Symposium Title: A Tribute to Stephen R. Schroeder: Risk Factors Associated with Self-injurious Behavior

Chair: Jennifer Zarcone¹ and Maria Valdovinos²

Discussant: William MacLean³

Overview: This symposium is a tribute to the late, great Stephen Schroeder whose impact on the field of disabilities has brought light to the causes and treatment of self-injurious behavior (SIB). The four presentations focus on different risk factors associated with SIB and their implications. In the first presentation, Dimian and Symons conducted a review of the literature to identify the most common risk factors associated with SIB. In the second presentation, Rooker et al. evaluated several factors related to the risk for injury based on topography of SIB. Courtemanche et al. look at the effects of pain and stress and its relationship with SIB. Finally, Richman provides a review of the relationship between risk factors and markers for SIB in very young children in the US and in Lima, Peru based on a grant that he shared with Steve Schroeder.

1 Johns Hopkins School of Medicine
2 Drake University
3 Waisman Center

Paper 1 of 4

Title: Risk Factors For Self-Injury in Intellectual and Developmental Disabilities: A Critical Epidemiological Evidence-Based Synthesis

Authors: Adele F. Dimian & Frank J. Symons

Introduction: Self-injurious behavior (SIB) is a complex heterogeneous behavioral disorder that is difficult and costly to treat among individuals with intellectual and developmental disabilities (I/DD). For many individuals, once SIB is an established part of their behavioral repertoire, it becomes relatively stable and persistent (Murphy et al., 2005). Considering the persistence, the negative effects on quality of life, and the long-term cost of treatment, the development of effective early intervention and prevention programming is critical (Amendah et al., 2011; Emerson et al., 2001; Richman, 2008). The research to date, however, has not been evaluated from a robust epidemiological perspective. The purpose of this synthesis was to address the following questions: (1) of the prospective and retrospective cohort studies in the literature, what are the potential risk markers or factors identified for SIB, (2) among the prospective SIB cohort studies, were incidence and relative risk estimates reported, and (3) were common risk factors identified in the literature that can be translated to directed acyclic graphs to better understand causal pathways?

Method: An electronic search of the peer-reviewed literature was conducted using three literature databases. The articles identified through the searches were evaluated based on the following inclusion and exclusion criteria: (a) they were conducted between 1970 and the present, (b) were empirically based articles and were peer-reviewed, (c) the study design included a prospective cohort, retrospective cohort, or longitudinal design with at least 2 months of follow up and 2 time points, (d) the study included a measure of self-injurious behavior (SIB), and (e) the participants were at risk for or were diagnosed with an intellectual or developmental disability. The lead author excluded articles if only treatment of SIB was reported and if the participants only had a psychiatric diagnosis. Inter-observer agreement was conducted and was 93%. Twenty-two peer-reviewed articles were included in this review.

Results: The results from the twenty-two articles reflect a relatively recent proliferation of SIB specific studies centering on multiple possible psychosocial variables that increase the risk (i.e., putative risk factors) of SIB among individuals at risk for or with I/DD. A variety of age groups, populations, and putative risk markers (i.e., associated variables) were identified among the articles examined. Much less clear, however, is whether the variables advanced as ‘risk factors’ are causally related to the primary outcome of interest (i.e., SIB onset and SIB persistence). A majority of the studies reported point prevalence estimates and utilized odds ratios but very few reported cumulative incidence or relative risk estimates for SIB.

¹ Michigan State University
Discussion: Researchers in the field of neurodevelopmental disabilities have produced a series of observational studies over the last 40 years focusing on the prevalence, persistence, and characterization of SIB. Among the research conducted to date, there is increasing attention devoted to identifying and understanding specific causal risk factors for the development and persistence of SIB. The conventional wisdom about risk factors for SIB is plagued by terminological imprecision and historically tends to be based on cross-sectional methodology (although some longitudinal studies have been completed). The focus of the current review was to evaluate the findings from prospective and retrospective cohort studies investigating SIB. The literature reviewed is replete with incongruent findings, making it difficult to start creating a cohesive model of risk to inform early intervention and prevention programming. The validity evidence supporting the inferences and findings on potential risk factors for SIB are discussed and recommendations for how the field can improve future research are provided.

References/Citations:


Paper 2 of 4

Paper Title: Classification of Injuries Observed in Functional Classes of Self-Injurious Behavior

Authors: Griffin W. Rooker1,2, Nicole L. Hausman1,2,3, Alyssa B. Fisher2, Meagan K. Gregory2, Jennifer L., Lawell2, & Louis P. Hagopian1,2,3

1 Johns Hopkins University School of Medicine
2 The Kennedy Krieger Institute
3 University of Maryland, Baltimore County

Introduction: Limited research has examined how properties of self-injurious behavior (SIB) relate to the production of injuries and the location, type, or severity of those injuries. However, the function of SIB is an important variable in the occurrence of this behavior (Iwata et al. 1994). The purpose of this study was to classify the physical properties of SIB for groups of individuals where SIB was and was not automatically reinforced, and, for those with an injury, specifically classified the physical properties of SIB and injuries across groups of individuals with automatically and socially maintained SIB.

Methods: Clinical and medical records were coded for 64 individuals hospitalized for SIB. The physical properties of SIB for groups with and without injuries were examined. When injuries were present, the physical properties of SIB and injuries were assessed across groups of individuals with automatically and socially maintained SIB.

Results: Injuries were observed for 35 of the individuals who engaged in SIB. Individuals who engaged in a single form of SIB (sharp or blunt) were more likely to have injuries (p < .05). Individuals with SIB maintained by automatic reinforcement had significantly more severe injuries to the head (U = 24, p < .05).

Discussion: Although results are preliminary, the results provide evidence that some patterns of SIB may be more or less dangerous, resulting in more or less severe injuries. Further, these results suggest that the function of SIB may affect the physical properties of SIB and provide the basis for a preliminary model that could guide future research aimed at understanding the risk of injury from SIB.
**References/Citations:**


**Paper Title:** Assessing Signs of Pain and Stress in Children with Self-Injurious Behavior

**Authors:** Andrea Courtemanche¹, Jerrold Meyer², & William Black³

**Introduction:** Self-injurious behavior (SIB) that occurs at a high frequency and intensity may suggest altered activity in mechanisms related to pain and stress in individuals with intellectual and developmental disabilities. Researchers have reported that some individuals with SIB displayed increased behavioral signs of pain surrounding instances of SIB as well as during everyday routines. Relatedly, researchers have documented increased salivary cortisol levels in individuals with SIB compared to those without, indicating elevated levels of acute stress. However, less is known about the cumulative effect or chronicity of stress in SIB expression. Measuring cortisol in hair allows for the assessment of stress over the last three months. Elevated hair cortisol concentrations have been documented in populations experiencing chronic pain and stress, but have not yet been evaluated in individuals with SIB. The purpose of the present study was to assess the relationship between hair cortisol concentrations, the frequency of behavioral signs of pain, and the frequency of SIB in young children with developmental disabilities.

**Methods:** We recruited families with children (3-7 years) with less than 20 functional words and presented with a developmental disability. For each child, parents rated the frequency of nonverbal pain-related behaviors displayed by their child during the last week using the Non-Communicating Children’s Pain Checklist (NCCPC-R) (Breau et al., 2002). Parents also rated the frequency and severity of their child’s self-injurious behavior using the Behavior Problems Inventory (BPI) (Rojahn et al., 2001). Lastly, 10 mg of hair strands (3 mm in diameter and 3 cm in length) were collected from the back of each child’s head. Hair samples were stored at -20°C until analyzed in accordance with the protocol described by Meyer et al., 2014.

**Results:** We recruited 19 families who had children with minimal language and a developmental disability. The mean age of children was 4.8 years and the majority of these children were male (n=15; 79%) and had diagnosis of Autism Spectrum Disorder. Descriptive analyses suggested that children who engaged in more frequent and severe SIB had higher scores on the NCCPC-R (M=34.3, SD=20.3) compared to children without (M=20.0, SD=16.6) or with mild self-injury (M=26.1, SD=13.8). The hair samples are currently being analyzed and results will be discussed with respect to their relationship to scores on the NCCPC-R and the frequency and severity of SIB on the BPI.

**Discussion:** The preliminary findings of this study show that children with more frequent and severe SIB exhibit more behavioral signs of pain compared to those without SIB. These results add to a growing literature that both young children and adults with SIB display increased behavioral expressions of pain during their every day routines. Given emerging evidence linking chronic stress to pain experience, understanding stress and pain in individuals with SIB may highlight the need for targeted behavioral/psychological, pharmacological, and medical interventions for these individuals. Additionally, identifying idiosyncratic behavioral signs of pain and how they relate to instances of SIB may help caregivers identify times where more intensive interventions may be required.

**Key References:**


1 University of Saint Joseph
2 University of Massachusetts
3 Cincinnati Children’s Hospital Medical Center

Paper 4 of 4

**Paper Title:** The Lima, Peru Studies on Risk Factors and Markers for Severe Behavior Disorders in Very Young Children with Neurodevelopmental Disorders

**Author:** David M. Richman, Texas Tech University

**Introduction:** Dr. Schroeder was one of the most influential and prolific scientists to integrate several areas of research related to the ontogeny and maintenance of self-injurious behavior across species. He was the epitome on what is now referred to as a truly integrated scholar. He was one of the elite few that combined his research, teaching, and service all into one primary focus: To reduce human suffering for people that engage in severe behavior disorders. Although much of his work centered on early rodent modeling of self-injury, the focus on this talk will be a summary of his most recent research at the Centro Ann Sullivan del Peru that was funded by the National Institutes of Health Fogarty International Center.

**Method:** Archival descriptive review of journal indexing databases such as Scholar.google.com, PsychInfo, and PubMed Central. In addition to a formal summary of Dr. Schroeder’s most recent published research in Lima, Peru, I will also share personal photos and stories of our work at the Centro Ann Sullivan del Peru.

**Results:** Not only was Dr. Schroeder a prolific and influential scientist in the filed of severe behavior disorders and neurodevelopmental disorders, he was an outstanding mentor, wonderful friend, and a really, really nice guy to learn from.

**Discussion:** Results will be discussed in terms of future directions to assure that Dr. Schroeder’s research continues to be advanced posthumously.

**References/Citations:** None.