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# Insurance, Home Therapy, and Prophylaxis in U.S. Youth with Severe Hemophilia

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**Background:** Home infusion therapy, particularly on a prophylactic regimen, is linked with reduced morbidity among youth with severe hemophilia. However, the association of insurance coverage with these home therapies is unknown.

**Purpose:** This study explores the connections among insurance, home infusion therapy, and prophylaxis treatment in a nationwide cohort of 3380 boys and young men (aged 2 to 20 years) with severe hemophilia. These youth obtained care at one of 129 federally supported hemophilia treatment centers (HTCs), and enrolled in the CDC's bleeding disorder surveillance project.

**Methods:** Multiple regression was used to analyze the independent association among risk factors, including insurance, and both home infusion and prophylaxis. Data were obtained between January 1, 2008, and December 31, 2010, and analyzed in 2011.

**Results:** Ninety percent used home therapy and 78% a prophylaxis regimen. Only 2% were uninsured. Health insurance was significantly associated with prophylaxis, but not with home therapy. Lower prophylaxis utilization rates were independently associated with having Medicaid, "other," and no insurance as compared to having private insurance. Race, age, inhibitor status, and HTC utilization were also independently associated with both home therapy and prophylaxis.

**Conclusions:** Youth with severe hemophilia who annually obtain care within the U.S. HTC network had a high level of health insurance, home therapy, and prophylaxis. Exploration of factors associated with insurance coverage and yearly HTC utilization, and interventions to optimize home infusion and prophylaxis among youth of African-American and "other" race/ethnic backgrounds are warranted.

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## Introduction

For the past 35 years, multidisciplinary clinician teams at federally supported hemophilia treatment centers (HTCs) throughout the U.S. have educated youth with severe hemophilia and their parents/guardians in the skills required to intravenously infuse medication to treat and reduce the life-threatening and potentially disabling internal hemorrhages that characterize this uncommon chronic genetic disorder.[1–3] Intravenous medication can cost up to $300,000 annually in children with uncomplicated severe hemophilia,[4] and insurance coverage is imperative. Yet the association of insurance with two preventive hemophilia treatment approaches—home infusion therapy and prophylactic regimens—has not been studied within the context of the U.S. healthcare system.

Reducing hemophilia-related musculoskeletal damage is a key goal of treatment, and home therapy plays a chief role. International recommendations were promulgated in the 1970s.[5] Early studies documented that home therapy lessened pain, school absenteeism, and undertreatment associated with hospital-based care,[6–9] and facilitated rapid treatment and flexibility for family life.[10,11] Adults reported less fear, venipuncture pain, anger, depression, and work absenteeism plus greater self-confidence, independence, and lower costs.[12–15] Home therapy has been linked with increased life expectancy[16,17] and reduced hemorrhage-related hospitalization.[18]

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The standard home therapy treatment regimens are either episodic (treatment after a bleed has started) or prophylactic (routine infusions). The latter approach prevents and reduces the hemorrhage frequency, thereby diminishing related joint damage.[4,19,20] Prophylaxis works best when started at a young age, prior to repeated bleeding into joints.[21,22] It is associated with reductions in school and work absenteeism, outpatient visits, hospitalizations, and surgical procedures, and increased participation in a wider range of activities.[23–25] However, prophylaxis uses up to triple the amount of medication ("factor") as episodic regimens,[15,26] and more for individuals with inhibitors who receive immune tolerance.[27,28] Factor can account for 90% of the cost of hemophilia care.[29–32]

Higher risks of hospitalizations were recently found among uninsured and publically insured U.S. children with hemophilia.[4] Hemophilic youth access insurance through their parents'/guardians' employer-based or self-insured plans, or if they qualify, for TRICARE (military) or the Indian Health Service. Medicaid and Children's Health Insurance Plan eligibility are based predominantly on family income and assets, as determined by each state. In addition, children who have a disability as determined by the Supplemental Security Income (SSI) program of the Social Security Administration (SSA) and who have low income "deemed" by SSA qualify for Medicaid. Children with hemophilia whose families meet the income and asset criteria can qualify for SSI based on frequency of spontaneous bleeds or joint arthropathy. Some state and territorial Title V programs for special needs children do include hemophilia as an eligible condition; however, Title V benefits vary extensively by state. HTC core team members—hematologists, nurses, social workers, and physical therapists—help patients and families find and maintain insurance[33–35] consistent with national priorities to reduce barriers to care for children with special healthcare needs (CSHCN).[36] CSHCN who are poor, uninsured, or underinsured have higher unmet physical and mental health needs, less access to specialty care, and fewer physician contacts.[37–45] Minority CSHCN are more likely to be uninsured.[46]

Given the links between race/ethnicity and insurance, emerging disparities in hemophilia treatment merit attention. As compared to non-Hispanic whites, Hispanics and non-Hispanic blacks with hemophilia have higher rates of bleed-related hospitalizations[47] and are twice as likely to have an inhibitory antibody rendering infusion therapy ineffective.[48] Nonwhites with hemophilia appear to have greater limitations in joint range of motion than whites,[49] possibly related to their lower rates of hypercoagulation mutations.[50,51] Monahan et al.[52] in this supplement report that among youth with hemophilia, being non-Hispanic black or insured primarily by Medicaid were both independently associated with poorer physical health outcomes and increased school absenteeism as compared to counterparts of other racial/ethnic backgrounds or with other insurance. Barriers to HTC care were reported by Zhou et al.[53] in this supplement among patients with lower incomes and inadequate health insurance. Conversely, Hispanics and non-Hispanic blacks with hemophilia achieve high school graduation rates similar to or greater than their U.S. counterparts (i.e., those without hemophilia).[54]

Assessing the diffusion of home therapy and prophylaxis across the U.S. is challenging, as is the possible associations of insurance, because of hemophilia's low prevalence and its wide demographic and geographic disbursement. To our knowledge, this is the first nationwide examination of the levels of these two key hemophilia care prevention indicators in youth with severe disease since the landmark 2007 publication of the U.S. pediatric prophylaxis RCT.[4] Such information can offer benchmarks for quality improvement and help determine whether disparities exist, both necessary steps to devise appropriate public health responses. The detrimental effects of disparities—particularly among youth who have chronic conditions, are covered by Medicaid, are under- or un-insured, live in low-income households, or are minorities—warrant this investigation.

## Methods

Data were obtained from the CDC-sponsored Universal Data Collection (UDC) project, a voluntary surveillance system that has monitored bleeding disorder complications since 1998 among individuals who receive clinical care throughout the U.S. HTC network.[55] After obtaining consent from patients or parents of minors, HTC clinicians who were trained in study administration collected uniform clinical, demographic, and health services utilization information. This current study reports on the entire cohort of male UDC enrollees between January 1, 2008, and December 31, 2010, who were between 2 and 20 years of age and had been diagnosed with severe hemophilia factor VIII deficiency or factor IX deficiency. Analyses were conducted in 2011 and were based on data collected at the subject's most recent annual UDC re-enrollment or initial UDC registration.

Variable definitions from the UDC data forms were used in the analysis. Home infusion, the first outcome of interest, was defined as "patient receives treatment products intravenously outside of the medical setting" and, if yes, "product is infused by the patient, a family member, or a medical care provider." Prophylaxis treatment, the second outcome of interest, was defined as the recommendation to receive treatment products on a regular schedule (e.g., 3 days per week) either for an indefinite or intermittent period to prevent any and all bleeding. All who indicated that they were on home infusion or prophylaxis regimens since the last annual visit were included. Primary insurance coverage was not specifically indicated when multiple insurance coverage was reported. For the analysis, primary source of insurance was assigned based on this hierarchy: Medicare, commercial, Medicaid, all others, and uninsured.[56] The UDC's other insurance categories were collapsed for this analysis, and included publically sponsored insurance plans for

individuals who have difficulty purchasing insurance due to preexisting conditions (e.g., Title V, state high-risk pools), TRICARE, Indian Health Service, and self-insured.

Clinical, demographic, and health services utilization variables thought to be associated with insurance, home infusion, and prophylaxis were included in the analysis. Severe hemophilia was defined as a factor VIII or IX activity level <1%. Inhibitor status was deemed either low or high titer based on the highest lab value reported during the study period. Race/ethnicity categories were white (non-Hispanic), white (Hispanic), black (non-Hispanic), black (Hispanic), Asian/Pacific Islander, American Indian/Alaskan Native, and Other. HTC clinicians collecting UDC data were instructed to indicate the race/ethnic category that the participant considered himself to be. Participants were classified into three clinically and developmentally distinct age groups with respect to eligibility and responsibility for universal precautions and injection procedures demanded of home infusion and prophylaxis: aged 2–5 years, 6–13 years, and 14–20 years. HTC utilization was defined as actual visits to the HTC (not phone or written correspondence) on a frequent (annual), infrequent (every 2–3 years), rare (every 4 or more years) basis, or as first visit.

The independent association between insurance coverage and other patient characteristics with the use of home therapy or prophylaxis treatment was analyzed using logistic regression. ORs, with 95% CIs calculated from the SEs of the estimates, were used to evaluate the strength and significance of associations. Interaction effects between insurance coverage and other factors associated with use of home therapy or prophylaxis treatment were evaluated using logistic regression. The model included all variables so that the simultaneous influence of all studied characteristics between use of home therapy and prophylaxis treatment could be assessed. All hypothesis testing was two-tailed with ORs and CIs reported. All analyses were performed using SAS version 9.2 statistical software.

## Results

During the study period, 3380 participants met the inclusion criteria (Table 1). The cohort's racial/ethnic diversity reflected the general U.S. population of children. Less than 2% of the cohort was uninsured. Ninety percent were on home therapy, and 78% used prophylaxis. Twenty-two percent of participants reported more than one type of insurance (data not shown) and were assigned a primary insurance per the hierarchy described. Type of primary health insurance coverage was significantly associated with prophylaxis but not with home therapy (Table 2). Significant bivariate associations were found between home therapy ($p<0.01$) and three variables: age, inhibitor, and HTC utilization. Significant bivariate associations were found between prophylaxis ($p<0.0001$) and four other variables: race, age, inhibitor status, and HTC utilization.

Variables that were independently associated with home therapy and separately with prophylaxis—after adjusting for the effects of other study variables—are illustrated via multivariate logistic regression analyses in Tables 3 and 4, respectively. Health insurance, the main predictor variable, was again significantly associated with prophylaxis but not with home therapy. Participants insured by Medicare were significantly more likely to use prophylaxis than were those insured by commercial plans. Participants who had Medicaid, other insurance, or who were uninsured were significantly less likely to use prophylaxis as compared to participants with commer-

**Table 1.** Cohort characteristics (N=3380)

| | *n* (%) |
|---|---|
| **Diagnosis** | |
| Hemophilia A | 2893 (85.6) |
| Hemophilia B | 487 (14.4) |
| **Age groups, years** | |
| 2–5 | 555 (16.4) |
| 6–13 | 1433 (42.4) |
| 14–20 | 1392 (41.2) |
| **Race and ethnicity** | |
| Asian/Pacific Islander | 122 (3.6) |
| Black, Hispanic | 26 (0.8) |
| Black, non-Hispanic | 495 (14.7) |
| American Indian/Alaskan Native | 30 (0.9) |
| Other | 161 (4.8) |
| Hispanic, white | 578 (17.1) |
| White, non-Hispanic | 1968 (58.2) |
| **Inhibitor** | |
| Low | 340 (10.1) |
| High | 193 (5.7) |
| **Insurance** | |
| Medicare | 54 (1.6) |
| Commercial | 1754 (51.9) |
| Medicaid | 1314 (38.9) |
| Other | 207 (6.1) |
| Uninsured | 51 (1.5) |
| **Treatment type** | |
| Prophylaxis | 2634 (77.9) |
| Home therapy | 3032 (89.7) |
| **HTC use**[a] | |
| Frequent | 3079 (91.1) |
| Infrequent | 98 (2.9) |
| Rare | 8 (0.2) |
| First visit | 156 (4.6) |

[a]Data missing in 39 cases
HTC, hemophilia treatment center

**Table 2.** Factors associated with home therapy and prophylaxis among boys and young men aged 2–20 years, with severe hemophilia A or B (N=3380)

| | Home therapy | | | Prophylaxis treatment | | |
|---|---|---|---|---|---|---|
| | Yes (*n* [%]) | No (*n* [%]) | *p*-value | Yes (*n* [%]) | No (*n* [%]) | *p*-value |
| **Type of insurance** | | | 0.8721 | | | <0.0001 |
| Commercial | 1567 (89.3) | 187 (10.7) | | 1407 (80.2) | 347 (19.8) | |
| Medicaid | 1180 (89.8) | 134 (10.2) | | 999 (76.0) | 315 (24.0) | |
| Medicare | 49 (90.7) | 5 (9.3) | | 49 (90.7) | 5 (9.3) | |
| Other | 189 (91.3) | 18 (8.7) | | 157 (75.9) | 50 (24.1) | |
| Uninsured | 47 (92.2) | 4 (7.8) | | 22 (43.1) | 29 (56.95) | |
| **Race and ethnicity** | | | 0.1993 | | | <0.0001 |
| Asian/Pacific Islanders | 108 (88.5) | 14 (11.5) | | 100 (82.0) | 22 (18.0) | |
| Black, Hispanic | 25 (96.2) | 1 (3.8) | | 21 (81.0) | 3 (19.0) | |
| Black, non-Hispanic | 413 (87.5) | 62 (12.5) | | 356 (71.9) | 139 (28.1) | |
| American Indian/Alaskan Native | 28 (93.3) | 2 (6.7) | | 26 (86.7) | 4 (13.3) | |
| Other | 138 (85.7) | 23 (14.3) | | 107 (66.5) | 54 (33.5) | |
| Hispanic, white | 519 (89.8) | 59 (59.2) | | 456 (78.9) | 122 (21.1) | |
| White, non-Hispanic | 1781 (90.5) | 187 (9.5) | | 1568 (79.7) | 400 (20.3) | |
| **Age groups, years** | | | <0.0001 | | | <0.0001 |
| 14–20 | 1329 (95.5) | 63 (4.5) | | 1029 (73.9) | 363 (26.1) | |
| 6–13 | 1310 (91,4) | 123 (8.6) | | 1226 (85.6) | 207 (14.4) | |
| 2–5 | 393 (70.8) | 169 (29.2) | | 379 (68.3) | 175 (31.7) | |
| **Inhibitor status** | | | 0.0031 | | | <0.0001 |
| High | 173 (89.6) | 20 (10.4) | | 88 (45.6) | 105 (54.4) | |
| Low | 323 (95.0) | 17 (5.0) | | 275 (80.9) | 65 (19.1) | |
| No/None | 2536 (89.1) | 311 (10.9) | | 2271 (79.8) | 576 (20.2) | |
| **HTC use**[a] | | | <0.0001 | | | <0.0001 |
| Frequent | 2796 (90.8) | 283 (9.2) | | 2348 (79.2) | 641 (20.8) | |
| Infrequent | 88 (89.8) | 10 (10.2) | | 64 (65.3) | 31 (34.7) | |
| Rare | 5 (62.5) | 3 (37.5) | | 2 (25.0) | 6 (75.0) | |
| First visit | 121 (77.6) | 35 (22.4) | | 112 (71.8) | 44 (28.2) | |

[a]Data missing in 39 cases
HTC, hemophilia treatment center

cial insurance. None of the interaction terms between insurance and other predictors were significant.

Race, age, inhibitor status, and HTC utilization were all significant main effects associated with both home therapy and prophylaxis. Non-Hispanic blacks and Native Americans were significantly less likely to be on home therapy than non-Hispanic whites. Non-Hispanic blacks and people of other race/ethnicities were significantly less likely to be on prophylaxis than non-Hispanic whites. Home therapy significantly increased with age category ($p<0.0001$). Prophylaxis peaked among those aged 6–13 years ($p<0.0001$), and fell among participants aged 14–20 years. Prophylaxis was also lower among the youngest age cohort. Participants with low titer inhibitors were significantly more likely to be on home therapy as compared to those with no inhibitors. Annual HTC utilization was associated with significantly more participants on home therapy and prophylaxis. As compared to annual HTC users, people who attended the HTC for the first time or rarely were significantly less likely to be on home therapy; those who did not

attend the HTC at least annually were significantly less likely to be on prophylaxis.

## Discussion

This is the first national study to explore associations between insurance and both home therapy and prophylaxis among more than 3300 male patients (aged 2–20 years) with severe hemophilia who are enrolled at one of 129 U.S. federally supported comprehensive hemophilia diagnostic and treatment centers and who enrolled in the CDC UDC hemophilia complications surveillance project between 2008 and 2010. That 90% of the cohort was on home therapy and 78% used a prophylactic regimen points to the widespread implementation of these evidence-based prevention practices within the U.S. HTC network. A separate analysis (data not shown) documents increases in both home therapy and prophylaxis among this cohort—regardless of insurance presence or type—compared to those enrolled in the UDC before publication in August 2007 of the landmark prophylaxis versus episodic care randomized clinical trial.[4] The extensive adoption of home therapy suggests that the type or presence of insurance had no relationship with the ability of patients and families to acquire the complex technical skills demanded of intravenous therapy in the home setting.

**Table 3.** Independent associations between risk factors and home therapy use among boys and young men aged 2–20 years, with severe hemophilia A or B (N=3380)

| | OR (95% CI) | *p*-value |
|---|---|---|
| **Insurance; reference: commercial** | | |
| Medicaid | 1.13 (0.85, 1.50) | 0.3980 |
| Medicare | 1.53 (0.57, 4.14) | 0.3996 |
| Other | 1.29 (0.74, 2.26) | 0.3751 |
| Uninsured | 1.44 (0.47, 4.42) | 0.5253 |
| **Race and ethnicity; reference: non-Hispanic white** | | |
| Asian/Pacific Islanders | 0.71 (0.37, 1.33) | 0.2826 |
| Black, Hispanic | 1.42 (0.18, 11.24) | 0.7409 |
| Black, non-Hispanic | 0.55 (0.38, 0.78) | 0.0008 |
| American Indian/Alaskan Native | 1.32 (0.29, 6.12) | 0.7225 |
| Other | 0.70 (0.40, 1.21) | 0.1992 |
| Hispanic (white) | 0.78 (0.43, 1.14) | 0.1959 |
| **Age group; reference: 6–13 years** | | |
| 14–20 | 2.14 (1.55, 2.96) | <0.0001 |
| 2–5 | 0.22 (0.17, 0.29) | <0.0001 |
| **Inhibitor status; reference: no/none** | | |
| High | 1.54 (0.92, 2.66) | 0.0978 |
| Low | 2.49 (1.47, 4.24) | 0.0007 |
| **HTC; reference: frequent**[a] | | |
| First visit | 0.53 (0.34, 0.82) | 0.0045 |
| Infrequent | 0.52 (0.26, 1.06) | 0.0710 |
| Rare | 0.08 (0.02, 0.36) | 0.0010 |

[a]Data missing in 39 cases
HTC, hemophilia treatment center

However, having health insurance and insurance type were both associated with being on prophylaxis. Those with insurance were much more likely to be on prophylaxis (77%) as compared to those who were uninsured (21%). Only 1.5% of this cohort were uninsured versus 8.2% of U.S. children.[57] The finding of a higher prophylaxis rate among the small number of youth insured by Medicare is puzzling and merits further investigation. This may reflect a subcohort with unique characteristics because children are typically eligible for Medicare only if deemed disabled. The lower utilization of prophylaxis among those insured by Medicaid and other plans, as compared to commercial plan members, is also concerning, as this was not significant in the earlier period examined (1998 to August 31, 2007). However, in comparing those two different time periods, prophylaxis use rose among all groups, including the uninsured. In addition, prophylaxis rose from being just below significance to just above significance; therefore, whether this represents a real change or a minor data fluctuation requires further exploration. The finding that over three quarters of those insured by Medicaid and other plans are on prophylaxis suggests that HTCs do provide training and access to optimal therapy regardless of patients' income levels. This is in contrast to previously cited studies documenting less access to care for

**Table 4.** Independent association of factors and ORs with prophylaxis use among boys and young men aged 2–20 years, with severe hemophilia A or B

| | OR (95% CI) | *p*-value |
|---|---|---|
| **Insurance; reference: commercial** | | |
| Medicaid | 0.81 (0.66, 0.97) | 0.0356 |
| Medicare | 2.65 (1.02, 6.91) | 0.0457 |
| Other | 0.65 (0.45, 0.95) | 0.0251 |
| Uninsured | 0.21 (0.11, 0.38) | <0.0001 |
| **Race/ethnicity; reference: white non-Hispanic** | | |
| Asian/Pacific Islanders | 1.05 (0.63, 1.75) | 0.8487 |
| Black, Hispanic | 1.17 (0.42, 3.31) | 0.7613 |
| Black, non-Hispanic | 0.69 (0.53, 0.88) | 0.0034 |
| American Indian/Alaskan Native | 1.58 (0.53, 4.74) | 0.4137 |
| Other | 0.56 (0.38, 0.83) | 0.0034 |
| Hispanic, white | 0.86 (0.65, 1.14) | 0.2971 |
| **Age; reference: 6–13 years** | | |
| 14–20 | 0.47 (0.39, 0.58) | <0.0001 |
| 2–5 | 0.43 (0.33, 0.55) | <0.0001 |
| **Inhibitor status; reference: no/none** | | |
| High | 0.19 (0.13, 0.16) | <0.0001 |
| Low | 1.16 (0.86, 1.58) | 0.3354 |
| **HTC; reference: frequent[a]** | | |
| First visit | 0.71 (0.48, 1.14) | 0.0808 |
| Infrequent | 0.51 (0.32, 0.79) | 0.0029 |
| Rare | 0.09 (0.02, 0.47) | 0.0044 |

[a]Data missing in 39 cases
HTC, hemophilia treatment center

CSHCN who are poor. This finding is of further interest as the HTC UDC cohort had higher proportions on Medicaid than the general U.S. population (39% UDC versus 28% U.S.).

Black non-Hispanics and people of other races/ethnicities were significantly less likely to be on home therapy and prophylaxis than white non-Hispanics. This finding is concerning because of the better health outcomes associated with home therapy and prophylaxis. Further exploration is necessary to determine contributing factors at the patient, family, provider, and systems levels that might be amenable to intervention.

Those aged 14–20 years were twice as likely as those aged 6–13 years to be on home therapy. This was not surprising as venous access is difficult in some younger patients. The youngest (2–5 years) and oldest (14–20 years) age groups were significantly less likely to be on prophylaxis than patients aged 6–13 years. This, too, was expected. In the U.S., prophylaxis typically starts when children are over 3 years old, as they have reached sufficient size to facilitate better venous access, their bleeding pattern has been established, and families are ready to embark on this treatment approach. Older teens who may have been on prophylaxis as youngsters may determine appropriately to their age that they want to stop prophylaxis. One study of adolescents with hemophilia found that approximately 60% did not fully comply with prophylaxis treatment recommendations.[58] Adolescents, particularly those with chronic disorders, tend to lessen adherence to treatment regimens for many reasons, including an increase in risk-taking behavior and a desire to avoid being different from others.[59,60]

Patients with a highly reactive inhibitor were twice as likely as those without an inhibitor to use home therapy but significantly less likely to be on prophylaxis. Some patients with inhibitors are on treatments that are not captured by these data, and this requires additional investigation.

Patients who used the HTC annually had significantly higher levels of utilization of both home therapy and prophylaxis than those who visited the HTC less frequently or for whom this was the first HTC visit. Coordinated care managed by an HTC intentionally involves intensive patient education that encourages independence and competency in disease self-management, chiefly in the form of home therapy, and where indicated, prophylaxis. HTCs are specialty clinics operated by multidisciplinary clinician teams who use evidence-based medicine and maintain expertise on current treatments. These data suggest that annual care at an HTC maximizes access to home therapy and prophylaxis.

## Limitations

These data were collected on youth seeking care at HTCs who enrolled in the UDC. Hence, this natural history study has inherent limits on applicability to the pediatric hemophilia population who obtain their care outside this national network. However, an earlier study revealed that nearly 70% of all patients with hemophilia receive care at HTCs.[16] These data are only applicable to HTC patients who participate in this surveillance project; however, approximately 75% of HTC patients with severe hemophilia aged 2–20 years are enrolled. This analysis was cross sectional, and some patients may have changed insurance status and therapy regimen over time. The choice to utilize enrollment data from the latest annual visit within the two most recent calendar years increases the likelihood of reflecting current insurance status and treatment regimens. The national scope of this exploratory study lessens the potential for demographic or practice pattern biases intrinsic to smaller-scale examinations.

## Conclusion

The study results demonstrate that youth with hemophilia who obtained annual care at HTCs, and who enrolled in the UDC surveillance project, had high levels of insurance coverage, and had two important complication prevention interventions: home therapy and prophylaxis. This cohort's comparatively high level of insurance coverage was more favorable than the general U.S. populations of children[57] and those with special health needs. Insurance coverage is key to accessing care for this high-cost, life-long disorder. Children with special healthcare needs who are under- or un-insured have higher unmet medical needs than healthier youth. Investigation into predictors of high insurance levels among hemophilia patients seen at HTCs, and facilitators of annual HTC care are warranted. The relatively lower utilization of home therapy and prophylaxis among non-Hispanic blacks and people of other race/ethnicities is concerning and merits investigation to devise focused interventions.

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