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It's not what you say, it's how you say it: the impact of FTD on visual analogue scales

STATE OF THE ART: Self-report scales are widely used in clinical research, providing relatively straightforward and inexpensive assessments. However, they rest on assumptions about how respondents engage with tests and generate meaningful responses. We propose that these assumptions do not hold for those with syndromes related to frontotemporal lobar degeneration (FTLD, including behavioural-variant frontotemporal dementia and progressive supranuclear palsy).

METHODS: After OSF preregistration, we investigated differences in response patterns between 42 patients and 39 controls in a psychopharmacological study. Participants completed a 16-item visual analogue scale to assess mood and arousal. We pre-specified three primary response strategies: (I) invariance, (II) patterned, and (III) internally inconsistent. These strategies were quantified using maximum longstring analysis, entropy, and semantic synonyms respectively. Groups were compared using Bayesian statistics.

RESULTS: Patient responses featured more invariance and less internal consistency than controls, with Bayes Factor = 15.2 and Bayes Factor = 14.5 respectively, indicating strong evidence for group differences (versus no difference). Patients used a significantly more patterned response strategy than controls, but this result was dependent on the entropy measure used for analysis. The response pattern measures were good predictors of cognitive and functional measures. Both internal consistency and entropy were significant predictors of ACE-R score whilst invariance was a significant predictor of the FRS (in FTD) and PSPRS (in PSP).

CONCLUSION: These results have important implications for visual-analogue scale data from people with frontotemporal dementia or progressive supranuclear palsy. There is need for caution when interpreting self-report data, especially from clinical groups.

