Symposium Title: Anxiety and Mental Health in Autism: Symptoms, Supports and Interventions Across Home, School and Community

Chair: Jan Blacher

Overview: It is well recognised that anxiety is one of the most common co-occurring conditions for individuals with autism, with recent research documenting high rates in children as young as five (e.g. Keen et al., 2019) which remain high into adulthood (Hollocks et al., 2019). Given that anxiety is associated with poorer outcomes and quality of life (e.g. Park et al., 2019), it is important that researchers ensure that the symptoms of anxiety can be accurately identified and once identified, reduced with effective interventions.

This symposium will report on four studies from three continents which move from recognition of symptomatology through to psychological and pharmacological treatments for anxiety and mental health in autism. The presented studies use a range of methodologies, including content analysis, statistical and secondary data analysis, allowing for an exploration of the benefits and limitations of each approach for extending our knowledge around anxiety and mental health in autism. Collectively, panel members bring together information pertaining to home (Bolourian et al.), school (Adams et al.) and community settings (Drahota et al.), as well as to critical time periods for mental health -- that of transition from adolescence into adulthood (Bolourian et al.; Rydzewska et al.).

References/Citations:


Paper 1 of 4

Paper Title: How Worried Should We Be? Parent and Adolescent Self-Reported Anxiety of Youth with Autism

Authors: Yasamin Bolourian, Megan LeDoux, Bruce Baker, Jan Blacher

Introduction: Individuals with autism spectrum disorder (ASD) experience significantly greater levels of anxiety compared to those with typical development (TD). Research suggests that the co-occurrence of ASD and anxiety can have deleterious effects on family well-being, social relationships, and health care (e.g., usage and expenditure). As such, heavy research focus has been placed on understanding the presentation and impact of anxiety in ASD populations. While most studies in this area compare ASD and TD groups, relatively fewer include samples with intellectual disability (ID) and take into account self-evaluations of their mental health. Thus, using secondary data, the current study examined profiles of co-occurring anxiety among adolescents with ASD, ID, or TD through parent- and youth self-reports. From an ongoing follow-up, the second aim is to assess how the presence of anxiety among adolescents with ASD, ID, or TD may influence various outcomes (e.g., family well-being, social functioning, psychopathology, and service use) in young adulthood.

Methods: Data was drawn from the NICHD-funded Collaborative Family Study, a longitudinal project assessing families and their children, initially from ages 3-15. At age 15, youth with ASD (n=54), ID (n=45), or TD (n=98) and their parents completed the SCARED (Birmaher et al., 1999) and CBCL (Achenbach & Rescorla, 2001). Both measures have been previously recommended as screeners for symptoms of anxiety and have good internal consistency. Multivariate analyses of covariance (MANCOVAs) were
performed to test if SCARED total and anxiety-based CBCL subscale scores significantly differed by diagnostic group. Post hoc comparisons determined whether significant differences where based on mother, father, or adolescent ratings. Anxiety scores were then dichotomized by prescribed cut-offs of clinical significance. Frequencies were examined to determine the prevalence of elevated anxiety in the sample. Finally, a follow-up of family participants is currently underway to assess mental health and transition experiences during young adulthood (ages 22-24).

**Results:** MANCOVA using the SCARED total score was found to be statistically significant \((F(6, 244)=4.39, p<.001)\), with group differences existing only on mother and father reports \((p’s<.001)\). On the CBCL, MANCOVAs using the Anxious/Depressed (AD: \(F(6, 250)=6.13, p<.001\)) and Anxiety Problems (AP: \(F(6, 250)=8.67, p<.001\)) T-scores significantly differed by group, as per all three reporters \((p’s<.001)\). On the SCARED, adolescents reported the highest percentage of elevated anxiety (24.6%), and fathers reported the lowest percentage (5.2%). Similarly, on the CBCL AD Subscale, adolescents reported the highest percentage of elevated anxiety (8.7%), and fathers reported the lowest percentage (5.2%). On the CBCL AP Subscale, mothers reported the highest percentage of elevated anxiety (11.7%), and adolescents reported the lowest (7.6%). The ASD group had the highest percentage of elevated anxiety on each scale and across all three raters.

**Discussion:** Findings from this study have several implications and have generated hypotheses for our follow-up exploration in young adulthood: (i) As supported by the literature, adolescents with ASD in this sample had the highest prevalence of clinically significant anxiety symptoms, indicating that this group may be most at risk for poor outcomes in young adulthood. Follow-up quantitative data will be utilized to examine how this high-risk group compares 7-10 years later. (ii) The presentation of anxiety was also shown to vary depending on the assessment and reporter. Notably, regardless of diagnosis, adolescents reported more elevated symptoms on the SCARED than their parents. Follow-up qualitative data with parents and young adults will be analyzed to shed light in to how anxiety can be recognized differently across reporters. It is also important that, at least by adolescence, self-reports are taken seriously.

**References/Citations:**

Methods: Teachers of 63 students (aged 6-13) on the spectrum were asked a combination of open-ended and closed questions about signs of the student's anxiety. The data were analyzed using quantitative and qualitative methods (content analysis) in order to document teacher descriptors of the student’s anxiety at in the classroom and playground and explore how these may change with student age or gender.

Results: Approximately half of teachers (50.8%) felt their student was anxious in the classroom and a little over a third (34.9%) felt their student was anxiety out in the playground. Teachers most commonly reported increased activity levels as an indicator of anxiety in the classroom and peer interaction difficulties as an indicator of anxiety in the playground. The student withdrawing or hiding was frequently noted as an indicator of anxiety across both the classroom and playground.

When asked about the strategies they find effective to help support or reduce anxiety in the student on the spectrum, teachers most frequently identified simplified, calm communication and a calm, quiet or safe location for the child as effective strategies to reduce anxiety in the classroom. Strategies to support anxiety in the playground were more variable across the cohort.

Discussion: Through the use of teacher-led, open-ended responses, this study adds to the small but growing literature base reporting on the presentation of anxiety in students on the spectrum and the ways in which this anxiety is currently being managed or supported in the school setting. Given that anxiety is highlighted as one of the top three factors influencing school performance (Saggers et al., 2019), these results highlight the importance of understanding each student's profile of anxiety symptomatology, which may include behavioral, cognitive and/or emotional indicators. The results also document the variability in strategies being used by teachers both across students and between settings, with few being evidence-based and some being known to increase anxiety in neurotypical children, highlighting the need for more research into this area.

References/Citations:

3 Autism Centre of Excellence, Griffith University, Australia
**Paper Title:** Community-Based Provider-Level Predictors of Cognitive Restructuring and Gradual Exposure Use to Treat Anxiety in Youth with ASD in the United States

**Authors:** Amy Drahota⁴, Aksheya Sridhar⁴, Lauren Moskowitz⁵, Connor M. Kerns⁶, Matthew D. Lerner⁷, Allie Wainer⁸, Latha Soorya⁹, & Elizabeth Cohn⁹

**Introduction:** Anxiety in youth with ASD is highly prevalent, affecting youth with ASD at a greater rate than neurotypically developing children (White et al., 2009; van Steel et al., 2011). Furthermore, anxiety disorders are diagnosed only when anxiety-related symptoms cause interference above and beyond that due to core ASD symptoms (Wood et al., 2009). Cognitive behavioral therapy (CBT) is an evidence-based practice comprised of two distinct treatment strategies: cognitive restructuring (CR) and gradual exposure (EXP). Importantly, CBT has been found to be efficacious and effective to ameliorate anxiety symptoms and increase quality of life in clinical and community-based youth samples (Kreslins et al., 2015; Storch et al., 2015; Reaven et al., 2018). However, little is known about the frequency with which CBT is used to treat anxiety in youth with ASD in community-based, usual care settings, nor what provider-level characteristics predict greater use of CR and EXP within these settings. We examined provider-level predictors of CR and EXP use in the largest community-based usual care provider sample obtained to date in the United States (Wainer et al., 2017).

**Methods:** Utilizing the Usual Care for Autism Survey (UCAS; Kerns et al., 2019), 674 providers recruited from 5 U.S. sites were asked to rate their familiarity and use of 57 treatment strategies commonly used with youth with ASD and co-occurring anxiety problems, externalizing behaviors, and social skill deficits. Additionally, providers provided demographic information (i.e., discipline, educational attainment, years of experience working with individuals with ASD), and self-reported competency to deliver familiar strategies. Sixty-four percent of providers reported that they had treated youth with ASD and anxiety in the past year. In terms of discipline, this sample included 25.4% mental health, 24.9% educational, 16.2% allied health, 13.9% behavioral, 9.2% medical, and 10.4% “other” providers. Most providers had master’s degrees (64.4%), followed by doctoral degrees (20.8%), 4-year degrees (12.5%), and less than 4-year degrees (2.3%). Finally, 51.5% of the providers had worked with individuals with ASD for 0-10 years, 37.6% for 11-20 years, and 10.6% for 21 or more years.

**Results:** One hundred (23.1%) providers were unfamiliar with CR and 109 (25.2%) providers were unfamiliar with EXP; these providers were removed from the final data analyses. Generalized estimating equations (GEEs) identified significant differences in use of CR and EXP by provider discipline, educational attainment, years of experience working with individuals with ASD, and self-reported competency ($p$’s<.00). While post hoc analyses found no statistically significant differences between provider disciplines for cognitive restructuring; for gradual exposure, providers from “other,” behavioral and medical disciplines were significantly more likely to report using exposure with youth with ASD and anxiety than educational providers ($p$’s<.00). Mental health providers were significantly less likely to report using gradual exposure than educational providers ($p$<.00) but were not statistically different from allied health providers ($p$=.26). Further, providers with doctoral degrees were significantly less likely to report using CR than providers with master’s or 4-year degrees ($p$’s<.00) but were not significantly different in reported use than providers with less than 4-year degrees ($p$=.97). For EXP, providers with doctoral and less than 4-year degrees reported using exposure significantly more than providers with their master’s or 4-year degrees ($p$’s<.00). Providers who have worked with individuals with ASD for 11-20 years reported greater use of cognitive restructuring than providers who have worked with ASD for 0-10 years ($p$<.00). For years of experience and EXP use, all contrasts were significantly different ($p$’s<.00). Providers having worked with individuals with ASD for 11-20 years reported highest EXP use ($p$’s<.00), followed by providers having worked with ASD for 0-10 years. Providers who worked with ASD for 21 or more years were least likely to report using EXP to treat youth with ASD and anxiety. Finally, self-reported competency predicted use of both CR and EXP. Providers who rated themselves as “very
qualified” to delivery CR and EXP were significantly more likely to report using these strategies as compared with providers who rated themselves as “somewhat qualified” ($p's < .00$), “not too qualified” ($p's < .00$), and “not at all qualified” ($p's < .00$).

Discussion: Given the high prevalence rate of anxiety in youth with ASD, it is important that evidence-based practices are being used by community-based providers with this population. Understanding provider-level predictors of cognitive restructuring and gradual exposure use is a necessary first step to identify potential areas for dissemination or implementation interventions in order to improve the quality of services delivered to youth with ASD and anxiety.

4 Michigan State University  
5 St. John’s University  
6 University of British Columbia  
7 Stony Brook University  
8 Rush University Medical Center  
9 Hunter University

References/Citations:

Paper Title: Psychotropic Use and Comorbidities in Young People with Autism in, and Transitioning from, Special Education. Findings from The National Longitudinal Transitions Study-2 (NLTS2)

Authors: Ewelina Rydzewska10, Genevieve Young-Southward10, Jan Blacher3, Yasamin Bolourian3, Keith Widaman3, Chris Philo10, & Sally-Ann Cooper10

Introduction: Large-scale studies on trends in psychotropic prescribing for children and young people with autism are still scarce (Jobski et al. 2017). This study aimed to investigate trends and patterns of medication use in young people with autism across the transition period.

Methods: The USA NLTS-2 includes a nationally representative sample of youth initially aged 13-17 receiving special education services in grade 7 or above under the Individuals with Disabilities Education Act, followed up over 10 years in five waves of data collection from school year 2000/2001 to 2009/2010. Parent-reported data identifies individuals with autism, and comorbid emotional disturbance/behaviour disorder, or attention deficit disorder/attention deficit hyperactivity disorder (ADD/ADHD), and at waves 1-4, prescribed psychotropic medication for attention, behaviour, activity level, or mood.

Results: At Wave 1, data on autism diagnosis were available on 9,008/9,576 (94.1%) young people; 1,019 (11.3%) had autism. Of the cohort with autism, at wave 1, 67 (6.6%) had comorbid emotional disturbance or behaviour disorder, 331 (32.5%) had ADD/ADHD, and 652 (64.0%) had neither. 44.2%-46.7% were taking at least one psychotropic drug; there was high use of antipsychotics (19.2%-21.2%), antidepressants (21.7%-23.4%), and anxiolytics/hypnotics (5.0%-7.7%) across this period (ages 13-17 years, to ages 19-23 years), with little increase over time, demonstrating that psychotropic prescription was already established at the younger age of 13-17 years. CNS stimulant/drug for ADD/ADHD use fell over the transition period, from 17.5% to 10.4%, in keeping with the natural course of this condition. A notably high proportion of the youth with autism who had neither emotional disturbance/behaviour disorder nor ADD/ADHD were prescribed antipsychotics (15.6%-20.1%) with this increasing across the transition period, antidepressants (17.0%-20.0%), anxiolytics/hypnotics (4.6%-6.7%), and CNS stimulants/drugs for ADD/ADHD (4.5%-9.3%). Poly-psychotropic prescribing was also common in this group. The youth with autism who had emotional disturbance/behaviour disorder had the highest rates of prescribing of all these classes of drugs, except the CNS stimulants/drugs for ADD/ADHD, which were more commonly prescribed for the youth with that condition.

Discussion: There are high rates of psychotropic prescribing for young people with autism, including those for whom neither comorbid emotional disturbance/behaviour disorder nor ADD/ADHD are recorded, with little change over the transition period. This suggests either over-use of psychotropic medication, or under-recognition of comorbidities.

References/Citations:

10 University of Glasgow