

Caregiver Burden in PANS/PANDAS

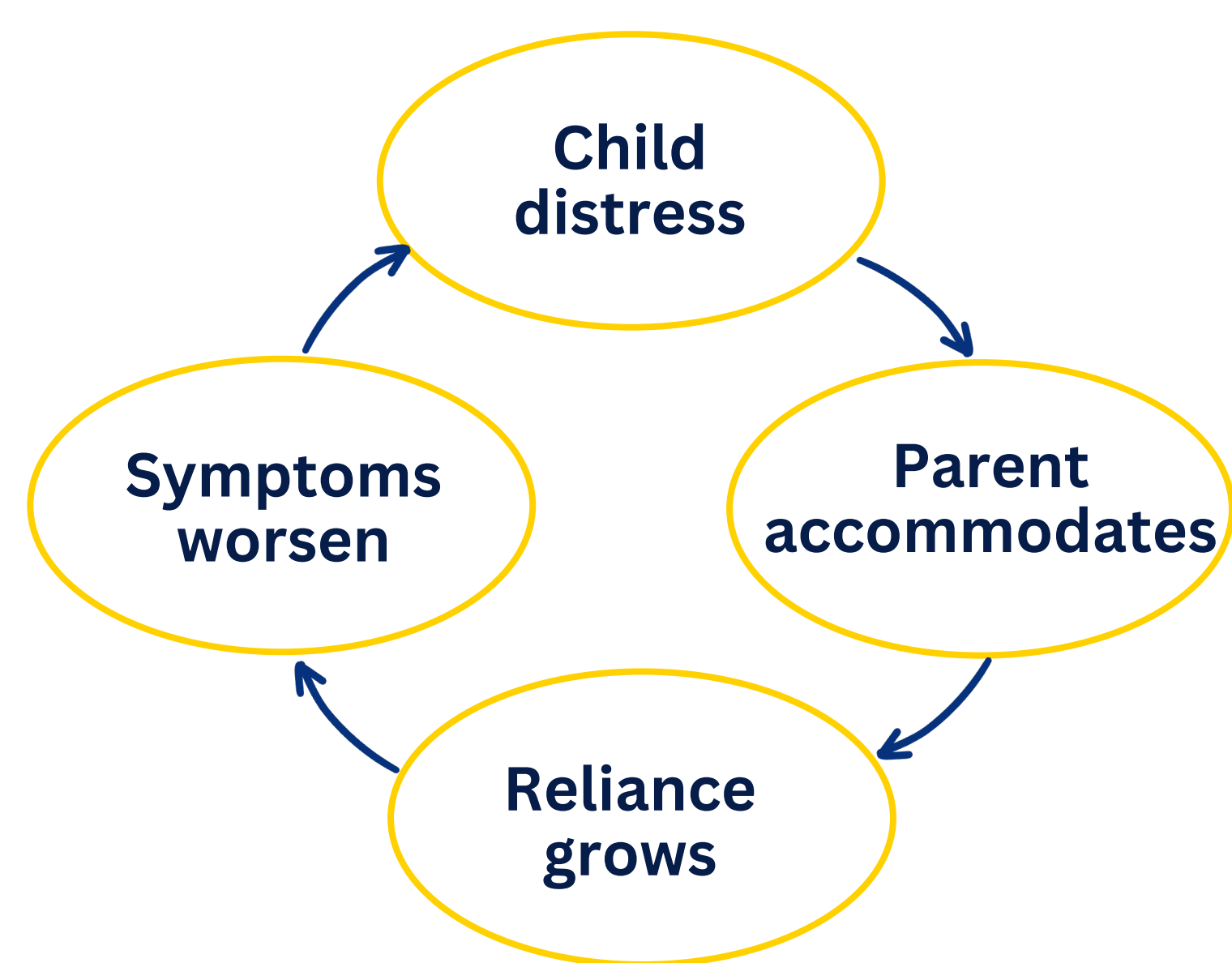
The Role of Family Accommodation, Symptom Severity & Flare Status

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PANS/PANDAS involves sudden-onset neuropsychiatric symptoms and unpredictable flares, placing substantial demands on families. Parents often adapt routines, provide reassurance or try to assist the young person to reduce distress. This is known as family accommodation. In paediatric OCD, this is associated with caregiver burden. Yet little is known about when family accommodation helps or adds to burden in PANS/PANDAS, where neuroinflammatory flares make the timing of support critical.

The psychological pathway: a reinforcement cycle

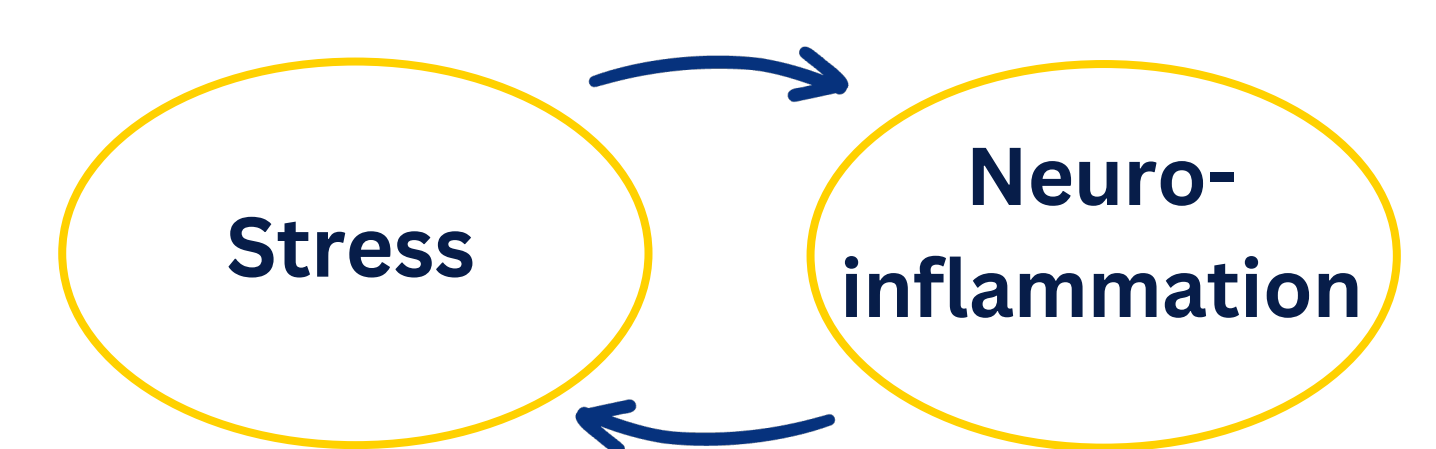
Family accommodation can bring short-term relief from a child's distress but may reinforce symptoms and increase reliance on parents over time (Lebowitz et al., 2012).



The biological pathway: neuroinflammation

PANS/PANDAS is understood as involving neuroinflammatory processes, so family accommodation approaches developed for OCD may need adaptation.

Evidence from the wider literature suggests that stress can influence neuroinflammatory processes and vice versa (Calcia et al., 2016).



Methodology

- N = 120 UK parents/caregivers of children with PANS/PANDAS
- Cross-sectional online survey
- Three questionnaires assessed symptom severity, caregiver burden and family accommodation.
- Multiple regression examined the independent contributions of symptom severity and family accommodation to caregiver burden. Additionally, flare and baseline groups were compared across all three measures.

Symptom Severity

measured by PANS 31-Item Symptom Rating Scale (PANS-31)
(Bernstein et al., 2024)

Family Accommodation

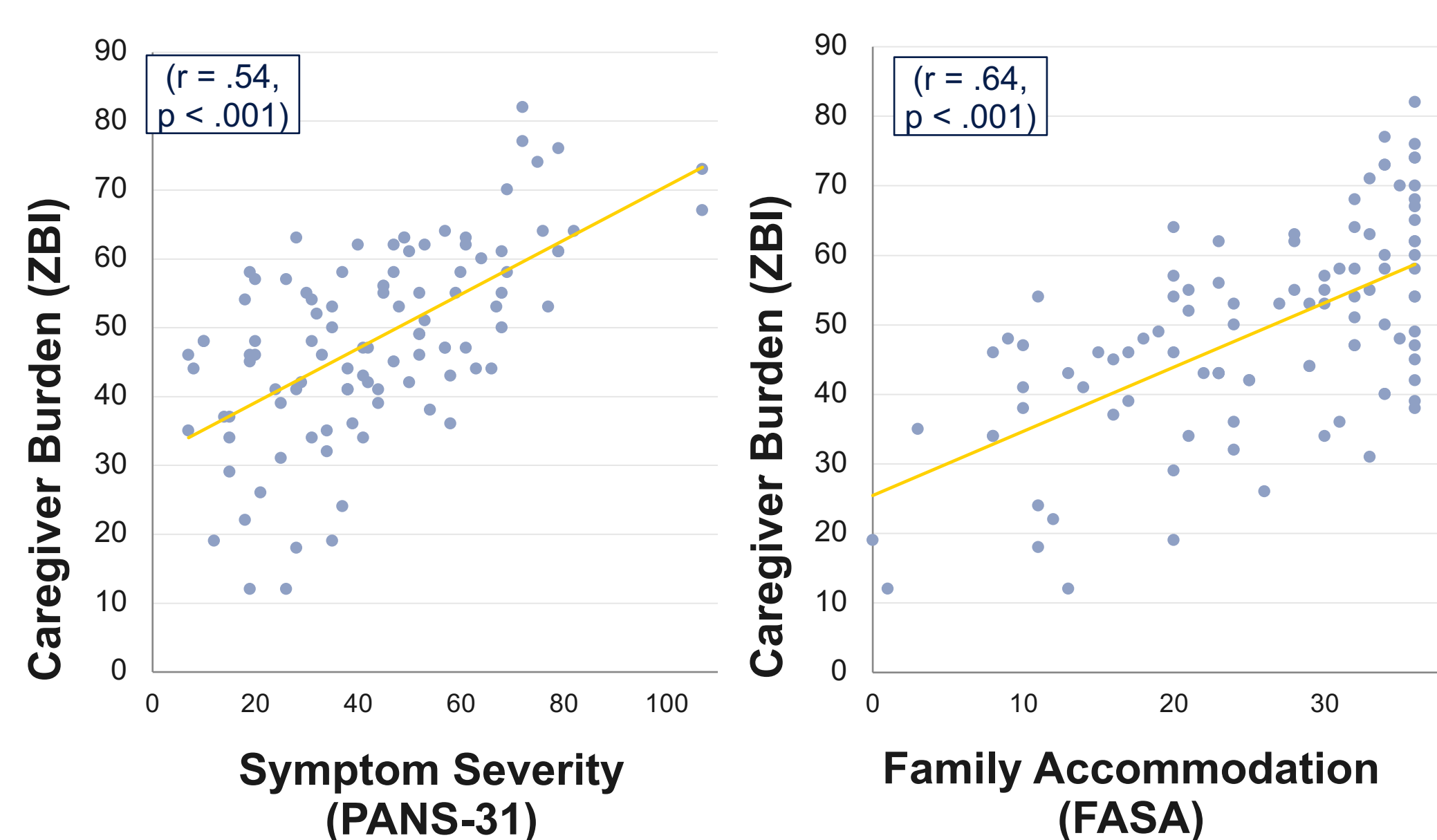
measured by Family Accommodation Scale for Anxiety (FASA)
(Lebowitz et al., 2013)

Caregiver Burden

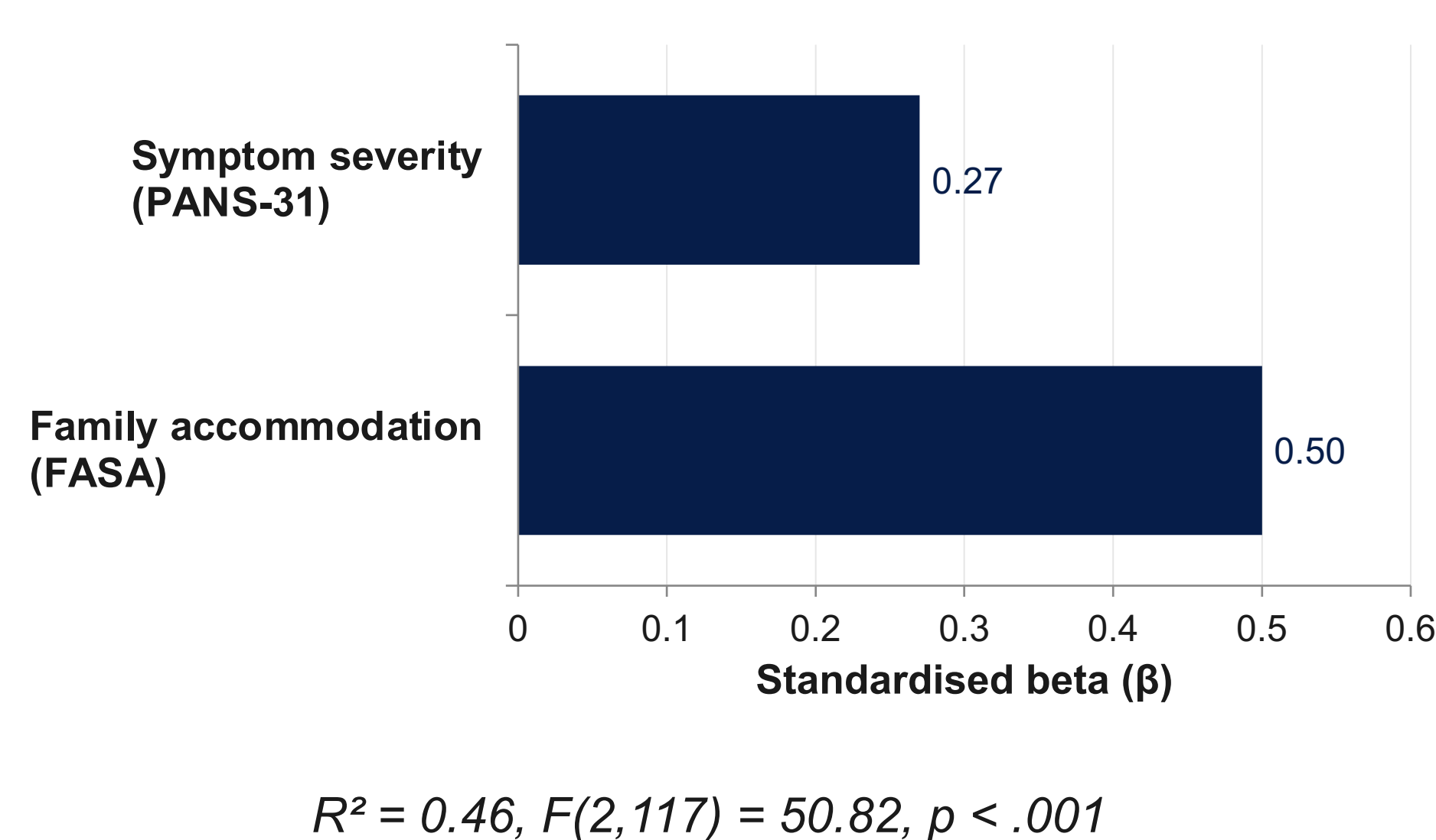
measured by Zarit Burden Interview (ZBI)
(Zarit et al., 1980)

Results

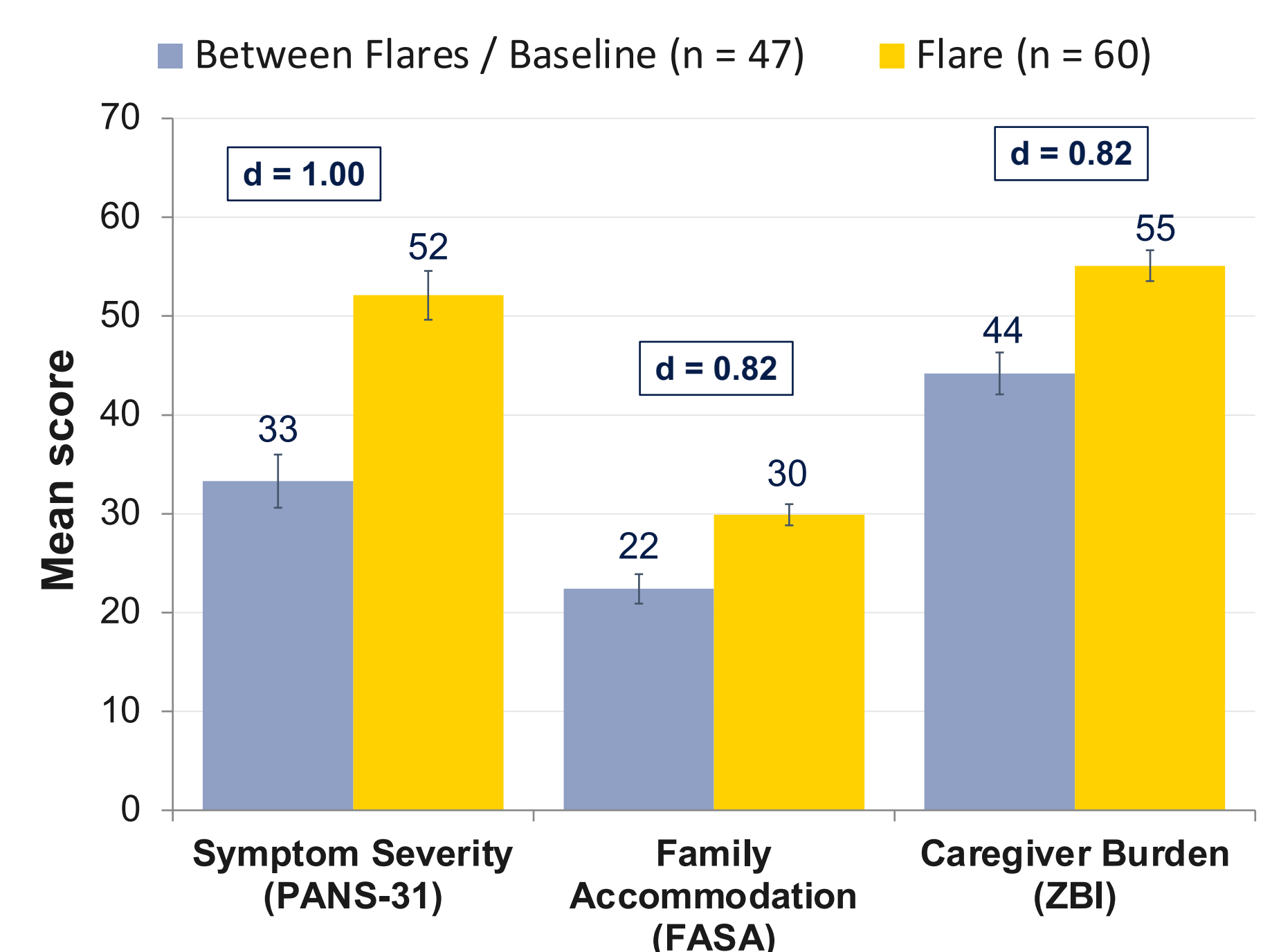
Each variable was positively associated with caregiver burden when examined separately.



Both predictors significantly contributed to caregiver burden, with family accommodation making a larger contribution.



All three measures were significantly higher during flares (all $p < .001$, $d \geq 0.80$).



Accommodation is a modifiable target but timing matters.

Implications

Family accommodation has a strong link with caregiver burden and is modifiable, making it a clear target for clinical support. Interventions already developed for OCD and anxiety disorders can be adapted but will need to account for neuroinflammatory flares and for when families are most able to engage.

This cross-sectional caregiver-report study identifies associations, not cause and effect.

References

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- Zarit et al. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist*, 20(6), 649–655.

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