AGGRESSION AND SELF-INJURY: RESEARCH NEEDS FOR THE SEVERELY AFFECTED END OF THE SPECTRUM

Matthew Siegel, M.D.

Associate Professor of Psychiatry & Pediatrics
Tufts University School of Medicine

VPMA, Developmental Disorders Service
Maine Behavioral Healthcare

Faculty Scientist II
Maine Medical Center Research Institute
## DISCLOSURES

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<tr>
<th>Source</th>
<th>Clinical Advisor</th>
<th>Employee</th>
<th>Research Funding</th>
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<td>Maine Behavioral Healthcare</td>
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<td>NIMH, Simons Foundation, NLM Family Foundation</td>
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Aggression and self injury – prevalence and impacts
Multi-disciplinary approaches to serious challenging behaviors
Studying the severely affected: The Autism Inpatient Collection (AIC)
Novel approach to challenging behaviors
Critical areas for further research
“My son is 19. Severely autistic. Can’t speak. Getting more and more aggressive !!! Not only bites his wrist, he bangs walls and breaks things, and then comes after us. I can’t keep locking myself in a room because he will bang the door down... No doctor in our area knows anything of what to do...Please, please I’m reaching out. There must be something for him...not fair for me and most certainly not fair to him! Cry for help!”
Up to 2/3 of youth with ASD develop aggression
- Kanne SM, Mazurek MO. J Autism Dev Disord. 2011

Aggression is one of the primary reasons youth with ASD use behavioral healthcare services

Families report that aggression is often of greater concern and negative impact than the core social and communicative deficits that define ASD
- Farmer CA, Aman MG. Res Autism Spectr Disord. 2011

Studies in ASD suggest that broadly-defined problem behaviors are heightened in ASD compared to typically developing (TD) and intellectually disabled (ID) samples; further, some ASD subgroups engage in persistent or increasing problem behaviors into adulthood.
Inability to efficiently report distress makes aggression seem to occur “out of the blue.”

Results in:

- Caregivers unable to anticipate an aggressive outburst
- Increasingly restrictive educational settings or exclusion
- Inability to access community
- High utilization of psychotropics, hospitalizations, out of home placements
- Limits opportunities for real-time prevention (calming strategies, de-escalation techniques, functional communication)

The unmeasured effect of serious problem behaviors is a bending of the developmental trajectory downward.
DEVELOPMENTAL DISORDERS SERVICE
MAINE BEHAVIORAL HEALTHCARE

Spring Harbor Hospital DD Unit, Spring Harbor Academy, Day Treatment, Outpatient Clinic, Autism Research Team
Aggression is a final common pathway symptom. 

- Psychiatric Co-Morbidity
- Behavioral Function & Reinforcement
- Functional Communication Deficits
- Side Effects
- Dysregulated Sensory System
  - Demands: abilities mismatch
- Family Changes
- Medical Illness/Pain
- Genetically Linked
- Emotion Regulation
Foundation of Treatment

- Highly individualized behavioral plan with embedded communication and occupational therapy supports
- Targeted psychopharmacology
- Transfer of management skills to parents, local school, in-home staff
MULTI-DISCIPLINARY TREATMENT TEAM

- Child Psychiatry and Pediatrics
- Behavioral Psychologist
- Behavioral Coordinator (BCBA)
- Special Education
- Speech Pathologist
- Occupational Therapist
- Nursing
- Social Work
- Milieu Coordinator (OT)
THERAPEUTIC APPROACHES FOR CHALLENGING BEHAVIORS

- Applied Behavioral Analysis
- Psychotropic Medication
- Communication strategies (AAC/Functional Communication)
- Treat Medical Problems
- Family treatment
- Parent Management Training (RUBI)
- Sensory regulation strategies
- Social skills / social cognitive strategies
- Psychotherapy approaches – CBT / Emotion regulation

30% of functional behavioral assessment studies are inconclusive about behavioral function

Significant side effects and inconsistent success
- Siegel M & Bealieu, A, JADD, 2011
Figure 1. Estimated Marginal Means of Abberant Behavior Checklist Irritability (ABC-I) Subscale Between Children with and without Autism Spectrum Disorder (ASD) Over Time

Siegel M, et al., JADD, July, 2014
Knowledge & treatment options continue to lag for those with autism who are non-verbal, have an intellectual disability and/or display challenging behaviors; under-represented in current, large data collections

- Communication: 30-50% do not develop functional verbal communication.
- Cognitive: 20-40% of individuals with Intellectual Disability (FSIQ<70)
- Behavioral: 20-30% with lifetime incidence of serious challenging behaviors

High volume of individuals - in a unique position to efficiently collect large amounts of data and improve understanding of this understudied portion of the ASD population

Inpatient setting an ideal platform to identify mechanisms underlying emotional and behavioral symptoms to inform treatment. Unique ability to study challenging behaviors in situ due to safety of inpatient environment and control over environmental factors
Goals: Standardized assessment, description of the population, resource for all investigators, research platform for measure development, mechanistic studies and treatment studies.

- To date, enrolled over 1000 probands and their biological parents
- Rigorous core assessment battery and ASD diagnostic reliability
- 48% minimally verbal, 42% Intellectual Disability (NVIQ <70; Molec Aut, 2015)
- Whole exome sequencing to be performed 2018-19
- Data available to approved investigators through SFARIBase
- On-line community to facilitate recontacting through
SFARI Base

SFARI Base is a central database of phenotypic and genetic information about families affected by autism and other neurodevelopmental disorders, provided as part of the Simons Foundation Autism Research Initiative (SFARI). It contains data from the following cohorts:

- Simons Simplex Collection (SSC)
- Simons Variation in Individuals Project (Simons VIP)
- Simons Foundation Powering Autism Research for Knowledge (SPARK)
- Autism Inpatient Collection (AIC)
Predictors of Psychiatric Hospitalization

Psychotropic Medication Use

Inpatient Outcomes

AIC Methods

Problem behaviors and verbal ability

Risk factors for Self-injurious behavior

Talking about death or suicide

Expression of Trauma

Sleep and problem behavior

Verbal ability and psychiatric symptoms

Development of the EDI

Anxiety

Sleep and caregiver stress

Health disparities

Parent stress and problem behavior
ABC-I Scores, n=350

- Significant reduction in problem behavior scores from admission to discharge, and 2-month follow-up ($p \leq 0.05$)
- Admission: 29.7(9.6)
- Discharge: 15.0(10.3)
- 2-Month Follow Up: 19.3(10.3)

- Pedersen K, et al., JADD, 2017
RYAN – THE NEED FOR NOVEL APPROACHES
Ryan O's Aggression Over Stay 2011

Days

# of Occurrences

AGG

Last 14 Days

Linear (Last 14 Days)
“Due to his inability to manage his emotions and communicate, he attacks us when he becomes agitated or stressed. This behavior is very unpredictable and often occurs with little to no warning signs. It has happened in our home, his school, in the community and sometimes while driving a car. It is so bad that we can no longer safely live in our home with Ryan.”

-Wendi
In typically developing youth, greater ability to modulate physiological arousal is associated with fewer behavior problems. -Calkins SD. *Dev Psychobilly*. 1997; Porges, S.W. *Dev Psyche*; 1996

Association between physiological arousal and problem behavior in ASD


Hypothesis: Individual with ASD engages in a problem behavior as an attempt to alleviate distress and reestablish physiological homeostasis.
Heart Rate Movement

Baseline Arousal Increase (Antecedent)
Challenging Behavior
Arousal Decrease (Consequence)
Baseline
Arousal Decrease (Antecedent)
Challenging Behavior
Arousal Increase (Consequence)
Baseline

Beats Per Minute

Acceleration

Time

Figure by Matthew Goodwin, PhD
CONCEPTUAL MODEL

Triggering stimulus

variable emotion regulation in ASD

aggression

Autonomic equilibrium

distress

physiological arousal

non-aggression
TRANSFORMING THE TREATMENT OF CHALLENGING BEHAVIOR – REAL TIME PREDICTION

1. Electrodermal activity (EDA)
2. Blood volume pulse (BVP)
3. Interbeat interval (IBI)
4. Accelerometry (ACC)
AUC values as a function of time to aggression, and signals used from past 3 minutes of data

- ~80 hrs of collection over ~70 naturalistic observation sessions
- Increasing accuracy as you increase # of signal streams utilized

ROC values for global and person-dependent models using all combined features from the past 3 minutes to predict the next 1 minute


- Ozdenizci, C…Mazefsky, C, Siegel, M,… & Goodwin, MS (in press). Time-series prediction of proximal aggression onset in minimally-verbal youth with autism spectrum disorder using physiological biosignals. Accepted to *40th International Conference of the IEEE Engineering in Medicine and Biology Society.*
Staff Monitoring

Self Monitoring
Critical Unmet Research Needs for the Severely Affected

- Novel approaches to aggression and self injury that utilize objective, mechanistically-informed data
- Natural history of aggression and self-injury across the lifespan in ASD
- Validated, clinically practicable diagnostic tools for psychiatric co-morbidity
- Emotion regulation measurement and treatment
- Sleep biology and relationship to challenging behaviors
- Study of complex, real-world treatment packages (comparative effectiveness studies)
- Study of residential treatment and in-home behavioral services.
SUMMARY

- Individuals with ASD can develop serious behavioral challenges, which can become more impairing than the ASD itself.

- Parents report it is the unpredictability and lack of warning that causes the greatest impairment.

- Aggression and self-injury are under-researched, and their underlying biology not well understood, particularly in those who are minimally verbal or have intellectual disability.

- Pilot data from the AIC suggests that measurement of physiological arousal, combined with other data streams, can be used to predict the proximal onset of aggression.

- Critical need for novel research approaches to the assessment and treatment of aggression, self-injury and other problem behaviors, focusing on objective, biological mechanisms and measures.
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Fostering Knowledge and Community for Autism and Beyond

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