Preliminary Development and Testing of the Risk Assessment Checklist for Self-Injury in Autism (RACSA)

Lisa Alberts, DNP
Bancroft, Haddonfield, NJ, USA

Autism spectrum disorders (ASDs) define a group of neurologically-based conditions associated with impairments in social communication and interactions, as well as evidence of restricted, repetitive behaviors (American Psychiatric Association, 2013). The prevalence of ASDs is increasing in the United States and other developed countries. The Centers for Disease Control and Prevention (CDC) published the 2014 report on the prevalence of ASD among 8 year-old children surveyed through the Autism and Developmental Disabilities Monitoring Network (ADDM). Prevalence estimates indicate that one in 68 children meet diagnostic criteria for ASD (CDC, 2014).

Self-injurious behavior (SIB) is a major treatment focus and area of concern for clinicians treating children with ASDs. Approximately 50% of individuals with ASD engage in some form of SIB (Minshawi et al., 2014). SIB describes a group of behaviors characterized by self-inflicted injuries causing tissue damage, such as head banging on hard surfaces, self-biting, eye-poking, and self-hitting. SIB can result in physical injuries, fractures, head injuries, detached retinas, and in extreme cases even death (Minshawi et al., 2014; Sisk, Motley, Yang, & West, 2013). Overuse of psychotropic medications, use of restraint or physical hold procedures, and injuries to staff and individuals in treatment are all possible effects of SIB.

A systematic review of the literature identified associations between a variety of medical conditions and SIB. Evidence from the literature also suggests that common physical conditions are more prevalent in individuals with ASD including allergies, gastroesophageal reflux disease, constipation, dental caries, and otitis media (Coury et al., 2015; Furtura et al., 2015; Malow et al., 2012; Mayer et al., 2014; Sikora, Johnson, Clemons, & Katz, 2012). Challenging behaviors such as aggression and SIB and communication deficits make it less likely that health problems will be diagnosed and treated in a timely manner. Patient compliance and difficulties with completing a physical exam impede assessment and treatment. Untreated health conditions can result in pain and suffering, leading to SIB. Certain behavioral topographies can be associated with underlying medical conditions. Chest tapping, chewing of clothing and pacing can be observed in individuals suffering from constipation (Bauman, 2010). Chin hitting, increased drooling and head hitting can be observed in individuals experiencing dental pain (Shanmugam et al., 2014). Targeted assessment and treatment is needed to reduce SIBs in children with ASDs.

No evidence based tools were located to assist the healthcare team in identifying underlying health issues that may contribute to the emergence of SIB in non-verbal children with autism. This project involved the development of and preliminary validation of a standardized assessment checklist for the physical, behavioral, and diagnostic evaluation of non-verbal children with autism and SIB living in residential care facilities. Instrument face, content, and expert validity was established. Expert review provided content validity of at least 75% on all checklist items. Satisfactory interobserver agreement (IOA) was established. Two registered nurse raters conducted the IOA. Percent-agreement scores were between 74-90% total, 83-95% agreement was established for any positive rating. Kappa scores ranged from .348-.792, with probability levels below .001 or highly significant, demonstrating intermediate to good agreement beyond chance.

The checklist was piloted on 10 individuals between the ages of 12 and 21 living in residential treatment. Each checklist item was rated using an ordinal scale, the physical items on the checklist were dichotomous. Each of the 60 items on the checklist were scored and subdivided into domains that included: gastrointestinal, head, eyes, ears, nose, and throat (HEENT), dental, and miscellaneous. During the pilot testing phase, total domain scores were calculated using the checklist and triangulated with a physical exam completed by an advanced practice registered nurse (APRN) and considered either a
match or no-match. Nine out of the 10 subjects were a match, demonstrating that the scores obtained using the checklist matched the findings of the physical exam. A high score on the checklist correlated with a positive physical exam finding, and a low score on the checklist correlated with a negative exam. A grand total score for the checklist was also calculated by summing the domain scores. The grand total score is useful as a longitudinal measure to assess the individual over time, and to establish an individual baseline.

Results of the project supported the literature, suggesting an association between underlying medical conditions and the emergence of SIB in non-verbal children with ASD. Preliminary validation suggests that the checklist can provide a means for earlier identification of underlying medical concerns and subsequently result in improved treatment outcomes and reduced pain and suffering for children with ASD. Educating nurses about ASDs and the impact illness has on the emergence of SIB in non-verbal children with ASD is critical to improving nursing knowledge and patient outcomes.

---

**Title:**
Preliminary Development and Testing of the Risk Assessment Checklist for Self-Injury in Autism (RACSA)

**Keywords:**
Autism, Checklist and Self-injury

**References:**


Abstract Summary:

Undiagnosed medical conditions are well documented in the literature as potential causes of self-injury in autism yielding tissue damage and overuse of psychotropic medications. The purpose of this project was to develop a risk assessment checklist to identify latent medical conditions contributing to self-injury in nonverbal children with autism.

Content Outline:

I. Autism spectrum disorders (ASDs): neurological condition, affect language, social behavior; repetitive behaviors

A. ASDs affect 1:68 children in the US (CDC, 2014)

B. 50% of children with ASD engage in self-injurious behavior (SIB): tissue damage, overuse of medications, (Minshawi et al., 2014)

II. Literature supports: underlying medical conditions are cause of SIB in non-verbal children with ASDs

A. Increased prevalence of undiagnosed medical conditions in ASD (Caroll et al., 2014)

   i. Children with ASD: communication deficits, non-verbal; assessment and treatment of medical conditions difficult

      a. Non-verbal children with ASD: on multiple medications causing constipation leading to abdominal pain

      b. Ear pain may manifest as head hitting or head banging

         1. Use of noise cancellation head phones due to sensory issues increases risk of ear discomfort

      c. Dental pain may cause chin hitting, mouth or head punching

      d. Common health conditions may be more prevalent in ASD population and harder to detect (Coury et al., 2015; Furtura et al., 2015)

   ii. Undiagnosed medical conditions can lead to pain and discomfort resulting in SIB as a means of pain attenuation

      a. Sensory differences vary in how individuals experience pain and discomfort
B. No standardized tools assist in identifying medical contributors to SIB
   i. Non-verbal pain scales not validated in ASD population
   ii. Topographies of SIB vary widely and may have other functions

III. The Risk Assessment Checklist for Self-injury in Autism (RACSA): tool to identify underlying health issues contributing to SIB
   A. 60 item checklist measuring three constructs that may predict SIB, completed by nurse through direct observation and staff interview
      i. Literature formulated RACSA items
   B. Extensive systematic literature review demonstrated:
      i. Few empirical studies
      ii. No randomized controlled trials
      iii. 24 articles in systematic review

C. Instrument development design used to test validity and reliability

D. Non-experimental observational study design: pilot testing

E. Convenience sample in a residential treatment setting

IV. Study: three phases

A. Phase 1
   i. Items developed-analysis of literature
   ii. Literature review
   iii. Clinical experience-face validity

B. Phase 2
   i. Validity and reliability
      a. Interobserver agreement (IOA) for reliability
      b. Kappa statistic used for further IOA
      c. Content validity by expert review-Content validity index (CVI) calculated
   ii. Field notes collected

C. Phase 3
i. Pilot testing
   a. RN performed rating, triangulated scores with Advanced Practice Registered Nurse (APRN)-
      physical exam
   ii. Field notes collected
   iii. Descriptive statistics analyzed

V. Results
   A. 74-90% total reliability (exact match)
   B. 83-95% reliability for any positive rating match
   C. 9/10 subjects matched through triangulation
   D. Descriptive statistics
      i. Ordinal and dichotomous data
      ii. Seven items with mean>1 identify more frequent risk indicators
      iii. Grand total scores can be used longitudinally and as individual baseline
      iv. Results support literature
      v. Face and content validity of 75% items

VI. Standardized assessment tool (RACSA): early identification and treatment of underlying health
    conditions
    A. Prevent over-use of psychotropic medications
    B. Prevent injuries improving quality of life
    C. Reduce pain and suffering in vulnerable population

First Primary Presenting Author

Primary Presenting Author
Lisa Alberts, DNP
Bancroft
Senior Clinical Director, Children's Health Services
Haddonfield NJ
USA

Autism Center of Excellence APN Grant Coordinator-Governor's Council for Research and Treatment of Autism, Center for Neurological and Neurodevelopmental Health, Voorhees, NJ Over 30 years of nursing experience in the field of intellectual and developmental disabilities and autism 15 years of experience as adjunct clinical faculty/instructor/preceptor

**Author Summary:** Dr. Alberts received her BSN from Duke University, MSN from La Salle University, a Post Masters Certification as a Psychiatric and Mental Health Nurse Practitioner from Drexel University, and a Doctor of Nursing Practice from La Salle University. Her practice focus is treating children and adults with autism and other developmental disorders. Her special interest is educating and mentoring nurses to increase knowledge and improve healthcare outcomes in this vulnerable population.