



# Assessing the Consequences of Caregiving for Individuals' Well-Being in a Representative Sample: A Longitudinal Analysis Using Survey and Wearable Data

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# Background



- ❑ Daily experiences are important for caregiver well-being and health
- ❑ Little understanding of how these daily experiences vary by:
  - Type of relationship (e.g., non-family and family)
  - Type of condition (e.g., ADRD vs non-ADRD)
  - Transitions into and out of caregiving



# UAS: Multimodal Data for National Surveillance of Health and Its Determinants



**Caregiving Lifecourse Experiences Assessed in Real-time (CLEAR):**  
representative, life-course sample of caregivers to follow longitudinally and collect real-time daily experience and physiological data via:

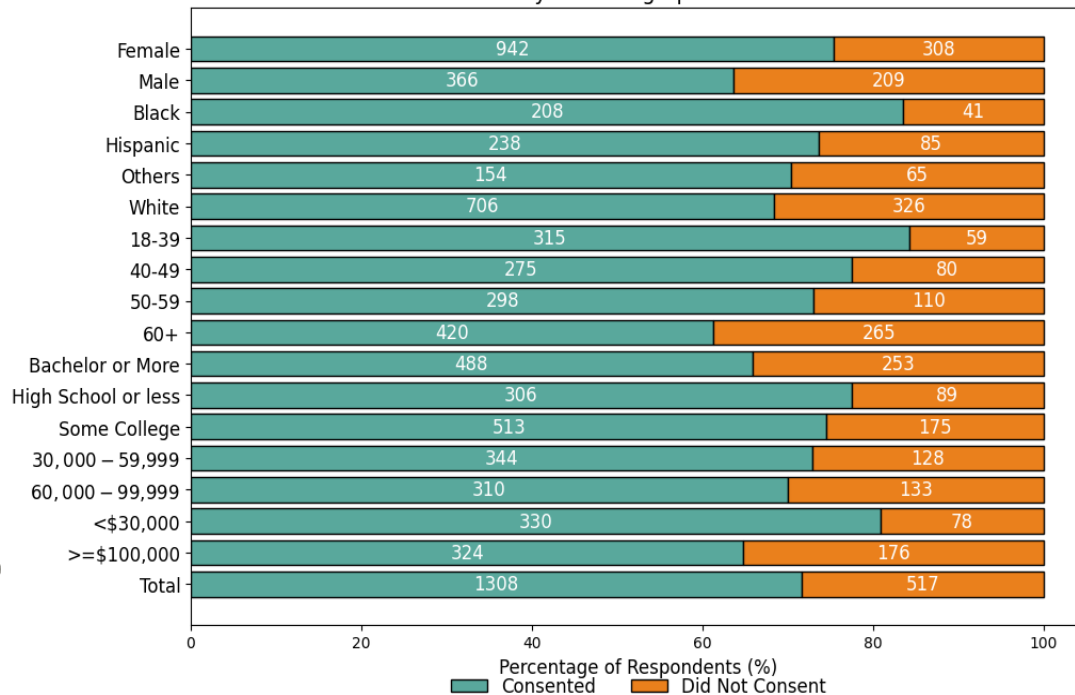
- ✓ Online surveys (annually and quarterly)
- ✓ EMAs of daily experiences for a week (smartphone app)
- ✓ Fitbits (continuous data collection for at least 1 year)

# UAS-CLEAR

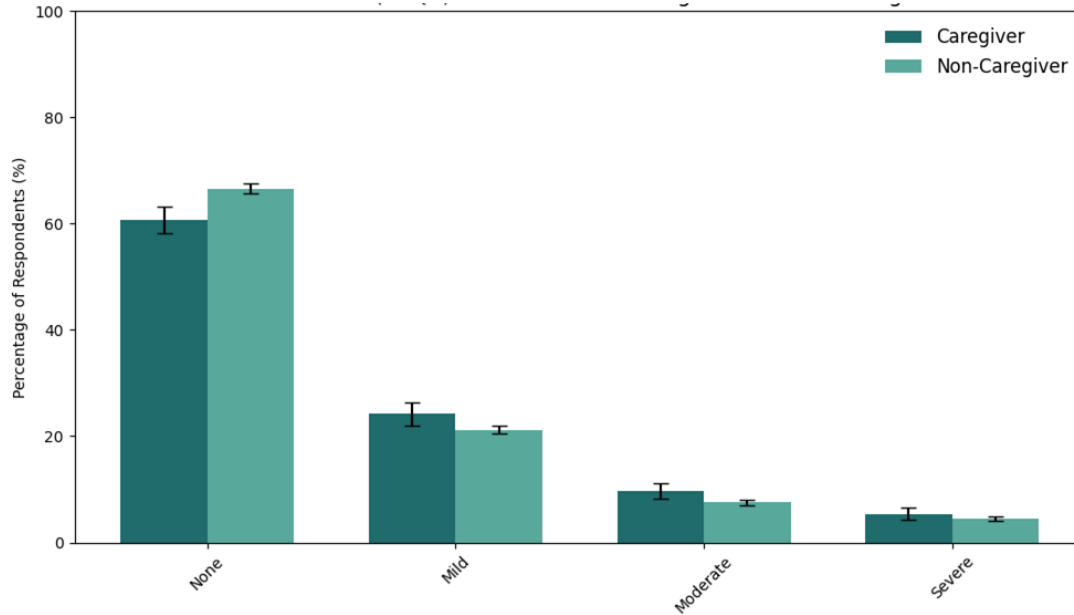


- ✓ Online surveys (quarterly and monthly)
  - 2,202 eligible caregivers recruited
  - 1,308 consented  
(to provide wearable data and do EMA for 1 week)
- ✓ Wearable devices (continuous real-time data)
  - 668 caregivers with fitbit data

Summary of Demographics in CLEAR

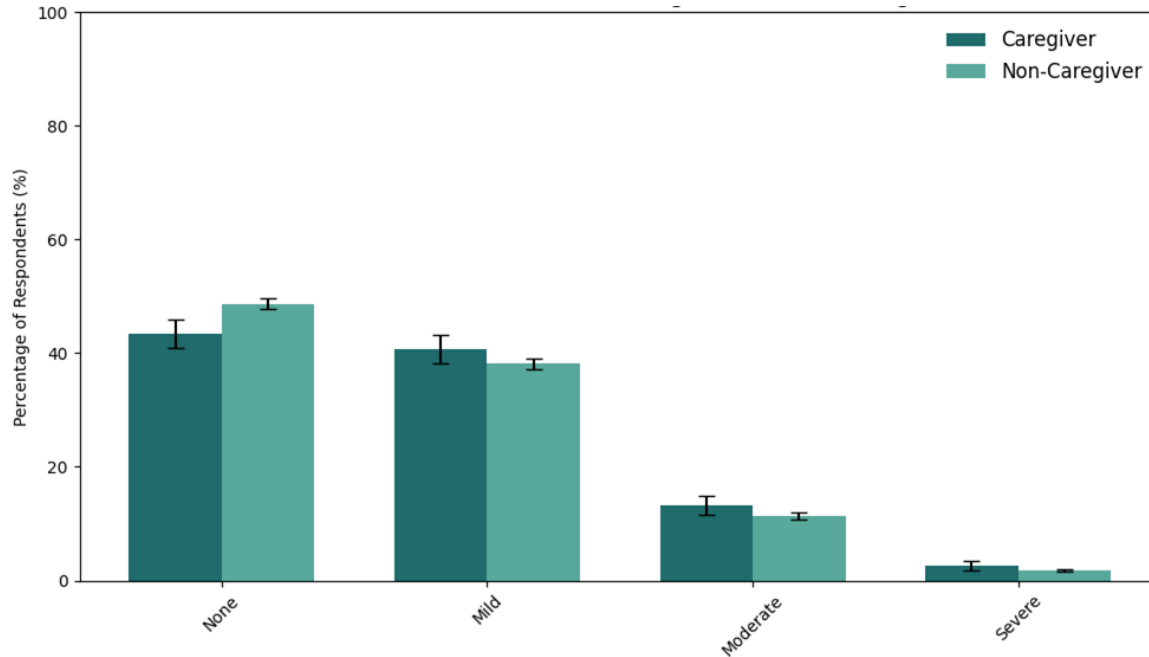


# Poor Mental Health: PHQ 4 Score Categories



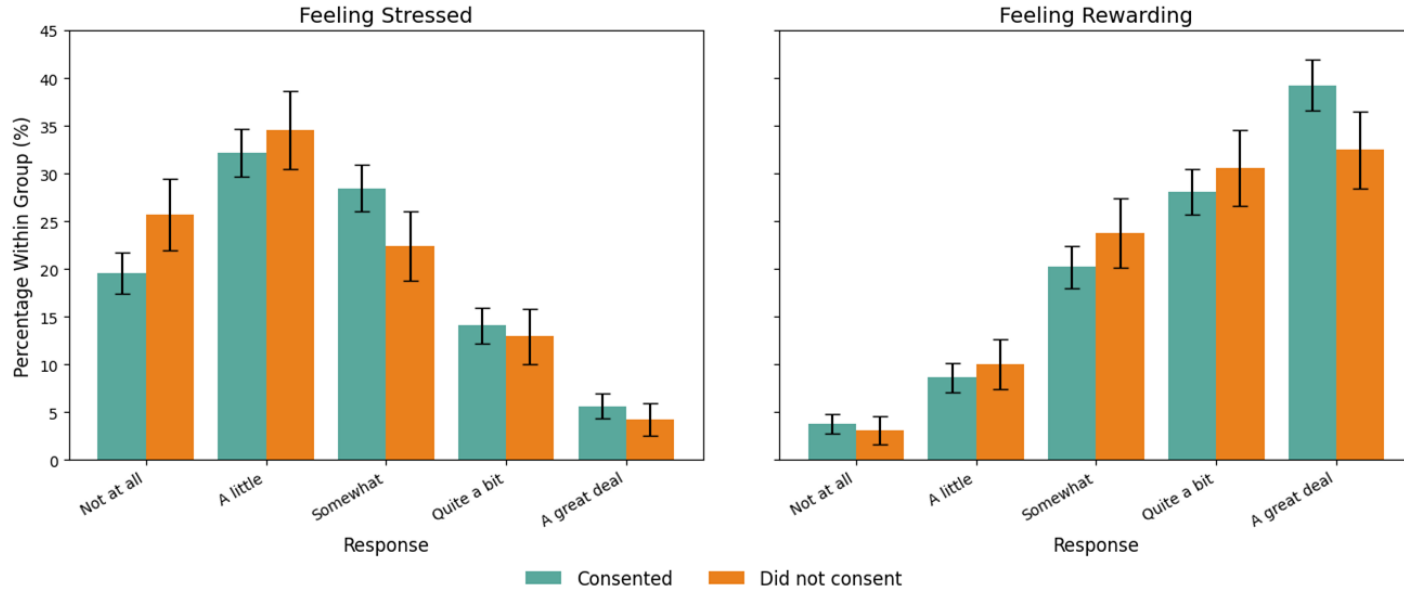
**Takeaway:** Caregivers experience more moderate and severe mental health burden than non-caregivers

# Stress: PSS4 Score Categories



**Takeaway:** Caregivers reported higher stress and pain scores than non-caregivers, and less overall health score than non-caregivers

# Feeling Stressed and Rewarded about Caregiving

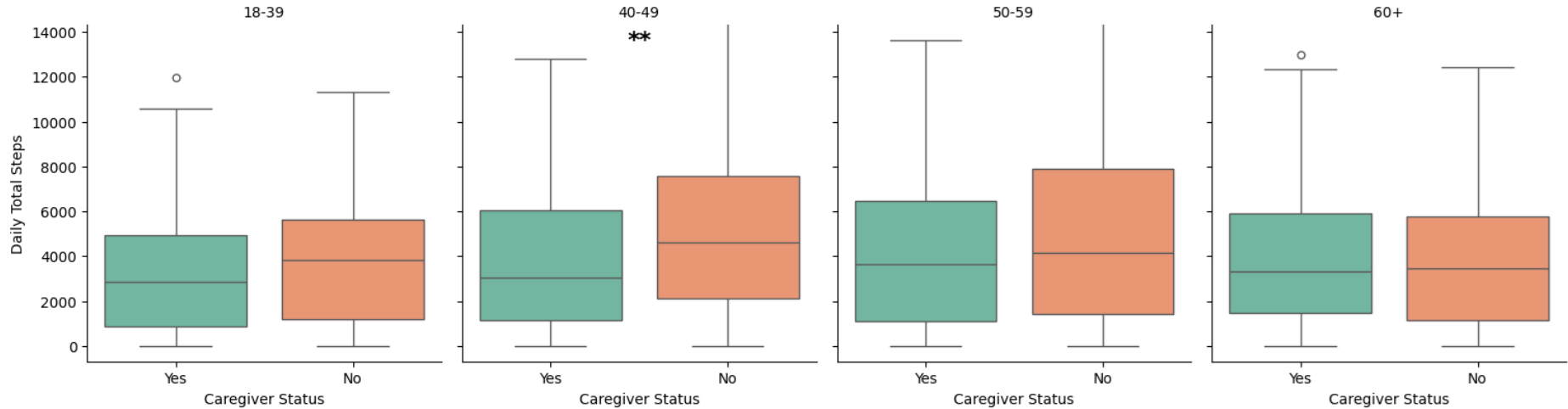


**Takeaway:** Overall, caregivers feel both stressed and rewarded. Consenters show significantly higher stress levels than non-consenters, and there is no meaningful difference in feeling rewarded

# Daily Activity: Steps

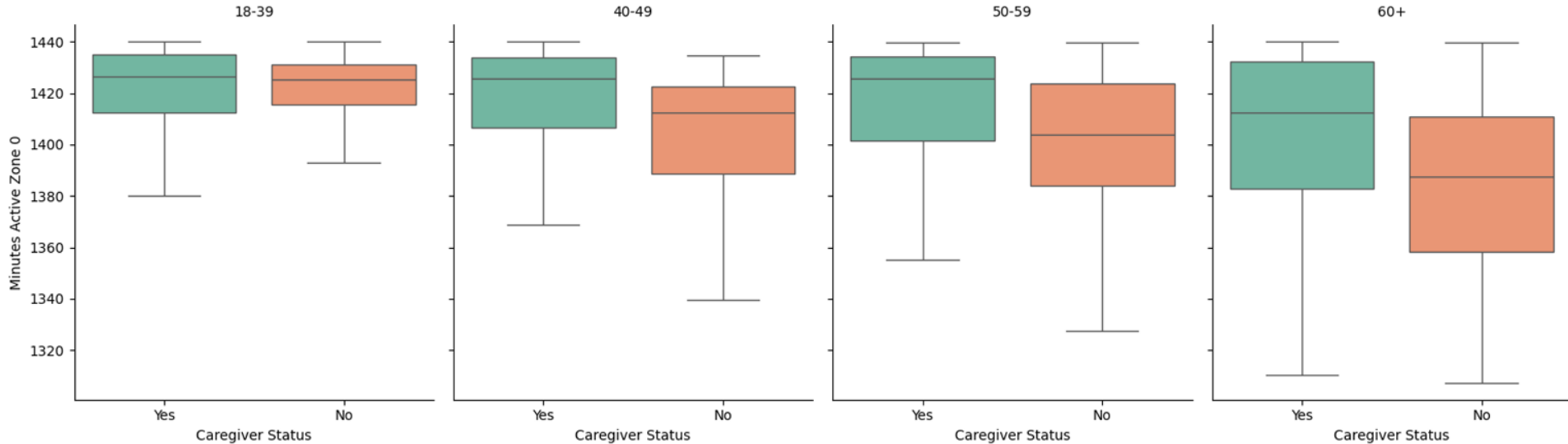


Daily Total Steps by Caregiver Status Panelled by Age Group (Person-level averages)



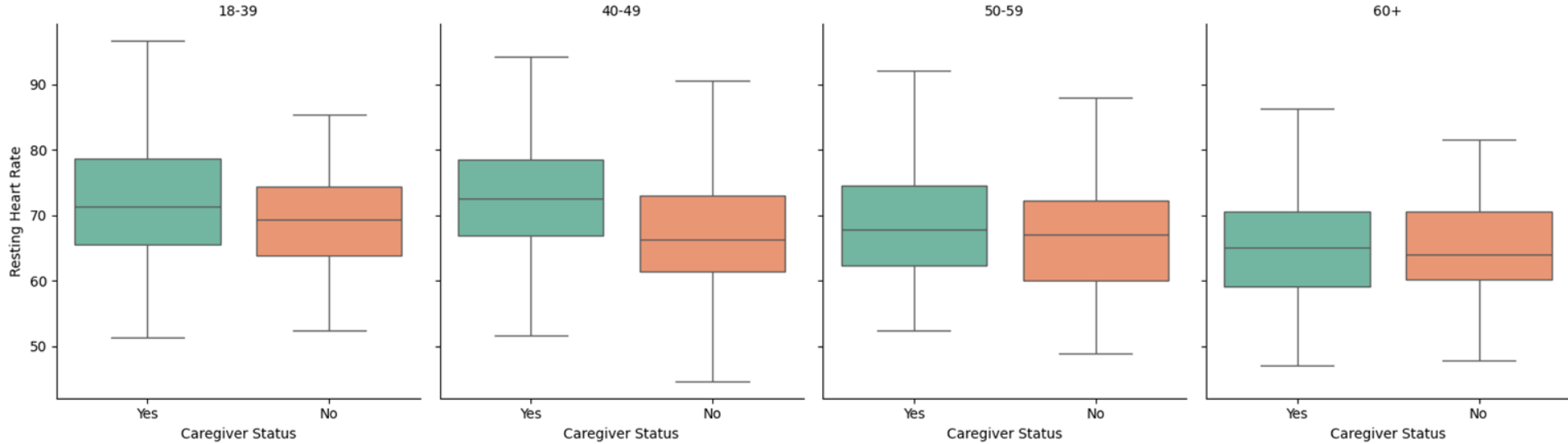
**Takeaway:** Caregivers are less active compared to non-caregivers in age 40-49 group

# Daily Activity: Minutes in Sedentary Zone



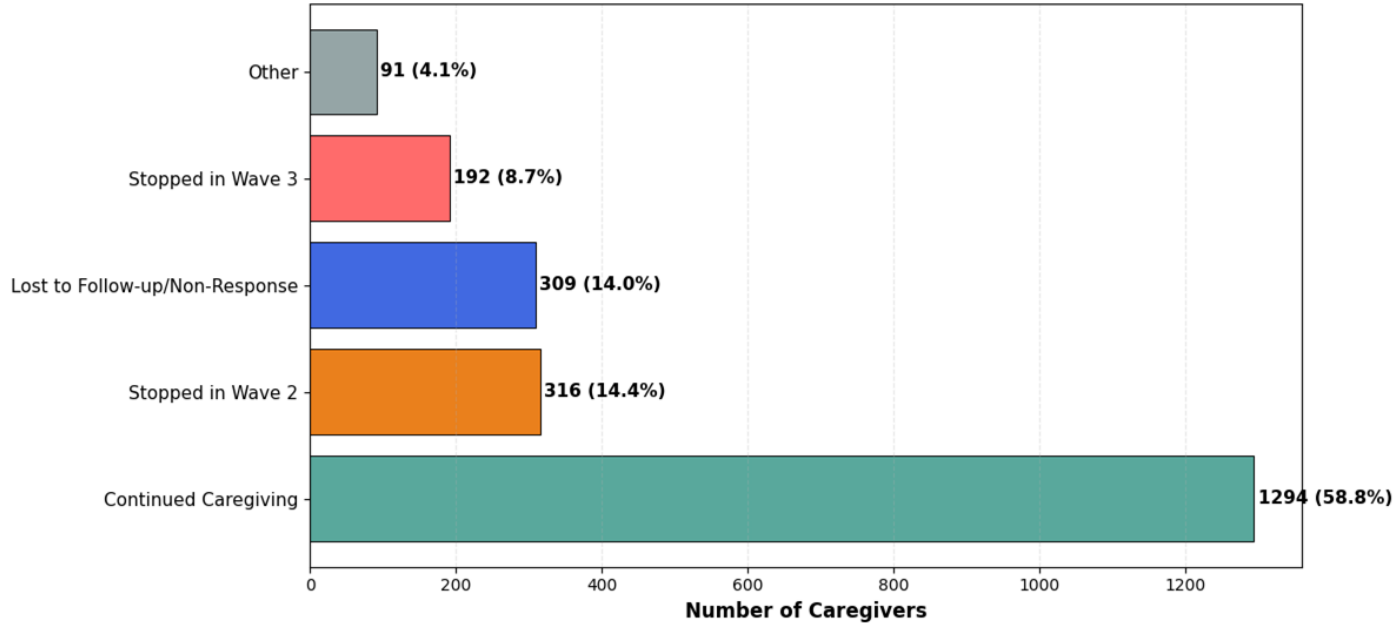
**Takeaway:** Caregivers spent more time in the sedentary zone than non-caregivers

# Resting Heart Rate



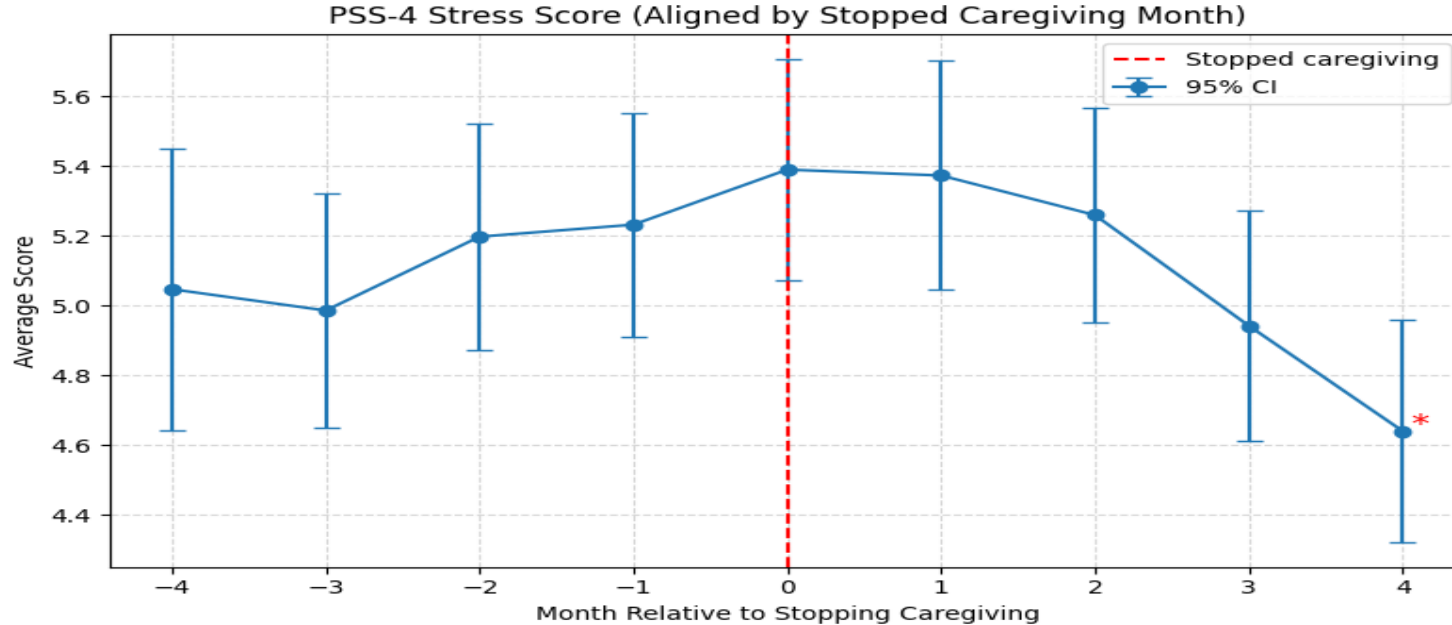
**Takeaway:** Similar or slightly higher resting heart rate for caregivers than non-caregivers

# Transition in Caregiving



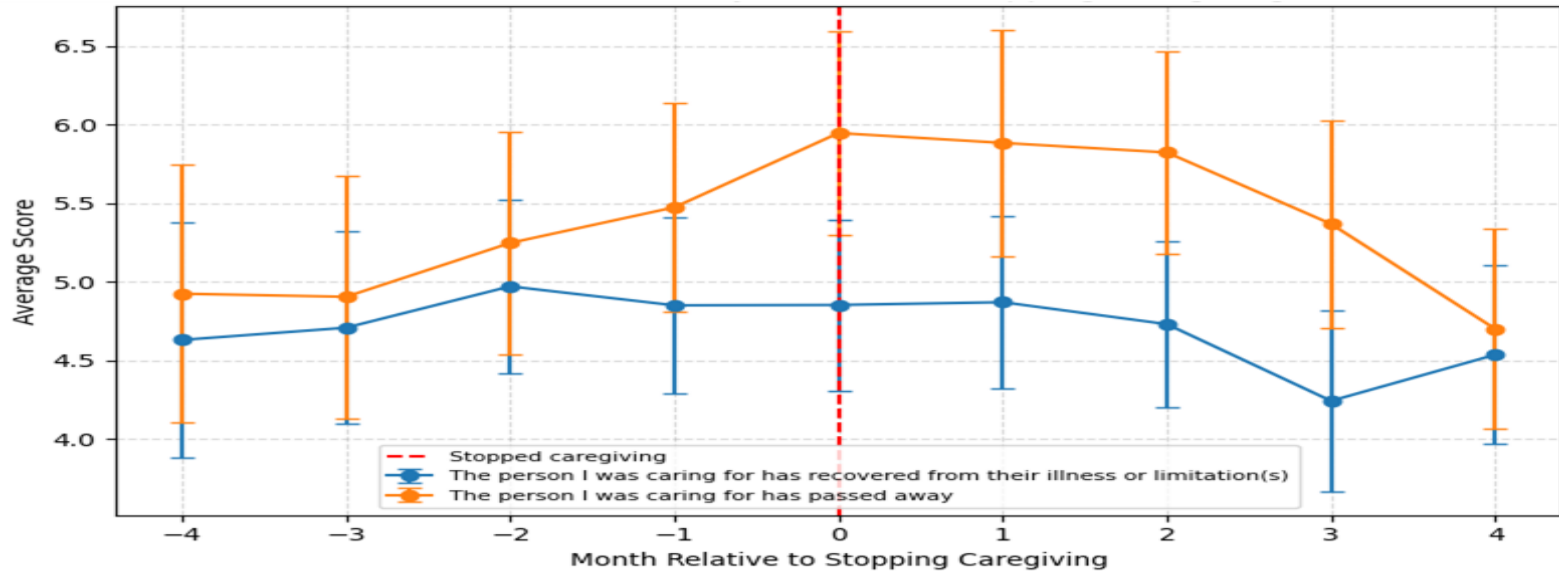
**Takeaway:** 58.8% participants continued caregiving and 23.2% participants stopped caregiving  
Two main reasons for stopped caregiving was that the care recipients passed away or recovered from their conditions

# Changes in Caregiving Status and Stress



**Takeaway:** Stress score starts improving a few months after caregiving cessation, with significant improvement observed by month 4

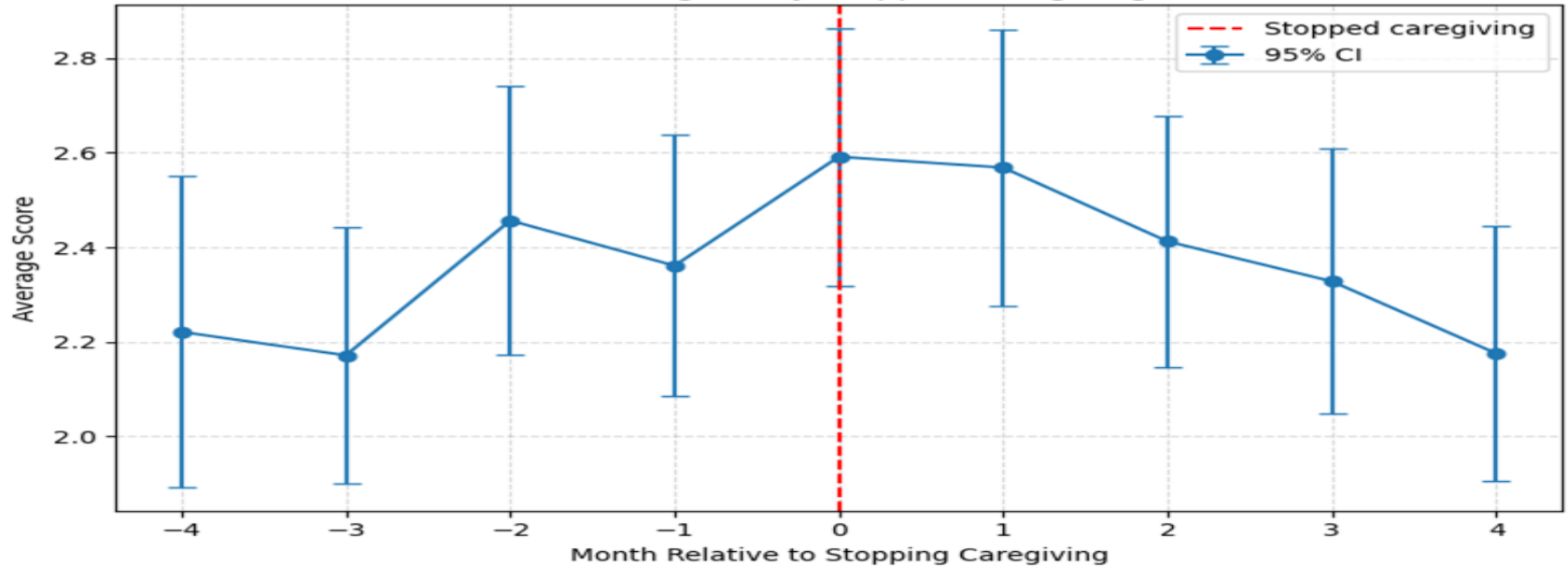
# Reasons for Stopping Caregiving and Stress



**Takeaway:** Stress level increased before care recipients passed away, and returned to the baseline value

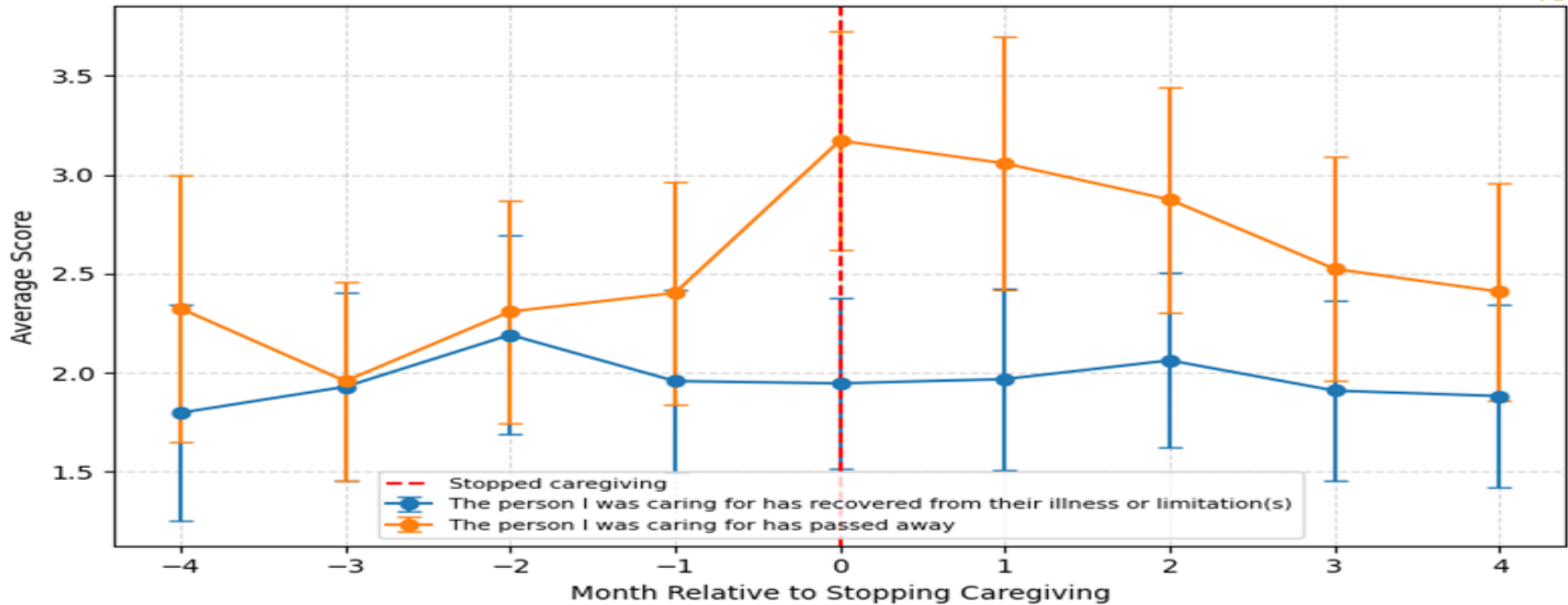
Relatively constant stress level for caregivers whose care recipients recovered

# Changes in Caregiving Status and PHQ4



**Takeaway:** PHQ4 score starts improving a few months after caregiving cessation

# Reasons for Stopping Caregiving and PHQ4



**Takeaway:** Sudden increase in mental health burden when care recipient passed away, and remains higher than that of caregivers whose care recipient recovered.

# Conclusions



- ❑ Data Design
  - ❑ Combine survey data and wearable device data to examine caregiver's daily experiences
  
- ❑ High frequency data collection allows us for first time to observe the effect of transition in and out of caregiving
  
- ❑ Psychosocial burden (stress, PHQ 4) improved after caregiving ended, largely for whose care recipients passed away
  - ❑ Psychosocial burden initially higher than that of other former caregivers.
  - ❑ Mental health subsequently recovered to levels comparable to their baseline



# Thank you!

Questions or comments?  
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