

Self Injury, Challenging Behaviors, and Stress Among Young Autistic Children

Andrew Medlin DDS, Adele Dimian PhD, Amy Esler PhD, Jessica Simacek PhD

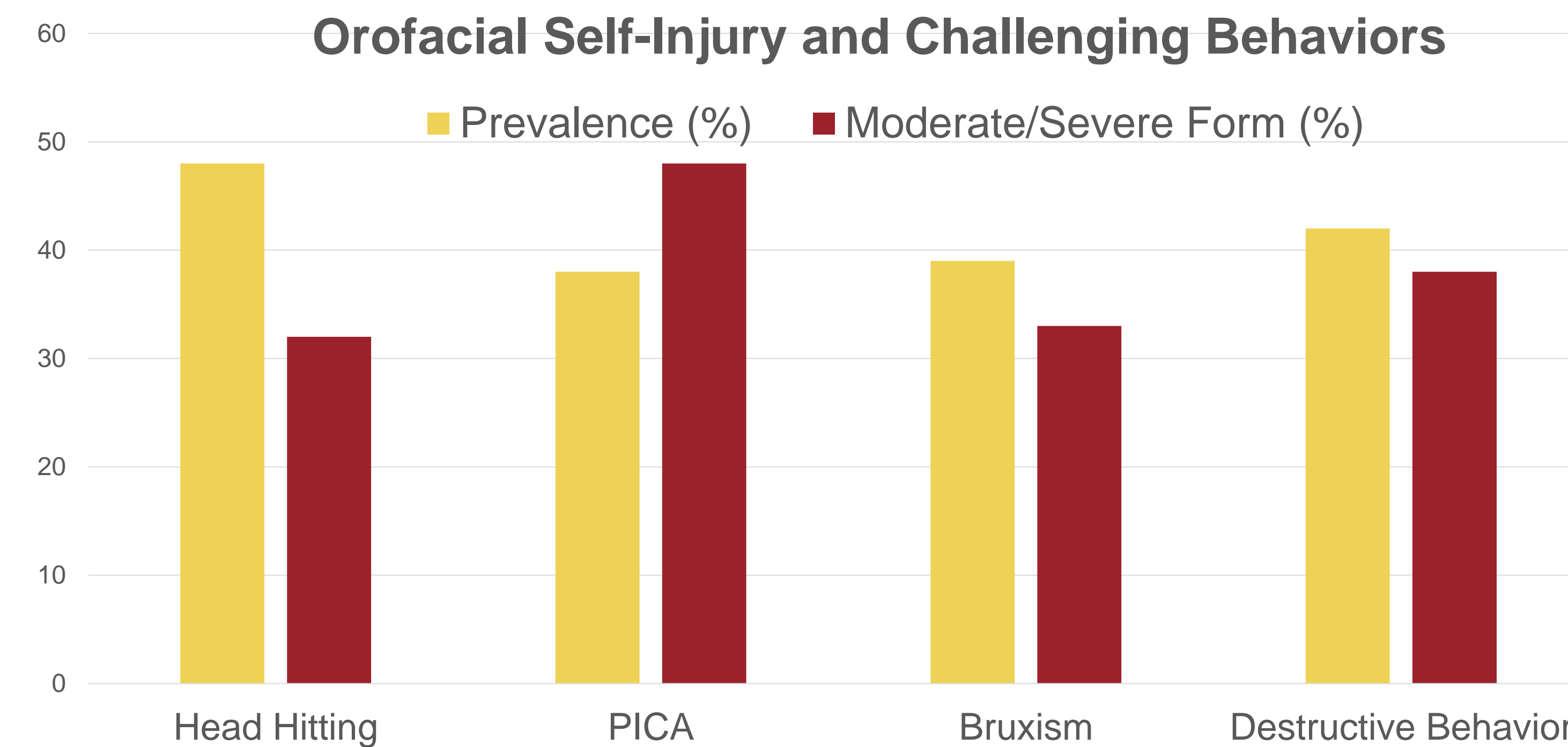
Introduction

- Autism spectrum disorder (ASD), characterized by **deficits in social communication** and the presence of **restricted, repetitive behaviors** or interests, is a neurodevelopmental disorder.^{8,9}
- The prevalence of ASD in young children is high, with 4-year-olds identified at a rate of 1 in 31 (approx. 3.2%). The average age of diagnosis is around 5 years.⁷
- Early repetitive challenging behaviors, including self-injurious behaviors (SIB), aggression, and tantrums, are common caregiver concerns.⁹
- Early intervention is critical for reducing the severity and persistence of challenging behavior and improving the quality of life for the child and family.^{10,11}
- This growing need for early intervention is met with an unfortunate reality of shortages of providers, geographic service deserts, and related barriers and disparities in care access, resulting in months to years of delayed access to care.⁶
- The purpose of this study was to better understand the incidence of orofacial self-injurious behaviors (SIB) and other challenging behaviors in autistic children 5 years and younger and to evaluate the correlation with overall family stress.**

Methods

- This study was an interprofessional collaboration between the University of Minnesota Institute on Community Integration and the Pediatric Dentistry program.**
- IRB approval (STUDY00013893).** Approval was initially received for the Autism First Bridging Barriers parent study and then amended to allow for the inclusion of this study.
- Participants and Recruitment.** Included children 1-5 years old who were waitlisted for either an evaluation for autism or early intervention and at least one caregiver. Recruited through evaluation clinics, community intervention providers, online, and through community events.
- Study Design.** Cross-sectional analysis
- Child Measures.** Caregivers completed electronic questionnaires upon entry to the study including the Behavior Problems Inventory¹, the Repetitive Behavior Scale for Early Childhood⁴, Autism Impact Measures², and the Autism Family Experience Questionnaire³. We also collected the Parenting Stress Index – Short Form⁵ to assess caregiver stress level. These surveys are measured using a numerical Likert scale to assess frequency (0-4) and severity (0-3), with 0 being the least.
- Analytic Methods.** Our preliminary analyses included descriptive analyses, Spearman Rank correlations, and hierarchical regression analysis to evaluate the relation between caregiver stress and challenging behavior.

Results



Participant Sample (N = 77)

(M age = 38.5 months; SD = 14 months) with the following child demographics: a) 44% endorsed a race other than white, b) 32% endorsed Hispanic ethnicity and 20% spoke Spanish as primary home language, c) 14% multi-race, d) 21% endorsed being single parents, e) 10% endorsed incomes below \$19,999 per year, and f) 10% resided in rural locations.

Mean Participant Scores from Caregiver Surveys (Table 1)

| | Group Mean | Standard Deviation | Scoring System | Test Measure |
|---|------------|--------------------|------------------|--|
| Child Cognitive Level | 73.84 | (19.62) | Standardized 100 | Assesses child cognitive development |
| Repetitive Behavior Scale (RBS-EC) | 54.62 | (26.23) | Likert 0-136 | Assesses restrictive, repetitive, ritualistic, and self-directed behaviors |
| Behavior Problems Inventory (BPI) Total | 31.4 | (18.36) | Likert | Assesses self-injurious, stereotyped, and aggressive behaviors in ASD and ID/D |
| BPI Severity score | 8.9 | (7.75) | Likert | Assesses maladaptive behavior severity |
| Autism Impact (AIM) | 207.17 | (49.28) | Likert 0-290 | Quantifies ASD features and validates intervention outcomes |
| Autism Family Quality of Life (AFEQ) | 133.36 | (23.21) | Likert 48-240 | Quantifies family experience for ASD children |

Pre-Intervention Children Engaged in High Levels of Aggression and Self Injury; Parent Stress Greater When Children Engaged in Self Injury But Not Aggression

Pre-intervention, 86% of the children engaged in aggression and 73% engaged in some self-injurious behavior (SIB). Severity of both aggression and SIB was significantly increased for those with more repetitive behavior and other autistic features (atypical behaviors, communication challenges, and difficulties with social reciprocity). Caregiver stress was statistically significantly greater if they endorsed SIB as occurring prior to intervention ($t(41)=-2.76, p=.009$), but wasn't for aggression ($t(41)=-0.61, p=.55$).

The Relation of Challenging Behaviors and Parent Stress

Total stress, parenting distress, parent child dysfunctional interaction, and difficult child scores were all positively correlated with with severity of autism symptoms ($r_s = .59, p < .001$), family quality of life ($r_s = .67, p < .001$; higher AFEQ scores indicate poorer outcomes), and overall repetitive behavior scores ($r_s = .60, p < .001$). The stepwise model fit significantly predicted caregiver total stress scores ($R^2 = 0.58, \text{Adj. } R^2 = 0.54, F(1, 34), p = .03$) with significant predictors including AFEQ ($R^2 = 0.62, p < .001$), behavior severity scores ($R^2 = 0.99, p = .03$), and age ($R^2 = -0.42, p = .03$)

Discussion

- The study surveys are designed to assess how ASD symptoms affect a child's everyday life. The results in Table 1 show the study participants are greatly affected in all aspects of life starting at a very young age.
- Newly diagnosed autistic families experience significant stress and uncertainty. Parents of children with SIB at study entry were more likely to endorse higher levels of stress.
- PICA and bruxism are considered self-injurious behaviors. Both conditions can cause significant damage to oral structures and affect quality of life.
- Having an established dental home is very important for these families to address concerns and receive guidance. These topographies can not only lead to loss of tooth structure, but also systemic affects.
- Early intervention is critically important to improve outcomes and limit challenging behaviors. Telehealth can be a bridge for families with limited access. Initial Bridging Barriers results show telehealth can be effective in decreasing severity of challenging behaviors with high rates of caregiver acceptance and low attrition rates.
- Limitations – Since this was a cross-sectional analysis, we were unable to interview the participants to assess their overall oral health status and past dental histories.
- Future studies could investigate predication models for how children will respond to interventions and how this relates with health outcomes.

References and Resources



- Pediatric dentists play an important role in advocacy as well as helping to connect families with local resources.
- Scan the QR code for access to study references as well as resource options available in Minnesota.

Funding & Acknowledgements

*The Autism First Project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under 6 R41MC42776-01-04 the Maternal and Child Health Autism Field-Initiated Innovative Research Study (FIRST) Program. This information or content and conclusions are those of the author(s) and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

