Comparing Endorsements of Self-Injurious Behavior Across Two Questionnaires for Parents of Individuals with Rett Syndrome and MeCP2 Duplication

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Introduction
- Self-injurious behavior (SIB) affects between 5-15% of individuals with intellectual and developmental disabilities (IDD)
- Can have profound impacts on the quality of life for individuals and their caregivers (Didden et al., 2012; Ruef & Turnbull, 2002).
- Questionnaires can be useful in the measurement of SIB
  - Efficient and cost-effective way of evaluating SIB for a multitude of purposes
  - A number of different tools have been developed.
- Little attention has been paid to the degree to which different measures result in the same prevalence estimates of SIB within and across groups.
- The purposes of this study were to:
  - Compare endorsements of SIB on two measures: the Aberrant Behavior Checklist (ABC) and the Diagnostic Assessment for the Severely Handicapped – II (DASH-II)
  - Evaluate differences in endorsement across diagnostic groups and in relation to other clinical characteristics.

Method
Participants:
- A convenience sample of 38 parents of individuals with RTT (N=23) and parents of individuals with MeCP2 duplication (N=15) was recruited.
- RTT participants age ranged 2-36 years (M=11.9) Twenty-two RTT participants were female one was male. MeCP2 duplication participants age ranged 1-22 years (M=8.8). Five MeCP2 duplication participants were female, ten were male.
- Parents were involved in a larger study and were included in this analysis if they had completed both the ABC and the DASH-II.

Measures:
- The ABC includes three general items relating to SIB (i.e., “Does physical violence to self”) that are rated on a severity scale from 0 (not a problem) to 3 (severe) as part of the irritability subscale.
- The modified DASH-II SIB subscale includes six topography-specific subscales rated on a frequency scale of 0 (never) to 2 (often).
- Simple agreement between the questionnaires was calculated by comparing parents who endorsed at least one SIB item (i.e., subscale score ≥1) on the two questionnaires.

Results
- Ten participants (26.3%) endorsed at least one item on the ABC, and 23 (63.2%) endorsed at least one item on the DASH-II (See Figure 1).
- Endorsement on the ABC was higher in the RTT group (49.4%) than in the DUP group (13%).
- Overall agreement of endorsement of SIB on both questionnaires was low across the combined sample (59.5%), but differed across the RTT (66.7%) and MeCP2 duplication (46.7%) groups (See Figure 3).
- Although absolute agreement was poor, parents who endorsed one or more ABC-SIB items also had higher total SIB scores on the DASH-II in both diagnostic groups.
- Suggesting number of topographies and/or frequency/severity of SIB may be related to endorsement of ABC-SIB items.

Discussion
- These results suggest that prevalence estimates of SIB based on parent report measures may be affected by the questionnaire selected, and potentially by participant characteristics.
- Identification of “SIB cases” using parent report may less reliable than is typically acknowledged.
- One limitation of study is that the rating scales used may not reflect the most appropriate, or most frequently used scales for identifying SIB in this population.
- Nevertheless, these scales, along with several other published and ad hoc measures, are being used as measures of SIB by researchers.
- Additional research is needed to identify the specific factors that affect caregivers’ responding if such instruments are to be used to classify participants in groups for research.

References

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