

Oregon Health & Science University
School of Medicine

Scholarly Projects Final Report

Title *(Must match poster title; include key words in the title to improve electronic search capabilities.)*

Hallpass Hemostasis: A Review of School Absenteeism Among Adolescents with Bleeding Disorders

Student Investigator's Name

Eni Nako

Date of Submission *(mm/dd/yyyy)*

03/17/2023

Graduation Year

2023

Project Course *(Indicate whether the project was conducted in the Scholarly Projects Curriculum; Physician Scientist Experience; Combined Degree Program [MD/MPH, MD/PhD]; or other course.)*

Scholarly Projects Curriculum

Co-Investigators *(Names, departments; institution if not OHSU)*

Mentor's Name

Dr. Kristina Haley

Mentor's Department

Pediatric Hematology & Oncology

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Concentration Lead's Name

Dr. David Buckley

Project/Research Question

- A. Primary objective: Determine the frequency of documentation of school absences for patients seen at the hemophilia center for any visit
- B. Secondary objectives:
 - A. Measure the frequency of referrals to education specialists for patients who report school absences
 - B. Identify any differences in mention of school absenteeism between menstruating and non-menstruating patients

Type of Project *(Best description of your project; e.g., research study, quality improvement project, engineering project, etc.)*

Quality improvement project

Key words *(4-10 words describing key aspects of your project)*

School absenteeism, pediatric, hematology, bleeding disorder

Meeting Presentations

If your project was presented at a meeting besides the OHSU Capstone, please provide the meeting(s) name, location, date, and presentation format below (poster vs. podium presentation or other).

Publications *(Abstract, article, other)*

If your project was published, please provide reference(s) below in JAMA style.

Submission to Archive

Final reports will be archived in a central library to benefit other students and colleagues. Describe any restrictions below (e.g., hold until publication of article on a specific date).

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Next Steps

What are possible next steps that would build upon the results of this project? Could any data or tools resulting from the project have the potential to be used to answer new research questions by future medical students?

After implementation of a "dot-phrase" during new patient consultations, another school-year period of patients could be evaluated to further investigate any significant relationship between bleeding disorders and school absences.

Please follow the link below and complete the archival process for your Project in addition to submitting your final report.

https://ohsu.ca1.qualtrics.com/jfe/form/SV_3ls2z8V0goKiHZP

Student's Signature/Date *(Electronic signatures on this form are acceptable.)*

This report describes work that I conducted in the Scholarly Projects Curriculum or alternative academic program at the OHSU School of Medicine. By typing my signature below, I attest to its authenticity and originality and agree to submit it to the Archive.

03/17/2023

Student's full name

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Report: Information in the report should be consistent with the poster, but could include additional material. Insert text in the following sections targeting 1500-3000 words overall; include key figures and tables. Use Calibri 11-point font, single spaced and 1-inch margin; follow JAMA style conventions as detailed in the full instructions.

Introduction (≥250 words)

School attendance is so highly regulated in the United States that in Oregon, it is considered a class C violation and punishable by fine if a parent or guardian is unable to ensure their child regularly attends school.¹ Portland Public Schools has issued their own policy on school attendance and absence, outlining the process of requesting exemption from compulsory attendance on the basis of several factors, one of which is disability status.² However, the list of “Compassionate Allowances Conditions”, which are outlined by the federal government and meet the Social Security standards for disability allowance, does not include hemophilia.^{3,4} Understanding to what extent children, particularly adolescent girls, miss school due to bleeding disorders may help shed light on the need for additional exceptions to compulsory attendance or the development of additional resources for families of children with bleeding disorders.

While chronic absenteeism can be due to a myriad of factors, including chronic illnesses such as bleeding disorders, the importance of decreasing instances of absenteeism for any reason is crucial for mitigating or possibly preventing any short- and/or long-term negative impacts on health, academic success, graduation rates, and social skills.⁵

A study investigating the quality of life (QOL) of 24 adolescent girls with untreated inherited bleeding disorders showed that 15 of them (62.5%) reported difficulties with schoolwork during menstruation and 10 of them (41.7%) reported missing school because of their periods.⁶ Even in the absence of a confirmed bleeding disorder, menorrhagia can inhibit school attendance. When investigating QOL of a group of 25 adolescent girls with menorrhagia, 13 of them (52%) reported missing school due to their menstrual periods.⁷ An Australian study found that bleeding disorders are diagnosed in approximately 10.4% of patients with prolonged menstrual bleeding.⁸ This number may be limited due to younger girls not being able to identify signs of heavy bleeding and thus not seeking appropriate medical attention for diagnosis. While a small number of investigations exist looking specifically into absenteeism among adolescents with bleeding disorders, few of the studies were based in the United States and few, if any, included information on males with bleeding disorders.

The proposed study aims to investigate the documentation of and frequency of school absences among adolescents with bleeding disorders and to highlight any deficiencies in documentation for this vulnerable population and possible respective reasons for their absences. These frequencies will also be measured among male patients seen at the same clinic as a comparison.

Methods (≥250 words)

To determine the feasibility of the study, Dr. Haley performed a sporadic review of approximately 5 patient charts to determine whether school absenteeism was addressed and found that it was. Patient charts were then identified by reviewing patients aged 12-18 years old who were seen at either the OHSU Spots, Dots, and Clots Clinic or the OHSU Hemophilia Clinic from September 2018 through June 2019 to simulate an academic “school year”. A retrospective chart review was then conducted and abstracted data was stored in a secure, protected RedCap database. Initially, the first five patients were reviewed by both investigators to ensure validity. Following that confirmation, chart review was performed independently by the author for the remaining patients.

Data points included demographic data, health data, and school data. Demographic data included name, date of birth, age at time of appointment, sex assigned at birth, race, ethnicity, and zip code. Health data included date of visit, reason for visit, end of visit diagnosis, co-morbidities, and menstrual status. School data included whether or not school attendance or absence was documented in the chart, the

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frequency of absences, the reason for absences, documentation of accommodations, documentation of bathroom access, and documentation of Education Specialist referral and follow up. For school attendance or absences to be considered “documented” in the encounter, mention of this was either included in the HPI or in the social history. If a chart did not seem to mention school attendance for a patient, the “search” feature in Epic was utilized using the words “school”, “class”, “grade”, “education”, and “miss” to ensure the reviewer did not miss this documentation in other sections of the chart note.

The above data were entered into RedCap as mentioned. A record of qualitative measures of school-related difficulties were recorded on a secure, password-protected word document as the author completed chart review. Raw data measures were compared to evaluate documentation trends. Statistical analysis was not performed.

Results (≥500 words)

In total, 246 patient encounters were identified. After reviewing validity, three encounters were nursing visits and were excluded from the study. Of the 243 encounters reviewed in detail, 143 of those encounters were of female patients and 100 of those encounters were of male patients with a total of 199 unique patients.

Of the 143 female encounters, school attendance was documented in 116 of them, and school absences were documented in 23 of them. Of the 100 male encounters, 75 of them had school attendance documented and 3 of them had school absence documented.

When reviewing chart notes for patients who were menstruating, we found that there were 140 such patients seen in clinic with 113 of those encounters documenting school attendance. Of those 113 encounters with documented attendance, 8 of those encounters reported absences compared to only 3 encounters with reported absence in the non-menstruating group. There was no documentation of referrals sent to education specialists for any of these 11 encounters. Of note, the patients who did receive referrals to the Education Specialist were seen within six months following the referral.

Determination of quantity of school missed is difficult to elicit as many of the recorded frequencies include “at times”, “rarely”, and “a great deal”. Additionally, many instances of documentation were missed by the study framework and were recorded as qualitative data. Examples of these include:

“He has had significant fatigue...he is unable to do some of his activities due to the pain. He also reports significant fatigue - sleeping through the night and into the day. He feels like school is very difficult right now and despite his own self-advocacy, he is still not getting access to school programs and classes that he feels are necessary.”

“...epistaxis sometimes interrupts school.”

“She has to change her...tampon every class period.”

“She is having difficulty at school due to rules regarding bathroom use.”

“She reports that she couldn't attend school at times due to pain and bleeding.”

“...has not missed school due to her period but she has had to leave early due to bleeding.”

“...has not missed school due to her period, but she is really careful to have all of the needed supplies at her disposal.”

“Last month, her bleeding was really severe and she just sat in the bathtub bleeding.”

“...has had to come home from school due to soaking through clothes.”

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"...had some difficulty at school this year due to her period - teachers were not understanding."

"She has frequent leaking/soaking - has ruined a lot of clothes, sheets, and furniture as a result."

"She thought she had urinated in her pants but it was all blood."

"...has had very heavy bleeding - she was wearing 3 overnight pads at a time during the day and soaking through every one hour. She has had a lot of trouble at school as a result as teachers are not always allowing her to use the bathroom."

Discussion (≥ 500 words)

Little research was found during initial review on impact of bleeding symptoms on school attendance in the adolescent population. Investigating the impact of bleeding disorders, especially heavy menstrual bleeding, is a critical piece in understanding barriers to education for female students and patients. The overarching aim of the study was to investigate any discrepancies in school attendance between individuals with and without bleeding disorders as well as discrepancies between male and female students with bleeding disorders. After initial review, the aims of the study pivoted to investigating whether or not these topics were being documented and addressed during clinical encounters and with which frequency.

Our data demonstrates that female patients more frequently had both school attendance (81% vs 75%) and school absences (20% vs 4%) recorded in their chart than male patients. Of those patients who reported missing school due to illness, 0% were referred to an education specialist. Additionally, menstruating patients had more frequently documented school absenteeism than non-menstruating patients (7% vs 4%).

In the immediate future, modification of the "New Patient" template can be made to include these parameters in the initial encounter. Additionally, for more widespread change and improved documentation, including these factors in the documentation of our Social Work colleagues can increase intervention and Ed. Specialist referrals. For improvement of documentation across clinics, a ".phrase" or "dot-phrase" can be adopted as below:

*"(patient name) does/does not usually miss school due to bleeding symptoms. Their school experience is affected by their bleeding symptoms by: ***. In the last month/year, (patient name) missed *** days of school due to ***. They are/are not encountering difficulties performing cares at school, including ***. They are/are not having difficulties with bathroom access. Referral to the Education Specialist was offered, and after discussion, patient and family accepted/declined."*

Following implementation of these changes, periodic data of dot-phrase utilization can and should be pulled to measure efficacy of these policy changes. Should utilization prove to be adequate during these times, future studies should be re-attempted to investigate the discrepancies in the original aims of the project.

Beyond these changes, this work can serve for preliminary data in supporting the addition of menstruation-specific questions to the Oregon Student Health survey in the hopes of eliciting more of this information and addressing disparities in care. Future investigations can and should additionally include availability of menstrual products at public schools.

The limitation of this study include it being a retrospective chart review. The largest limitation of data collection were the rigid outlines of what constituted documentation as many qualitative examples of disease severity on quality of life were present and reviewed.

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Conclusions (2-3 summary sentences)

School absenteeism due to illness is a problem that affects adolescents with bleeding disorders. Our study shows preliminary data which supports the hypothesis that menstruating adolescents miss more school than their non-menstruating counterparts though inconsistent documentation of these measures makes direct comparison difficult. With implementation of additional documentation practices, we hope to be able to investigate these disparities more deeply in the future and determine the magnitude of this problem on the adolescent population.

References (JAMA style format)

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