035>

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