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High School Completion Rates Among Men with Hemophilia

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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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Introduction

The benefits of receiving a high school diploma or equivalency degree are well documented. U.S. Census data for 2007 indicate that annual income is much higher for people with a high school diploma compared to those without one ($27,915 vs $18,734).[1] In addition, those with a high school diploma are not only less likely to be living below the poverty level[2] but also more likely be in good health, maintain a healthy lifestyle,[3] and have health insurance.[4]

Most studies of children with chronic illnesses, such as type 1 diabetes, epilepsy, and sickle cell disease, all of which can affect cognitive function, show that children with these conditions have lower levels of academic achievement than their healthy peers.[5–7] A study of per-

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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.[8] 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.[9]

There are few studies that address academic achievement in individuals with hemophilia. Hemophilia is a rare, chronic, inherited bleeding disorder in which abnormalities in blood clotting occur because of a deficiency of factor VIII or IX. About 50% of people with hemophilia have the severe form of the disorder and experience frequent, spontaneous joint hemorrhages that, without appropriate treatment, can lead to progressive joint disease and loss of functional ability. Those with no history of meaningful head trauma or intracranial hemorrhage typically have no cognitive impairment.

Nonetheless, studies involving children with hemophilia have revealed below average levels of academic achievement. In one study,[10] standardized achievement tests were administered to 22 children with hemophilia. Although the participants received average grades in school, 27% scored more than two levels below their grade on standardized reading tests, and 45% scored more than two grade levels below on standardized math tests. These children missed an average of 18 days of school each year compared with an average of 11 days missed by their peers. However, factors such as excessive absenteeism and severity of disease were unrelated to lower academic achievement in that study.

Another study[11] involving 131 children aged 6–12 years with severe hemophilia found that excessive absences from school resulted in lower levels of academic achievement. Patients with extenuating medical circumstances, including treatment with inhibitors, and patients 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 ($\geq$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.[12] 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 $\geq$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 years, 18–24 years, and ≥25 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.[13] 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 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 1. High school graduation rates for U.S. men and for men with hemophilia (% [95% CI] unless otherwise indicated)[a]

Age (years)	Population	*n*	Race or ethnicity					*p*-value[b]
			All	White	Black	Hispanic	Other	
≥18	U.S. men	107,843	83.9	89.1	80.5	59.0	NA	
	Men with hemophilia A	6,040	**85.2 (84.3, 86.1)**	88.8 (87.9, 89.8)	76.8 (73.6, 79.9)*	**71.8 (68.4, 75.3)**	81.5 (77.4, 85.5)	<0.001
	Men with hemophilia B	1,802	80 (78.1, 81.8)*	80.4 (78.3, 82.5)*	79.6 (73.7, 85.4)	**73.1 (65.1, 81.1)**	83.3 (75.4, 91.3)	0.2
≥18–24	U.S. men	14,422	76.5	80.8	73.8	62.8	NA	
	Men with hemophilia A	2,137	**79.9 (78.2, 81.6)**	**84.1 (82.2, 86.0)**	71.7 (66.4, 77.0)	**70.1 (65.0, 75.1)**	76.6 (70.0, 83.2)	<0.001
	Men with hemophilia B	529	70.3 (66.4, 74.2)*	71.2 (66.7, 75.8)*	63.6 (50.9, 76.4)	66 (52.9, 79.1)	76.3 (62.8, 79.1)	0.5
≥25	U.S. men	93,421	85.0	90.2	81.9	58.2	NA	
	Men with hemophilia A	4,095	**88.1 (87.1, 89.1)**	91 (90.0, 92.1)	79.8 (76.1, 83.5)	**75.1 (70.7, 79.6)**	84.8 (80.0, 89.7)	<0.001
	Men with hemophilia B	1,317	83.6 (81.6, 85.6)	83.6 (81.3, 85.8)*	84.8 (78.7, 91.0)	**78.9 (69.4, 88.4)**	87.8 (78.6, 96.9)	0.6

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.
[a]Men 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 race groups for hemophilia patients
*Significantly lower values compared with U.S. men
NA, not available

Table 2. High school graduation rates by age group for U.S. men and for men with hemophilia[a]

Age (years)	Population	Hemophilia severity (% [95% CI])			p-value[b]
		Mild	Moderate	Severe	
≥18	U.S. men	83.9	83.9	83.9	
	Men with hemophilia A	**86.8 (85.2, 88.5)**	85.5 (83.5, 87.6)	84.2 (83.0, 85.5)	0.053
	Men with hemophilia B	82.1 (78.6, 85.5)	74.5 (71.2, 77.9)*	84.1 (81.3, 86.9)	<0.001
≥18–24	U.S. men	76.5	76.5	76.5	
	Men with hemophilia A	**81.3 (77.8, 84.8)**	79.9 (75.9, 83.9)	**79.4 (77.1, 81.6)**	0.7
	Men with hemophilia B	74.3 (65.9, 82.6)	65.7 (59.0, 72.3)*	72.6 (66.8, 78.4)	0.2
≥25	U.S. men	85	85	85	
	Men with hemophilia A	**89.2 (87.5, 91.0)**	**88.6 (86.3, 90.8)**	**87.3 (85.9, 88.7)**	0.2
	Men with hemophilia B	84.2 (80.5, 87.9)	77.8 (74.1, 81.5)*	**89.6 (86.8, 92.4)**	<0.001

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.
[a]Men 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

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.

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

Residence in area with Amish residents	*n*	Hemophilia B severity		
		Mild	Moderate	Severe
Yes	169	25.7	30.2	88.9
No	1629	86.6	83.9	84.0

[a]Men aged ≥18 years who visited U.S. hemophilia treatment centers

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.[14–16] 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

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.[15] 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 the 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.[16] 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.

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References

1. Bergman M. U.S. Census Bureau. College degree nearly doubles annual earnings, Census Bureau reports [press release]. Washington DC: 2005 March 28.
2. Cohen RA, Martinez ME, Free HL. Health insurance coverage: early release of estimates from the National Health Interview Survey 2007. Hyattsville MD: National Center for Health Statistics, 2008. www.cdc.gov/nchs/data/nhis/earlyrelease/insur200806.htm.
3. Robert Wood Johnson Foundation Commission to Build a Healthier America. Reaching America's health potential among adults: a state-by-state look at adult health. www.commissiononhealth.org/Documents/AdultHealthChartbookFullReport.pdf.
4. USDHHS. 2007 national healthcare quality and disparities reports. AHRQ Publication No. 08-0041. Rockville MD: Agency for Healthcare Research and Quality, 2008.
5. Tara H, Pots-Datema W. Chronic health conditions and student performance at school. J Sch Health 2005;75(7):255–66.
6. Schatz J, Finke RL, Kellett JM, Kramer JH. Cognitive functioning in children with sickle cell disease: a meta-analysis. J Pediatr Psychol 2002;27:739–48.
7. Holmes DS, O'Brien B, Greer T. Cognitive functioning and academic achievement in children with insulin-dependent diabetes mellitus. School Psychology 1995;10(4):329–45.
8. Fowler MJ, Johnson MP, Atkins SS. School achievement and absence in children with chronic health conditions. J Pediatr 1985;106(4):683–7.
9. Charlton A, Larcombe IJ, Meller ST, et al. Absence from school related to cancer and other chronic conditions. Arch Dis Child 1991;66:1217–22.
10. Woolf A, Rappaport L, Reardon P, Ciborowski J, D'Angelo E, Bessette J. School functioning and disease severity in boys with hemophilia. J Dev Behav Pediatr 1989;10(2):81–5.
11. Shapiro AD, Donfield SM, Lynn HS, et al. Defining the impact of hemophilia: the academic achievement in children with hemophilia study. Pediatrics 2001;108:e105. www.pediatrics.org/cgi/content/full/108/6/e105.
12. Usner DW, Donfield SM, Sirois PA, Gomperts ED, Bale JF Jr, Mitchell WG. Hemophilia morbidity, cognitive functioning, and academic achievement. J Pediatr 1998;133(6):782–7.

13. U.S. Census Bureau. Educational attainment in the U.S.: 2007. www.census.gov/population/www/socdemo/education/cps2007.html.
14. Baker JR, Crudder SO, Riske B, Bias V, Forsberg A. A model for a regional system of care to promote the health and well-being of people with rare chronic genetic disorders. Am J Public Health 2005;95(11):1910–6.
15. Hoots WK. Comprehensive care for hemophilia and related bleeding disorders: why it matters. Curr Sci 2003;2:395–401.
16. Grosse SD, Schechter MS, Kulkarni R, Lloyd-Puryear MA, Strickland B, Trevathan E. Models of comprehensive multidisciplinary care for individuals in the U.S. with genetic disorders. Pediatrics 2009;123(1):407–12.