

PI 74

HemoFOCUS Screener for Inattention, Hyperactivity and Impulsivity: A Quality Improvement Intervention for Children with Severe Hemophilia

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Submission Group

Psychosocial Issues

Abstract

Objectives: Psychosocial professionals within the St. Jude Children's Research Hospital's Hematology Clinic observed trends of inattention (IN) and hyperactivity/impulsivity (HI) concerns reported by teachers and parents of children with severe hemophilia. Although these observations are anecdotally shared by members of the bleeding disorder community on a frequent basis, this concern has not been well documented in the literature. Traditional community-based avenues of intervention are not consistent, leaving this population largely unserved. Children with severe bleeding disorders coupled with IN and/or HI are at high risk for school and family dysfunction. The main objective of this QI is to initiate early identification of children with severe hemophilia at-risk for IN and/or HI and to establish a feasible, systematic process for screening patients in a fast-paced outpatient hemophilia clinic for medical management. **Methods:** Hematology educator and social worker targeted a population of patients aged (3-16) with severe hemophilia and utilized the following assessment tools: open ended questions about academic or behavioral concerns, neuropsychological assessment referral if history of brain hemorrhage, and the Conners 3 assessment as a main tool to assess risk for ADHD and common comorbid problems and disorders in children. Psychosocial professionals approached caregivers with open-ended questions about IN and HI to triage the testing tool to be administered. As needed, psychological or neuropsychological testing was referred to Psychology clinic and the results were evaluated in conjunction with Hematology staff. **Summary:** In this cohort of 28 patients with Severe Hemophilia, the risk of ADHD was identified and diagnosis confirmed in 50% (n=14) of children evaluated. 21.4% (n=6) of patients were identified at risk for ADHD but require additional testing for diagnosis. The number of patients identified with no risk for ADHD was 28.6% (n=8). **Conclusions:** The Conners 3 is a useful tool for psychosocial providers to use with caregivers in the outpatient hemophilia clinic and effectively identified children with needs. This Quality Improvement (QI) project increases awareness among staff and community providers regarding how IN and/or HI can directly impact patient outcomes, validates caregiver concerns, and eases the course of action to get support. Within this cohort, 50% of severe hemophiliacs presented with elevated IN and HI with a formal diagnosis of ADHD, which is significantly higher than that reported in the general population of 3-7% (Mash & Barkley, 2014). These results are being used to facilitate interventions in the school setting via providing staff education, establishing behavioral plans, and advocating for classroom accommodations through The Individuals with Disabilities Education Act (IDEA) or Section 504. Overall, the QI project provides preliminary results and confirms the need for additional research required to assess the potential link between inattention and hyperactivity/impulsivity and severe hemophilia.