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Authors
Drake, John H
Soucie, J. Michael
Cutter, Susan C
et al.

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High School Completion Rates Among Men with Hemophilia

John H. Drake, MSN, RN, J. Michael Soucie, PhD, Susan C. Cutter, MSW, MPA, Ann D. Forsberg, MA, MPH, Judith R. Baker, MHSA, Brenda Riske, MS, MBA, MPA

Background: The benefits of a high school diploma are well documented. Studies indicate that people with hemophilia have lower than average academic achievement, particularly if they have >12 bleeding episodes annually.

Purpose: This study compares the high school graduation rate of men with hemophilia to that of the U.S. population of men.

Methods: Data were obtained from the Universal Data Collection Program, a surveillance project conducted by approximately 130 hemophilia treatment centers in the nation. Data from 7842 men aged ≥18 years were evaluated to determine high school graduation status and were analyzed by race/ethnicity and severity of hemophilia. These data were collected between 1998 and 2008, and analysis was conducted in 2009.

Results: Men with hemophilia A had higher or similar high school graduation rates across all racial/ethnic groups and all levels of hemophilia severity, compared with U.S. men of the same age. Graduation rates for black and Hispanic men with hemophilia B were higher or similar to rates of U.S. men, but rates for whites were lower, especially among those with moderate and mild disease. However, when graduation rates were controlled for areas where Amish populations reside, differences in graduation rates for whites disappeared.

Conclusions: In this study, participants obtained hemophilia care at comprehensive hemophilia treatment centers. This multidisciplinary, family-centered care emphasizes prevention of complications, encourages medically supervised disease management, and facilitates psychosocial development. The care aims to maximize the affected child’s participation in school. This care approach may partially explain the higher-than-expected high school graduation rates among the study population, which is affected by a rare, chronic, and potentially debilitating disorder.

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formance on standardized tests in North Carolina found that 270 students with various chronic medical conditions scored in the 51st percentile, whereas their statewide peers scored in the 63rd percentile. However, differences in achievement in that study were related more to socioeconomic issues and specific aspects of chronic conditions than to absences from school.

The underlying causes of poorer academic performance for chronically ill children who are not cognitively impaired are less well defined than they are for those with cognitive impairments resulting from chronic illness. Although excessive absenteeism in children with chronic illness has been well documented for many years, research results have been mixed regarding the impact of absences on academic achievement in children with chronic illness. The participants received average grades in school, with considerable developmental, mental, and/or psychiatric disorders were excluded from the study. Mean academic achievement scores for the group were average. However, when patients were separated into two groups based on number of bleeding episodes, differences in academic performance were notable. A higher number of bleeding episodes (≥12) correlated with increased school absences and below-average aptitude in math and reading.

A 4-year longitudinal study of 333 children with hemophilia found that, overall, participants had intelligence quotients (IQs) in the average range. However, participants who experienced high levels of physical impairment from their hemophilia had lower academic achievement and intellectual abilities, even after adjustments were made for other intervening variables such as intracranial hemorrhage and HIV infection. The researchers concluded that marked physical impairments resulted in hindered ability to concentrate and learn, excessive absenteeism, and limited participation in non-academic activities that can enhance intellectual growth.

The purpose of the current study was to use collected data on participants of a public health surveillance system to compare high school graduation rates of men with hemophilia with graduation rates of the general U.S. population of men. This project demonstrates the practical applicability of IQ ranges and academic achievement studies in children and how this affects their high school graduation and ability to become productive members of the community.

Methods

Data for this project were collected as part of the Universal Data Collection Program (UDC), a surveillance system sponsored by the CDC and conducted by approximately 130 federally supported hemophilia treatment centers (HTCs) throughout the U.S. since 1998. Participants give informed consent, and data are collected annually by HTC staff using standardized data forms.

Demographic information collected includes gender, race/ethnicity, first 3 digits of the ZIP code of current residence, and month and year of birth; birth information was used to calculate age at most recent HTC visit. Clinical and diagnostic data include hemophilia type (A or B) and baseline factor activity (FA) level relative to normal. The FA level was used to categorize hemophilia severity as either mild (FA 6%–50%); moderate (FA 1%–5.9%); or severe (FA <1%). The highest education level achieved was obtained by self-report during the most recent UDC re-enrollment. Ninety percent of the data used were from UDC evaluations after 2001, and 75% were from UDC evaluations after 2004.

All men who had hemophilia A or B and were aged ≥18 years were eligible to participate in the study. Of the 8936 patients for whom data were available, 94 were ineligible because their high school graduation status could not be determined from information provided; after this exclusion, 7842 men remained in the study. No additional exclusions occurred. Subjects who reported completing 12 years of
schooling or who had education beyond high school, such as 1 year of college, were considered high school graduates. The proportion of subjects who completed high school was calculated for four categories of race and ethnicity (white, black, Hispanic, and other) and three levels of hemophilia severity. For each category, 95% CIs were calculated. Rates were also calculated separately for each of three age groups (18–24 years, 25–29 years, and ≥30 years). These rates were compared with those for the general population of men in the same age groups, based on 2007 U.S. Census data. Graduation rates with CIs outside the bounds of the national rate for each category of age and race or severity were considered significantly different at the 95% confidence level.

Results

Overall, men with hemophilia A had significantly higher high school graduation rates compared with U.S. men for the three age groups (Table 1). In contrast, those with hemophilia B had significantly lower overall graduation rates in two of the three age groups. White men with hemophilia A tended to have rates similar to those of U.S. men, and white men with hemophilia B had uniformly lower rates than the U.S. population of men. Black men with hemophilia tended to have similar high school graduation rates as U.S. black men. Hispanic men with hemophilia tended to have higher graduation rates than U.S. Hispanic men; however, graduation rates for neither black nor Hispanic men showed variation by hemophilia type.

In general, men with hemophilia A, especially those with mild disease, had graduation rates similar to or exceeding those of U.S. men (Table 2). However, the pattern was strikingly different for men with hemophilia B. Although men with mild and severe disease tended to have graduation rates similar to those of U.S. men, those with moderate disease had significantly lower graduation rates for all three age groups. Rates across severity levels within age groups were significantly different for men with hemophilia B in the aged 18–24 years and aged 25 years groups only. Differences in rates by severity were of borderline significance for men with hemophilia A in the aged 18 years group only.

The Amish population in the U.S. has a particularly high prevalence of hemophilia B owing to a founder effect. The Amish have a high degree of homogeneity, and those with hemophilia are primarily affected with mild and moderate hemophilia B. They traditionally live in rural areas, and most boys in this population stop their formal education after the 8th grade.

To test whether the low graduation rates observed among moderate hemophilia B patients might result

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>Population</th>
<th>All</th>
<th>White</th>
<th>Black</th>
<th>Hispanic</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>≥18</td>
<td>Men with hemophilia A</td>
<td>6,040</td>
<td>88.1 (87.1, 89.1)</td>
<td>89.1 (88.3, 89.9)</td>
<td>76.4 (73.6, 79.2)*</td>
<td>71.8 (68.4, 75.3)</td>
</tr>
<tr>
<td></td>
<td>Men with hemophilia B</td>
<td>1,802</td>
<td>80.8 (79.0, 82.5)</td>
<td>77.0 (75.2, 78.9)</td>
<td>79.8 (77.3, 82.4)</td>
<td>73.1 (69.6, 76.5)</td>
</tr>
<tr>
<td>≥18–24</td>
<td>Men with hemophilia A</td>
<td>2,137</td>
<td>79.9 (78.2, 81.6)</td>
<td>84.1 (82.2, 86.0)</td>
<td>84.1 (82.2, 86.0)</td>
<td>70.1 (65.0, 75.5)</td>
</tr>
<tr>
<td></td>
<td>Men with hemophilia B</td>
<td>529</td>
<td>70.3 (67.5, 73.1)</td>
<td>71.2 (68.6, 73.7)</td>
<td>72.8 (70.0, 75.5)</td>
<td>68.2 (61.9, 74.5)</td>
</tr>
<tr>
<td>≥25</td>
<td>Men with hemophilia A</td>
<td>4,095</td>
<td>88.1 (87.4, 89.1)</td>
<td>91.0 (89.2, 92.7)</td>
<td>89.8 (87.4, 92.2)</td>
<td>79.6 (76.1, 83.1)</td>
</tr>
<tr>
<td></td>
<td>Men with hemophilia B</td>
<td>1,317</td>
<td>83.6 (81.6, 85.6)</td>
<td>83.6 (81.3, 85.9)</td>
<td>84.1 (82.2, 86.0)</td>
<td>75.1 (70.7, 79.6)</td>
</tr>
</tbody>
</table>

Note: Data in bold indicate significantly higher values compared with U.S. men. The CI does not include the value for the general male population and, therefore, is significantly different at the 5% level of significance.

Table 1. High school graduation rates for U.S. men and for men with hemophilia (% [95% CI] unless otherwise indicated).

NA, not available.

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from low high school graduation rates among Amish men, the first 3 digits of the ZIP code were used to identify geographic areas in which Amish populations were concentrated. Graduation rates by severity level and residence in a geographic area were then compared with and without Amish residents for men aged 18 years who had hemophilia B (Table 3).

In areas with no Amish residents, graduation rates for men with hemophilia B were similar to those for men with hemophilia A (Tables 2 and 3). In areas with Amish populations, graduation rates of men with mild and moderate hemophilia B were only 25.7% and 30.2%, respectively, well below the graduation rates for men with mild and moderate hemophilia B in non-Amish communities. The graduation rates for men aged 18–24 years with severe hemophilia B were higher than those for men with severe hemophilia A (Table 2).

In addition, when men with hemophilia B living in the geographic areas with high concentrations of Amish were excluded from analysis, overall graduation rates among men with hemophilia B increased to levels similar to those among men with hemophilia A for all three age groups (Table 1). Graduation rates for all racial and ethnic groups, and white men with hemophilia B, increased to rates nearly as high as those among white men with hemophilia A; graduation rates among black and Hispanic men with hemophilia B remained unchanged.

**Discussion**

This is a large nationwide study comparing high school graduation rates of men with hemophilia with graduation rates for the general U.S. population of men. The results suggest that men with hemophilia A graduate from high school at a similar or higher rate than the national population of men. Studies conducted 10 years ago showed lower academic performance levels among children with hemophilia. Since that time, the recommended treatment regimen has changed from on-demand therapy to prophylactic therapy that prevents bleeding episodes and thus decreases days lost from school. Presumably, improved attendance in school contributes to a higher graduation rate. All participants in this study attended federally supported comprehensive HTCs, where they received multidisciplinary care. The focus of this care addresses not only medical treatment, but also psychosocial development of chronically ill patients, notably children with special healthcare needs.

During childhood, a key priority of the hemophilia center partnership with the family is to maximize the

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**Table 2.** High school graduation rates by age group for U.S. men and for men with hemophiliaa

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>Population</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>p-valueb</th>
</tr>
</thead>
<tbody>
<tr>
<td>≥18</td>
<td>U.S. men</td>
<td>83.9</td>
<td>83.9</td>
<td>83.9</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Men with hemophilia A</td>
<td>86.8 (85.2, 88.5)</td>
<td>85.5 (83.5, 87.6)</td>
<td>84.2 (83.0, 85.5)</td>
<td>0.053</td>
</tr>
<tr>
<td></td>
<td>Men with hemophilia B</td>
<td>82.1 (78.6, 85.5)</td>
<td>74.5 (71.2, 77.9)*</td>
<td>84.1 (81.3, 86.9)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>≥18–24</td>
<td>U.S. men</td>
<td>76.5</td>
<td>76.5</td>
<td>76.5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Men with hemophilia A</td>
<td>81.3 (77.8, 84.8)</td>
<td>79.9 (75.9, 83.9)</td>
<td>79.4 (77.1, 81.6)</td>
<td>0.7</td>
</tr>
<tr>
<td></td>
<td>Men with hemophilia B</td>
<td>74.3 (65.9, 82.6)</td>
<td>65.7 (59.0, 72.3)*</td>
<td>72.6 (66.8, 78.4)</td>
<td>0.2</td>
</tr>
<tr>
<td>≥25</td>
<td>U.S. men</td>
<td>85</td>
<td>85</td>
<td>85</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Men with hemophilia A</td>
<td>89.2 (87.5, 91.0)</td>
<td>88.6 (86.3, 90.8)</td>
<td>87.3 (85.9, 88.7)</td>
<td>0.2</td>
</tr>
<tr>
<td></td>
<td>Men with hemophilia B</td>
<td>84.2 (80.5, 87.9)</td>
<td>77.8 (74.1, 81.5)*</td>
<td>89.6 (86.8, 92.4)</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

Note: Boldface indicates significantly higher values compared with U.S. men. The CI does not include the value for the general male population and, therefore, is significantly different at the 5% level of significance.
aMen aged ≥18 years who visited U.S. hemophilia treatment centers compared with U.S. men in the same age groups based on U.S. Census data for 2007.
b*p-values for tests of difference in percentages of high school graduation across levels of disease severity in hemophilia patients

*Significantly lower values compared with U.S. men

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**Table 3.** High school graduation rates among men with hemophilia B (% unless otherwise indicated)a

<table>
<thead>
<tr>
<th>Residence in area with Amish residents</th>
<th>n</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>169</td>
<td>25.7</td>
<td>30.2</td>
<td>88.9</td>
</tr>
<tr>
<td>No</td>
<td>1629</td>
<td>86.6</td>
<td>83.9</td>
<td>84.0</td>
</tr>
</tbody>
</table>

aMen aged ≥18 years who visited U.S. hemophilia treatment centers
affected child’s participation in school, both in academic and non-academic arenas. Hemophilia center clinicians work directly with parents and the schools, particularly when the child enters a new school. The purpose of these early interventions is to identify and resolve potential barriers to the child’s regular school attendance. Interventions include creating adaptations to reduce tardiness and absenteeism due to acute or chronic mobility difficulties and to eliminate potentially inappropriate school restrictions (e.g., prohibition from physical education).

The ongoing coordinated involvement of the hemophilia center team, usually beginning at the child’s birth, can establish a pattern of assisting the family in understanding the importance of reducing barriers to school attendance and, beginning in primary school, assisting in reducing those barriers. As the child ages, the team focuses on assisting the child and family in transitioning to adult health care, work, and independence; this step fulfills Healthy People 2010 National Health Objectives and goals of the Division of Services for Children with Special Health Care needs, a division of the Health Resources and Services Administration’s Maternal and Child Health Bureau, a federal agency that provides grant support for the U.S. Hemophilia Center network. Hemophilia center teams encourage adolescents to pursue careers that do not require extensive manual labor; such work is inadvisable for men with hemophilia. Because careers without manual labor tend to require higher education, the staff counsels adolescents to remain in school; this ongoing encouragement may be a factor in the higher graduation rates among children with hemophilia, especially among Hispanics and blacks who have a high dropout rate in the general population.

This study is limited because it is a descriptive analysis that did not control for factors related to SES in comparisons of patients with hemophilia, especially those of racial and ethnic groups such as blacks and Hispanics, with U.S. men. For example, we know that poverty is a major risk factor for poor academic achievement. Thus, a potential for bias exists and may explain the higher graduation rates for blacks and Hispanics in the UDC data compared with the general population of men in the census. Geography may also play a role in this study results. Additionally, we cannot directly compare the results with those of previously cited studies that used academic performance measures, because the outcome here was high school graduation rates, which are not necessarily a measure of academic performance.

The comprehensive-care, multidisciplinary team approach of the federally supported HTCs may be associated with the higher-than-expected rates of high school graduation among the study population. Advocacy groups for other chronic diseases and for children with special healthcare needs are moving toward adoption of the comprehensive care model. Because all men participating in the UDC surveillance study were seen at an HTC, whether adolescents with hemophilia not seen at the HTCs also have a higher high school graduation rate than average is unknown. Further research is warranted to determine whether differences exist in high school graduation rates among HTCs in the national network and, if so, to identify factors contributing to those differences.

No financial disclosures were reported by the authors of this paper.

References


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