



Study Partners' Experiences:

Informal caregiving and participants' clinical characteristics



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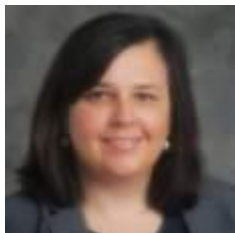


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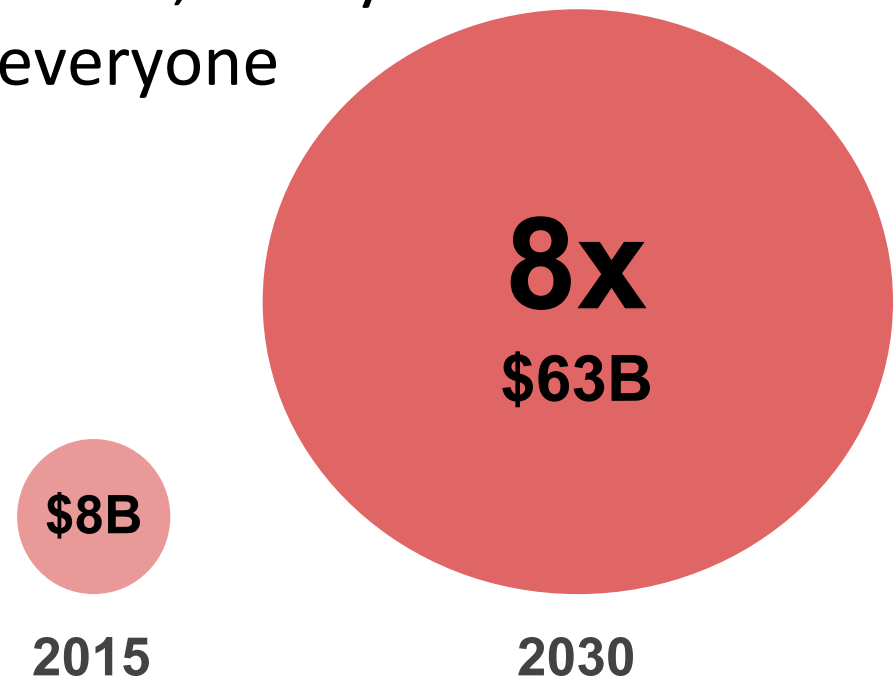
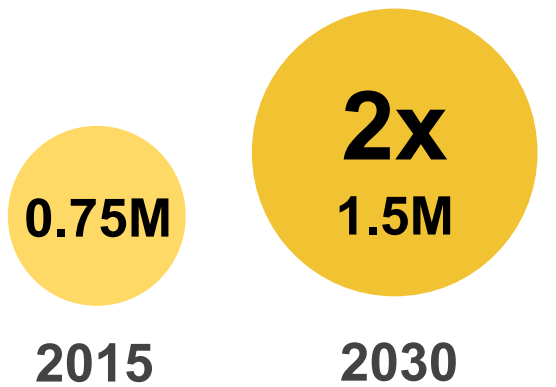


Many Many Others

- Anthony E. Lang
- Sandra E. Black
- Michael Borrie
- Corrine Fischer
- Sanjeev Kumar
- Morris Freedman
- Dallas Seitz
- Andrew Frank
- Elizabeth Finger
- Lorne Zinman
- David A. Grimes
- Mario Masellis
- Kelly M. Sunderland
- Brian Tan
- Malcolm A. Binns
- Stephen C. Strother

Motivation

- Many study partners provide informal care
- Informal care comes with costs
 - Social & personal: exhaustion, worry
 - Health & well-being: of everyone
 - Economic & financial:



What ONDRI can tell us

- Measure impact on participants as well as family and friends
- Caregiving differences across diagnoses and symptoms
- Where to better direct resources

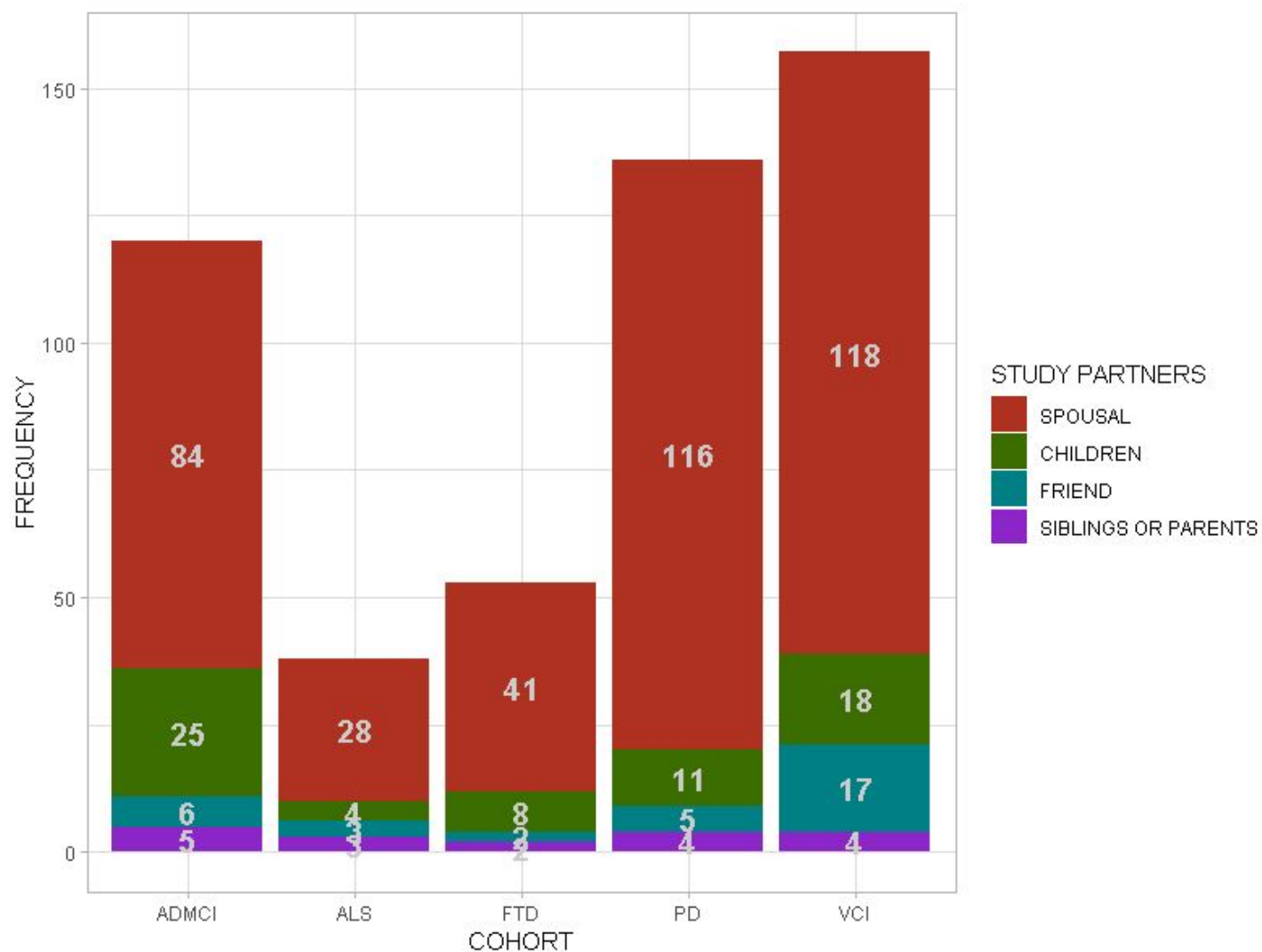
ONDRI

- 520 participants
 - Across multiple diagnoses
- Participants' study partners
 - Know the participant well
 - Regular interactions
 - Help provide information on the participant's everyday symptoms

Two measures in particular

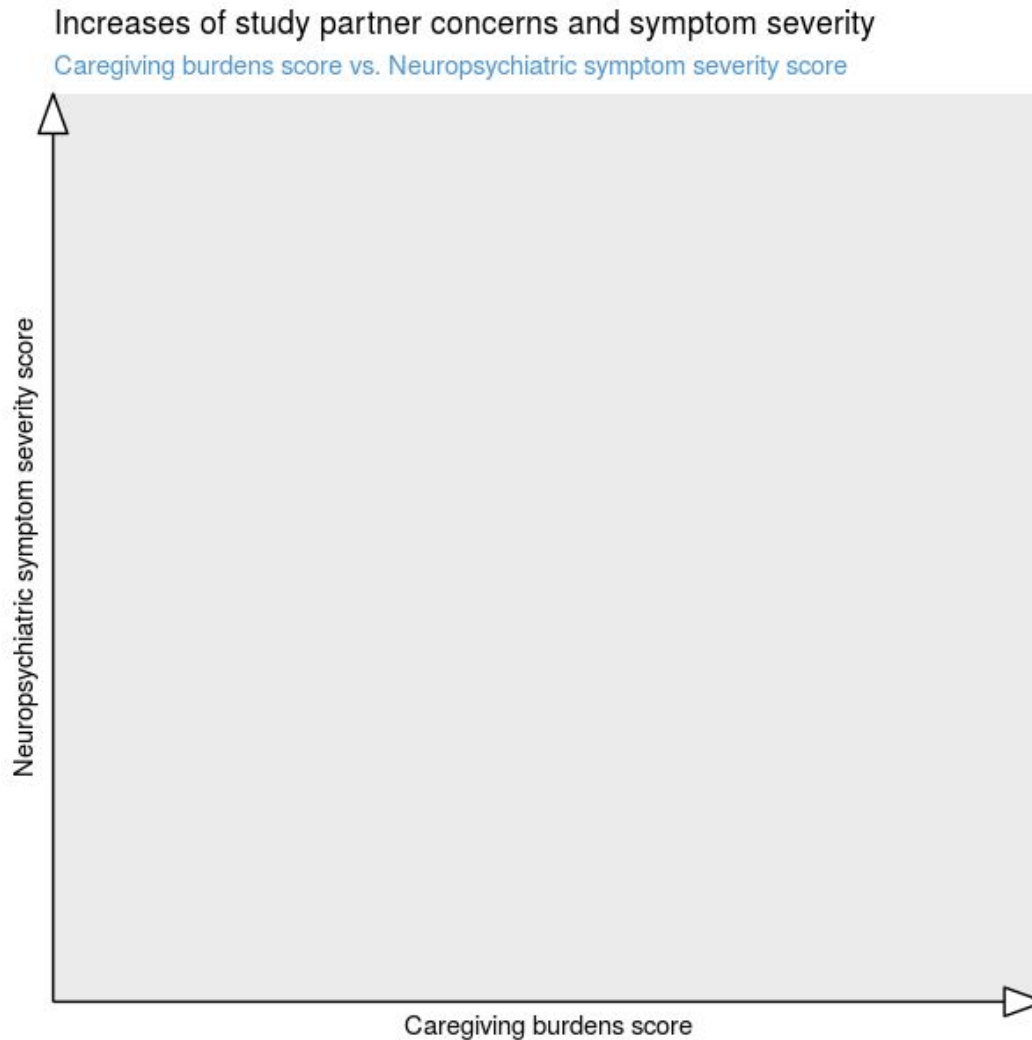
- Zarit's "Caregiving Burdens" survey
 - Ratings of experiences and concerns by study partner
- Neuropsychiatric Inventory
 - Study partner rates various symptoms of participant

Who are the Study Partners?

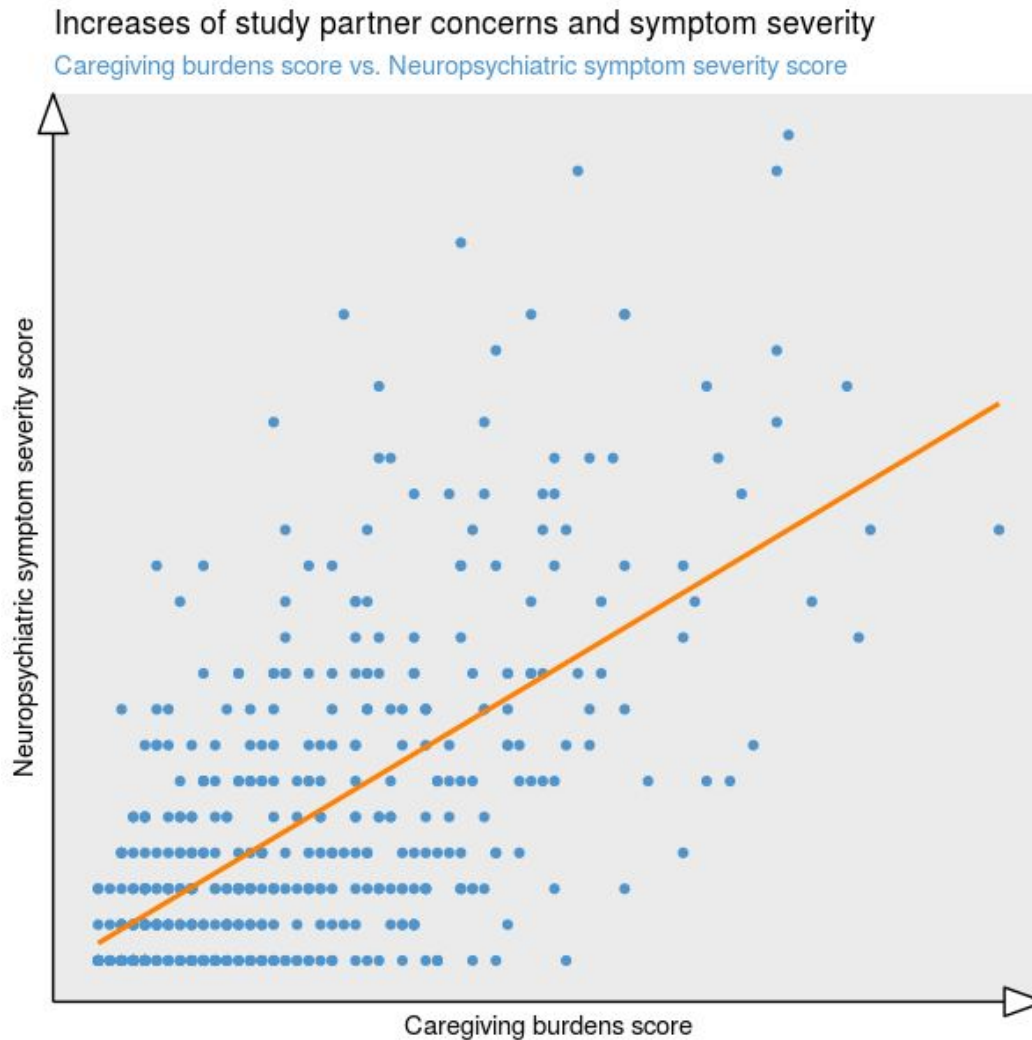


Overall concerns and symptoms

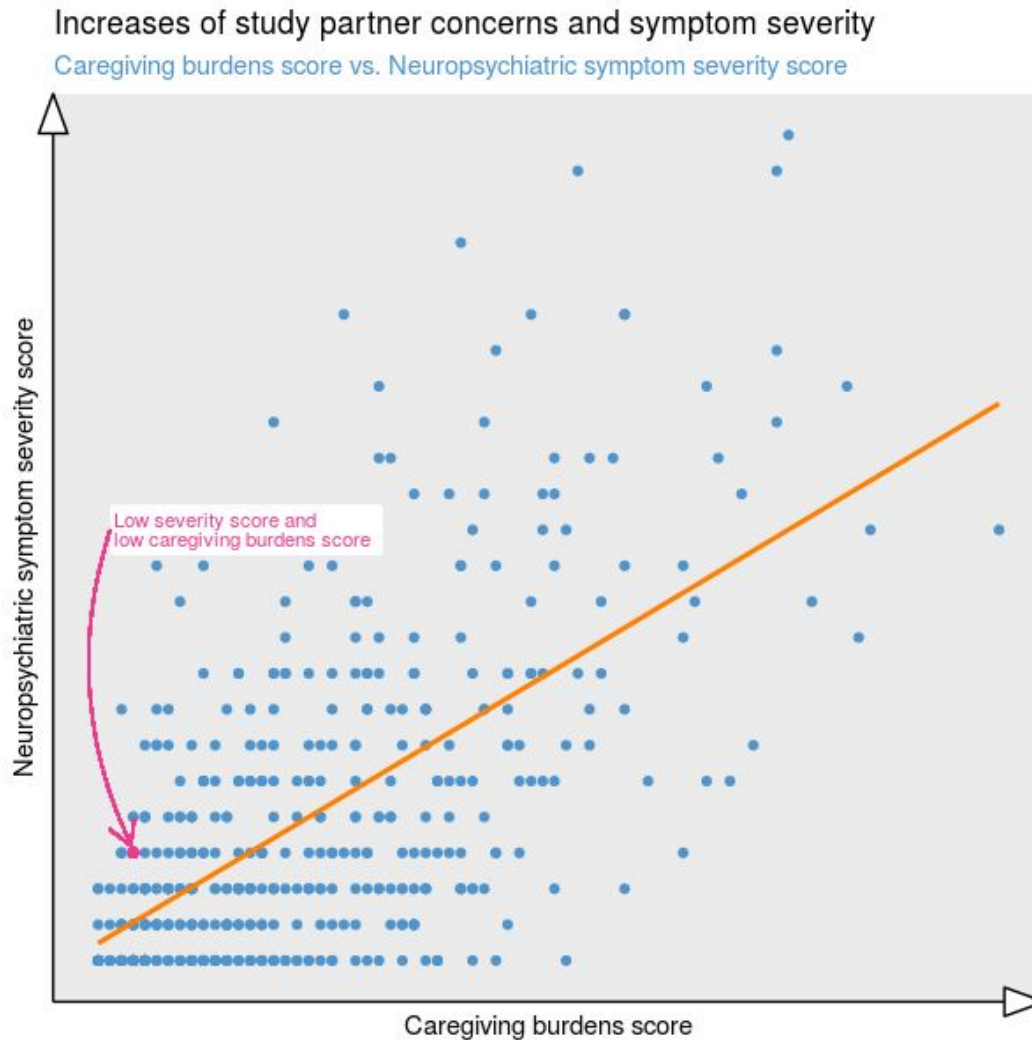
Overall concerns and symptoms



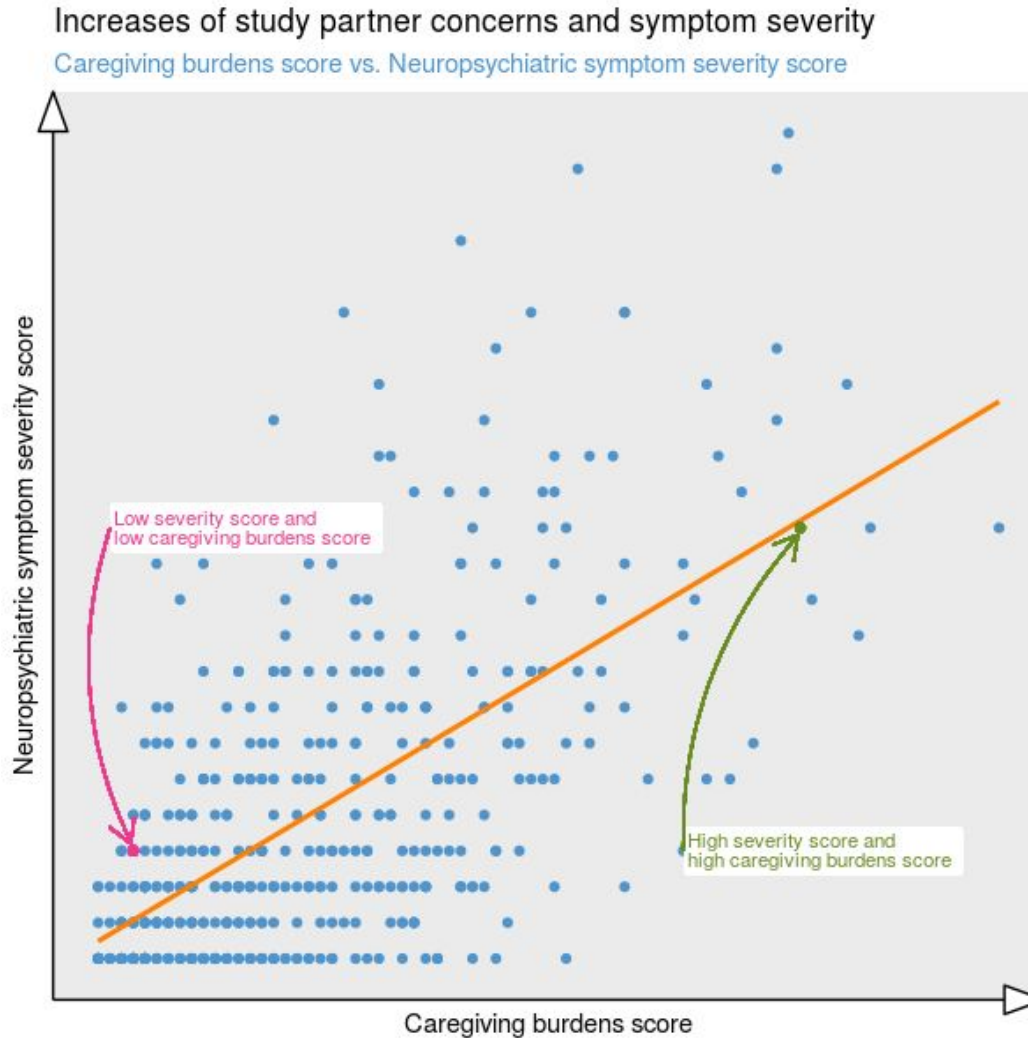
Overall concerns and symptoms



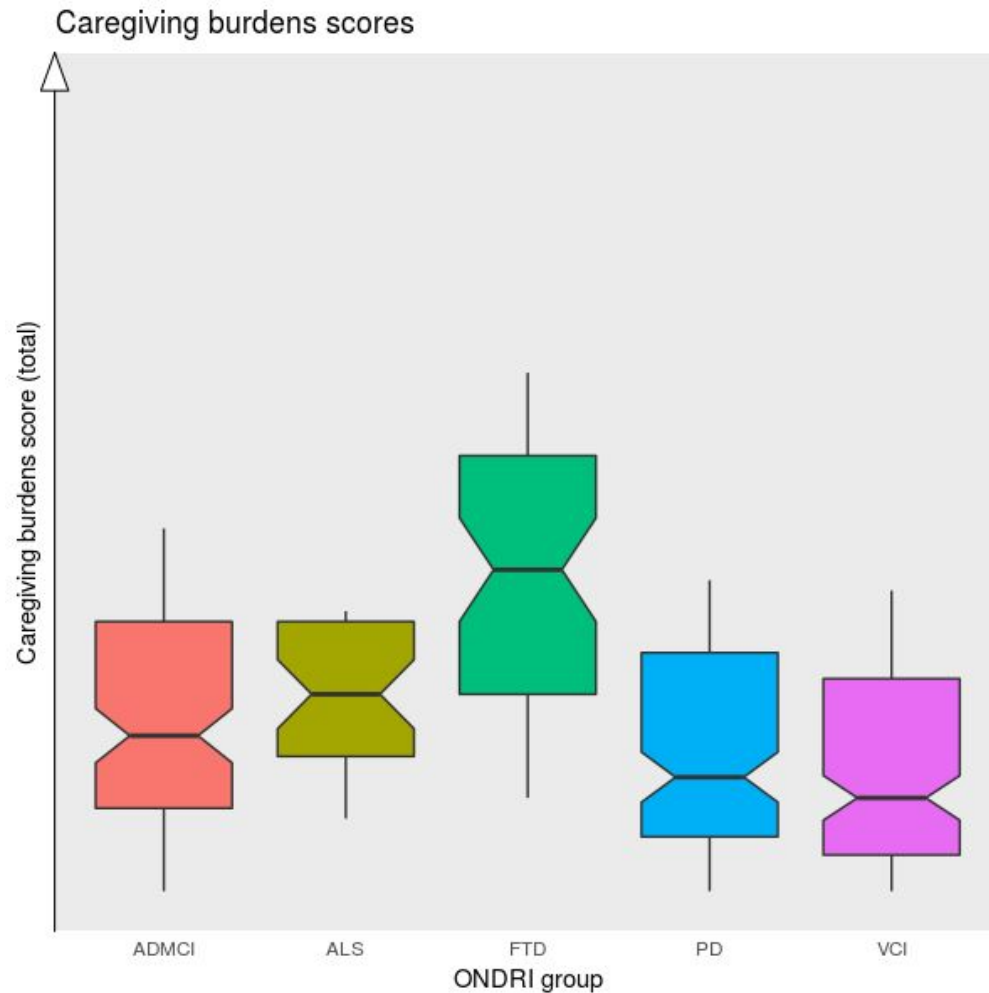
Overall concerns and symptoms



Overall concerns and symptoms



Group differences in overall concerns



Four types of study partner concerns



Four types of study partner concerns



Four types of study partner concerns

Social, family, job strain

Partner-participant strain

Four types of study partner concerns

Uncertain how to provide care

Social, family, job strain

Partner-participant strain

Four types of study partner concerns

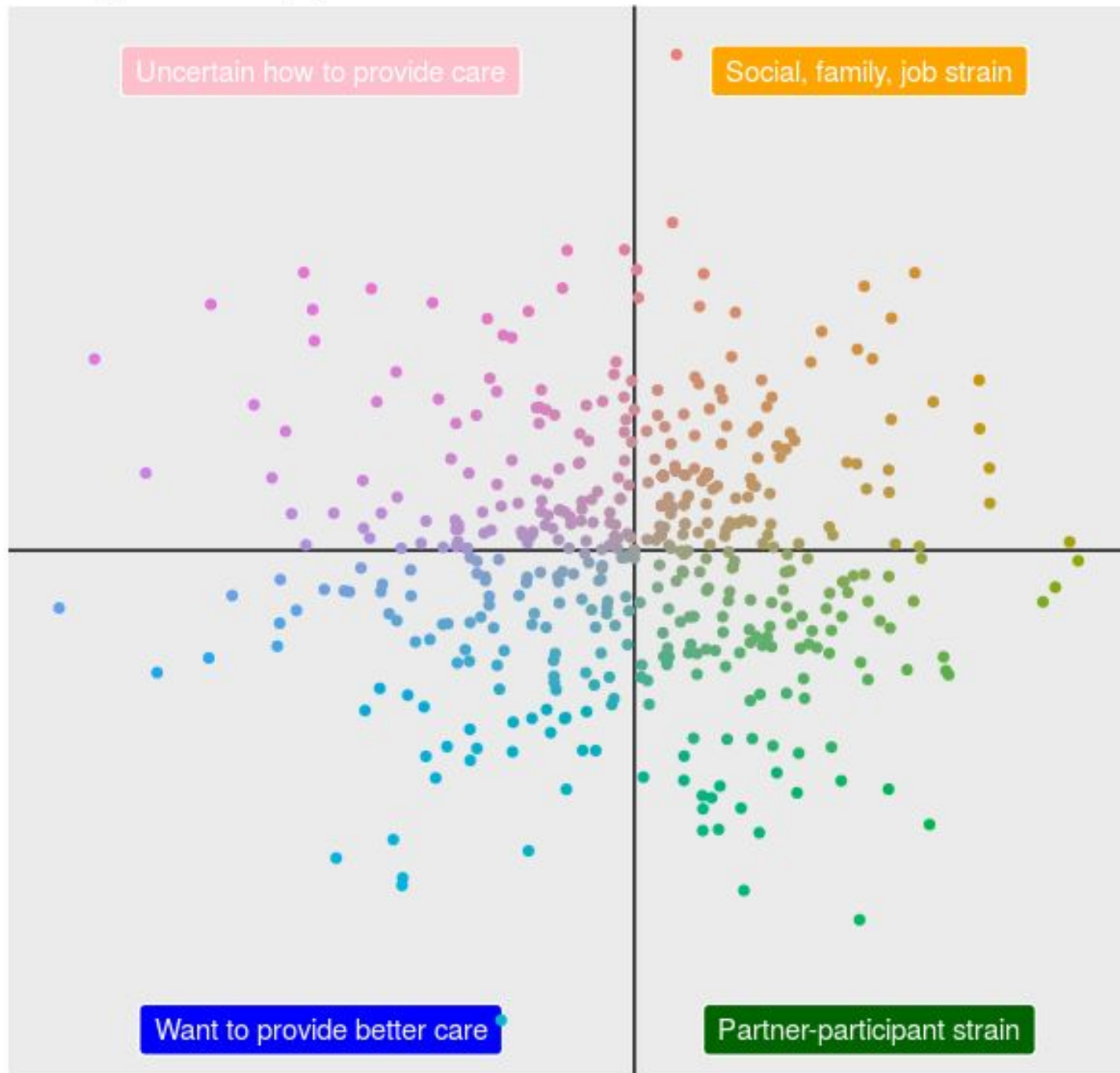
Uncertain how to provide care

Social, family, job strain

Want to provide better care

Partner-participant strain

Four types of study partner concerns



Take aways

- Overall increases of concerns
 - With symptoms
 - Within some groups
 - But that's not the whole story
- Four types of Concerns & Experiences
 - But we don't know all the reasons why yet
- Lots of data over time
 - Baseline + follow up for 2+ years
 - From genes and brains to behavior

What can we do with these findings?

- Education, information, and advocacy
 - For patients and relations
- Funding and resources
 - Health and research
- Outreach
 - OBI's Patient and Community Advisory Committee
 - Organizations such as Heart & Stroke, Alzheimer's Society of Canada

Thank you

- Working group
- ONDRI
- Ontario Brain Institute
- Participants, study partners
- PCAC
- All of you

References

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