Inadequate Recognition of Education Resources Required for High-Risk Students With Sickle Cell Disease

Students with chronic illness, such as sickle cell disease (SCD), diabetes mellitus, cancer, or asthma are at risk for poor academic attainment. Students aged 5 through 19 years with SCD have an additional burden, as this disease is associated with multiple painful episodes resulting in hospitalizations and strokes. In 1997, we reviewed the status of 17-, 18-, and 19-year-olds with SCD followed up by the Hematology/Oncology Center at St Louis Children’s Hospital (St Louis, Mo). Only 4 (15%) of 26 patients were on target to completing high school. Given the poor education attainment, we expected that most of these students would have received educational support and/or had Individual Education Plans (IEP) to which they were entitled through the Individuals with Disabilities Education Act. The poor high school graduation rate for these young adults prompted us to consider the adequacy of educational support for students with SCD who are considered to be at increased risk for poor academic attainment, defined as those with strokes or multiple painful episodes requiring hospitalization in a 12-month period. As a result of the initial survey, we systematically assessed the academic performance, school attendance, and availability of IEPs for students with SCD believed to be at high risk for academic difficulties.

Thirty-nine high-risk students—24 with strokes and 15 with 3 or more hospitalizations for pain in 1 year—were identified in 1999. Twenty-eight percent (stroke, n = 8; pain, n = 3) of the students had been retained at least 1 grade before the 1999-2000 academic year. Students missed an average of 15.5 and 38.4 school days from the stroke and pain group, respectively. Seventeen (70%) of 24 of the stroke group and 2 (13%) of 15 of the pain group had been evaluated for or had an IEP. All students in both groups would have been expected to have received an assessment for an IEP based on either documented cognitive impairments or high absentee rates. Fifteen students were between the ages of 14 and 18 years and in high school. Only 5 (33%) of 15 were scheduled to graduate or had graduated from high school within 4 years. Two students with strokes received certificates of completion indicating that they had attended high school, but had not met the minimum academic requirements for graduation. No student was scheduled to complete a vocational training program.

Students with SCD and strokes or multiple admissions for pain are particularly vulnerable for poor academic achievement. Inadequate educational resource allocation for this group and the necessary steps to optimize academic potential has not been previously recognized. We believe that a multidisciplinary approach that includes partnerships with students, parents, medical staff, and educators is essential for the early identification and prompt educational assistance for students with SCD at risk for academic failure.

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Error in Measurement. In the article titled “Bilateral Upper Limb Weakness and Stridor,” published in the September issue of the ARCHIVES (2002;156:941-943), on page 941, second column, under “Laboratory Data,” neutrophilia should have been given as 24 200/uL.