Characterizing Excessive School and Work Absenteeism in Hemophilia A: Hemophilia Utilization Group Study Part Va (HUGS Va)

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INTRODUCTION

- The Hemophilia Utilization Group Study Va (HUGS Va) was a two-year, prospective, multi-center cohort study designed to collect information on healthcare utilization and burden of illness in persons with hemophilia A.
- Hemophilia A is a rare chronic disease with high costs, morbidity and impact on quality of life. Morbidity and economic impact due to hemophilia A may be quantified in terms of missed days from work or school.
- In adults, excessive missed days from work may have important productivity and economic implications. In children, excessive missed days from school may affect academic performance, future career, and economic stability.
- Persons with hemophilia A were recruited from six federally supported Hemophilia Treatment Centers (HTCs) in the United States (US) that provide care to patients in seven geographically and ethnically diverse states (California, Colorado, Indiana, Massachusetts, Montana, Texas and Wyoming).

OBJECTIVE

- To identify variables associated with excessive missed school or workdays in persons with hemophilia A in the US.

METHODS

- Between June 2005 and July 2007, 329 persons aged 2 to 64 years with hemophilia A were recruited at the participating HTCs.
- Data were collected through an initial interview, chart review, and follow-up surveys. Parents completed the survey for children less than 18 years of age.
- This analysis includes employed or school-going adults aged 18 to 64 years and school-going children between 5 and 17 years of age .
- Baseline data included sociodemographic characteristics, clinical characteristics, health insurance coverage, treatment patterns, comorbidities [including human immune deficiency virus (HIV)], access to care, self-rated joint pain and motion limitation, and health-related quality of life (HRQoL).
- Participants were followed monthly in the first year and semi-annually in the second year in order to collect information on patient-reported outcomes. These included days missed from work or school ("Total" and "Due to hemophilia A") and number of bleeding episodes. Annual mean figures were obtained by taking the average of two-year data.
- HRQoL was assessed using the Short Form-12 (SF-12) version 1 for adults. The PedsQL was used for participants under 18 years of age, either through self-report or proxy-report by parents.
- Self-reported joint pain was measured by a question that assessed pain on a five-point scale, and self-reported motion limitation was measured by a question that assessed limitation of motion on a four-point scale.
- Definition of outcomes of interest:
  - "Excessive missed days from work due to hemophilia A" for adults is defined as missing more than the US average missed work days for the general population of 8.39 days per year. This may result in both earnings and productivity losses[1].
  - "Excessive missed days from school due to hemophilia A" for children follows the US general population definition of missing 11 or more school days/year, which impacts a child's ability to function as other children do[2].
- Non-parametric comparisons and logistic regression were used to demonstrate the association of excessive missed work or school days to demographic, insurance and clinical characteristics, and patient outcomes.

[1] Yassin A. Cost of lost work and bed days for us workers in private industry--national health interview survey, 2003. J Occup Environ Med. 2007 Jul;49(7):736-47.

[2] National Survey of Children with Special Health Care Needs 2005–2006. http://mchb.hrsa.gov/cshcn05/NF/2healthfs/missed.htm

RESULTS

- These analyses include complete data from HUGS Va on 80 employed or student adults and 91 school-aged children between 5 and 17 years of age.
- Table 1 describes the baseline characteristics of participants by age group.
- Figure 1 shows the annualized mean missed days of work or school for the study population both in total and due to hemophilia A only. The range of total missed work or school days was zero to 223.2 days for adults and zero to 121.3 days for children. The range of missed work or school days due to hemophilia A was zero to 223.2 days for adults and zero to 83.6 days for children.
- Figure 2 shows the distribution of participants by mean number of days missed from work or school due to hemophilia A per year. Although the majority of adults (84.8%) did not miss work due to hemophilia, 16.3% missed work more than the US average days missed of 8.39 days/year. The majority of school children (55.0%) in this study missed at least one day of school per year due to hemophilia, with 12.1% missing more than 11 days (approximately 2 school weeks) a year.
- Table 2: Adults with excessive missed days of work or school had significantly more bleeding episodes annually (p=0.0030), greater number of comorbidities (p=0.0475) and poorer SF-12 physical component score (p=0.0325). A significantly smaller proportion of adults who had excessive missed work or school days had lower household income (p=0.0490). A significantly larger proportion of adults with excessive missed work or school days were HIV positive (p=0.0265).
- Table 3: Children with excessive missed days of school had significantly more bleeding episodes annually (p<0.0001) and also experienced significantly poorer health-related quality of life (p<0.05), compared to those who did not.
- After controlling for age, hemophilia severity, treatment type and race, multivariate logistic regression showed that for every additional bleeding episode experienced each year, children are 1.15 times more likely to have excessive missed days from school (p=0.0048). In adults, for every additional bleeding episode experienced each year, they are 1.07 times more likely to have excessive missed days from work or school (p=0.0454).

Table 1: Baseline Characteristics

Characteristics	Adults (N=80) ¥	Children (N=91) ¥
Mean age (SD)	30.7 (10.9)	10.6 (3.7)
Race: White (%)	61 (76.3)	62 (68.1)
Household income ≥$40,000 (%)	49 (62.0)	60 (65.9)
Insurance (%)		
Public Insurance	18 (22.5)	25 (27.5)
Private Insurance	59 (73.8)	65 (71.4)
No Insurance	3 (3.8)	0 (0)
Severe hemophilia (%)	52 (65.0)	58 (63.7)
Prophylaxis: all severities (%)	29 (36.3)	54 (59.3)
Comorbidities (excluding HIV) (SD)*	1.8 (1.7)	-
HIV positive (%)	17 (21.3)	-
Mean annual bleeding episodes (SD)	13.0 (14.2)	6.5 (8.3)
SF-12 (SD)≅		
Mental Component Score	52.3 (9.0)	-
Physical Component Score	46.2 (9.6)	-
PedsQL (SD) †		
Total PedsQL	-	84.0 (14.8)
Physical Functioning	-	87.2 (16.7)
Psychosocial Functioning	-	82.4 (16.3)
Joint pain (%)		
No pain/Pain only when bleed	31 (38.8)	65 (71.4)
Some pain/Pain most of the time/Severe pain	49 (61.3)	26 (28.6)
Motion limitation (%)		
No limitation/Limitation only when bleed	38 (47.5)	78 (85.7)
Some limitation/Severe limitation	42 (52.5)	12 (13.2)

¥Children: Aged 5 to 17 years; Adults (Employed or School-going): Aged 18 to 65 years
**Children: N= 89; ≅Adults: N=78; †Children: N=90*

Figure 1: Annualized Mean Missed Days of Work/School

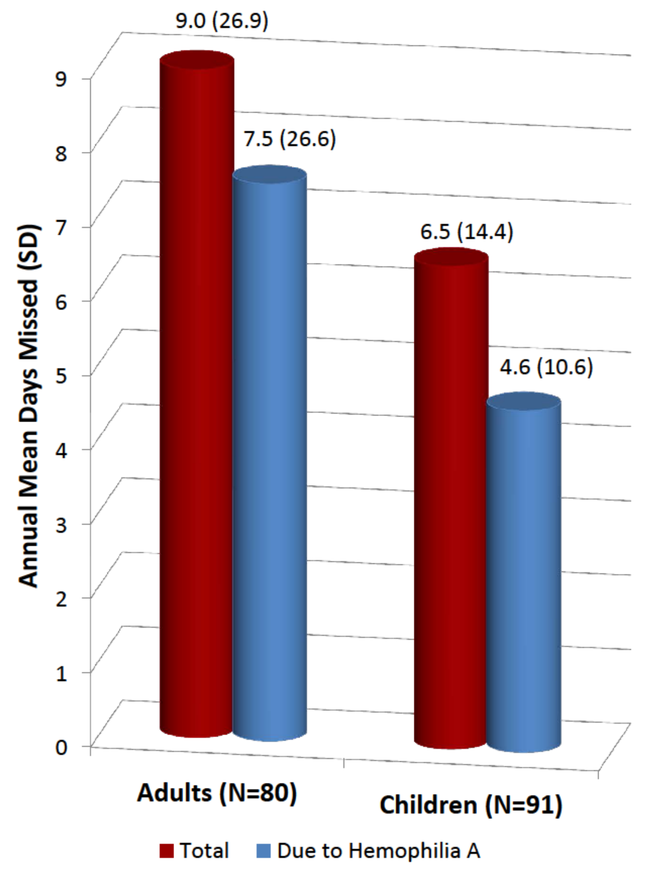

Figure 2: Distribution of Participants by Missed Days due to Hemophilia A

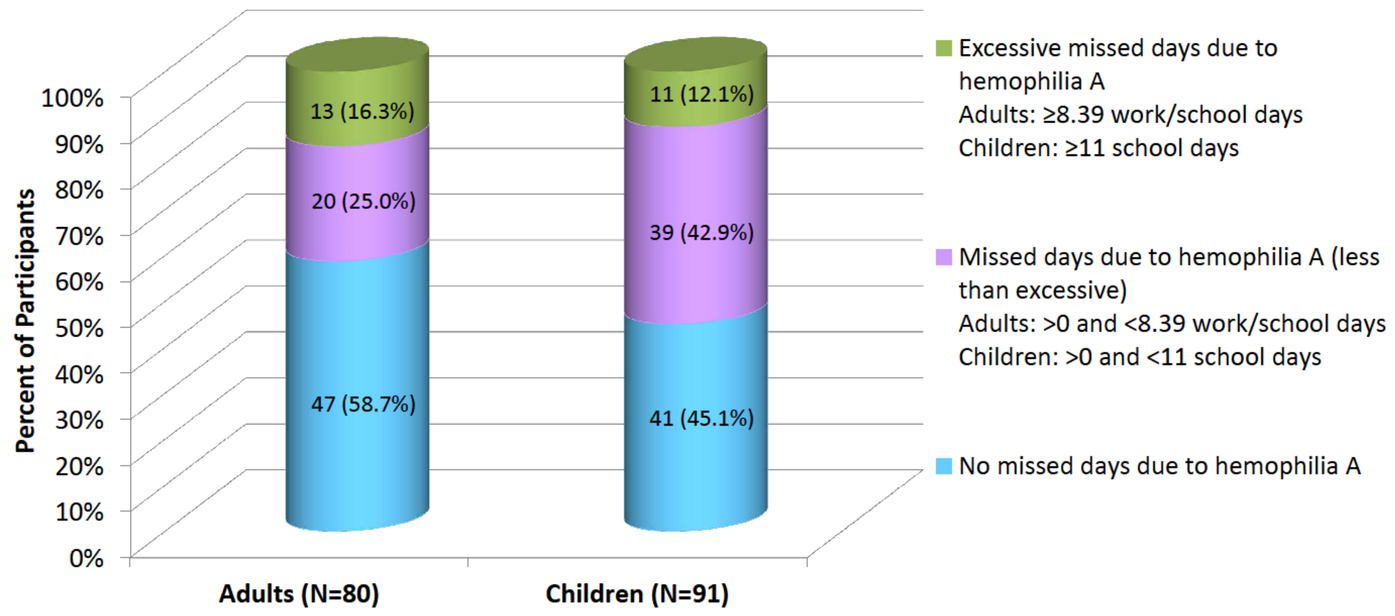

Table 2: Adults - Comparison of Outcomes

Characteristics	Excessive (N=13)	Not Excessive (N=67)	p-value*
Mean age (SD)	33.8 (13.2)	30.0 (10.5)	0.2484
Race: White (%)	9 (69.2)	52 (77.6)	0.4959
Household income ≥$40,000 (%)	**4 (33.3)**	**45 (67.2)**	**0.0490**
Insurance (%)			0.3903
Public Insurance	4 (30.8)	14 (20.9)	
Private Insurance	8 (61.5)	51 (76.1)	
No Insurance	1 (7.7)	2 (3.0)	
Severe hemophilia (%)	11 (84.6)	41 (61.2)	0.1254
Prophylaxis: all severities (%)	5 (38.5)	24 (35.8)	0.8562
Comorbidities (excluding HIV) (SD)	**2.5 (1.3)**	**1.7 (1.7)**	**0.0475**
HIV positive (%)	**6 (46.2)**	**11 (16.4)**	**0.0265**
Mean annual bleeding episodes (SD)	**25.3 (18.3)**	**10.7 (12.0)**	**0.0030**
SF-12 (SD)			
Mental Component Score	49.1 (9.4)	52.9 (8.8)	0.0899
Physical Component Score	**40.4 (11.1)**	**47.4 (9.0)**	**0.0325**
Joint pain (%)			0.0694
No pain/Pain only when bleed	2 (15.4)	29 (43.3)	
Some pain/ Pain most of the time/Severe pain	11 (84.6)	38 (56.7)	
Motion limitation (%)			0.1868
No limitation/Limitation only when bleed	4 (30.8)	34 (50.7)	
Some limitation/Severe limitation	9 (69.2)	33 (49.3)	

Table 3: Children – Comparison of Outcomes

Characteristics	Excessive (N=11)	Not Excessive (N=80)	p-value*
Mean age (SD)	10.2 (2.9)	10.7 (3.8)	0.7469
Race: White (%)	7 (63.6)	55 (72.4)	0.7223
Household income ≥$40,000 (%)	8 (72.7)	52 (71.2)	1.000
Insurance (%)			0.4905
Public Insurance	4 (36.4)	21 (26.6)	
Private Insurance	7 (63.6)	58 (73.4)	
Severe hemophilia (%)	7 (63.6)	51 (63.8)	1.000
Prophylaxis: all severities (%)	6 (54.6)	48 (60.0)	0.7528
Mean annual bleeding episodes (SD)	**18.0 (8.0)**	**4.9 (7.1)**	**<0.0001**
PedsQL (SD)			
Total PedsQL	**67.8 (21.6)**	**86.3 (12.2)**	**0.0025**
Physical Functioning	**71.3 (29.2)**	**89.4 (12.9)**	**0.0126**
Psychosocial Functioning	**65.9 (23.0)**	**84.7 (13.8)**	**0.0087**
Joint pain (%)			0.2833
No pain/Pain only when bleed	6 (54.6)	59 (73.8)	
Some pain/ Pain most of the time/Severe pain	5 (45.5)	21 (26.3)	
Motion limitation (%)			0.1608
No limitation/Limitation only when bleed	8 (72.7)	70 (88.6)	
Some limitation/Severe limitation	3 (27.3)	9 (11.4)	

**P-values for Tables 2 and 3 are calculated from Chi-square/Fisher exact tests for categorical variables and Wilcoxon non-parametric tests for continuous variables*

DISCUSSION & CONCLUSIONS

- Excessive school absenteeism compromises a child's education and his social interaction with peers. In the short-term, it may affect a child's academic performance, and in the long-term, it may have both career and economic repercussions. In this analysis, we have found that excessive absenteeism also has a negative association with a child's physical and psychosocial health-related quality of life.
- In adults, having excessive missed work/school days potentially compromises productivity and also has economic implications. This analysis also shows the negative association of excessive absenteeism with health-related quality of life.
- Identifying variables associated with missing school/work in hemophilia can guide development of interventions to reduce absenteeism. This analysis suggests that annual bleeding episodes may be a key variable of interest.
- Due to the small sample size in our study population, the estimates from the multivariate logistic regression presented above may not be generalizable to the entire hemophilia population, but they serve as a good reference point. Larger sample sizes are needed for further analyses.

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