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ORIGINAL ARTICLE

"If I wasn't a girl": Experiences of adolescent girls with heavy menstrual bleeding and inherited bleeding disorders

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Abstract

Background: Heavy menstrual bleeding (HMB) is a presenting symptom of an inherited bleeding disorder (BD) and results in hospitalizations, limitations of daily activities, and a reduction in quality of life. Adult women with BD report a sense of stigma, difficulties understanding their bleeding, and challenges with diagnostic labels. The experiences of adolescents with HMB and BD are unknown despite advances in medical management through the rapidly growing network of young women's hematology programs.

Objectives: The objective of our qualitative study was to describe the experiences of adolescents with HMB with a BD and the impact on their day-to-day lives.

Patients/Methods: Our qualitative study utilized semistructured interviews with adolescents with HMB after a BD diagnosis. We included adolescents with a BD within a multidisciplinary Young Women's Bleeding Disorders Clinic who had achieved menarche within the preceding 3 years and conducted interviews until theme saturation. All interviews were transcribed verbatim and analyzed using qualitative thematic descriptive analysis.

Results: We identified the following themes in nine participants: anxiety and embarrassment, especially related to school; isolation and "otherness"; increased cautiousness and planning because of HMB and BD; and empowerment and identity formation because of the diagnosis of a BD.

Conclusions: Our study uncovers previously unappreciated experiences of adolescents with HMB and a BD. HMB is an isolating and stressful experience in adolescents, but a BD diagnosis results in identity formation and empowerment. Psychological support and facilitating connections to others with similar life experiences soon after diagnosis represents key areas for targeted interventions.

KEYWORDS
adolescents, bleeding disorder, heavy menstrual bleeding, menstruation, von Willebrand disease

Essentials

- The experiences of adolescents with heavy menstrual bleeding and bleeding disorders are unknown.
- We performed a qualitative study of adolescents treated at a Women's Hematology Program.
- Four themes emerged to describe the experiences of adolescents with a bleeding disorder.
- A bleeding disorder diagnosis in our cohort resulted in empowerment and identity formation.

1 | INTRODUCTION

Heavy menstrual bleeding (HMB) is a common presenting symptom of an inherited bleeding disorder (BD).[1-3] Heavy menstrual bleeding results in hospitalizations, iron deficiency anemia, depression, and limitations of daily activities.[4-7] Among adolescents with HMB, up to 30% are diagnosed with an underlying BD in tertiary care settings.[2,8] Bleeding disorders are treatable and their complications are preventable. However, delays in the diagnosis of a BD are common because of a lack of patient awareness and gaps in provider knowledge of BDs.[9-11]

Early data about the lack of support for women's health issues within hemophilia treatment centers led to the impetus for dedicated Women's Hematology Clinical Programs.[12] Guidance for developing such programs and research priorities to address this population's unique needs in the United States and Europe have been published.[13-18] A joint project by the Neonatal/Pediatric and Women's Health Scientific and Standardization Subcommittee of the ISTH defined "appropriate" HMB care for early identification of a BD in adolescents.[19] These efforts primarily involved BD experts, and information generated by patients about care experiences and preferences was not included.

Adult women with BDs experience diagnostic delays, misdiagnosis, and difficulties understanding their bleeding symptoms.[20] Additionally, stigmatization, isolation, and bullying are common.[12] Women with von Willebrand disease (VWD) expect proactive support from providers to treat HMB.[21] It is unknown whether the experiences of adolescents with BDs are like adult women. The rapidly growing evidence in the management of adolescents with BDs necessitates an equal focus on patient experiences to improve clinical outcomes.[22] Therefore, the objective of our qualitative study is to describe the experiences of adolescent girls with HMB secondary to an inherited BD and the impact on daily lives. We specifically focused on experiences related to managing HMB and receiving a diagnosis of a BD.

2 | MATERIALS AND METHODS

2.1 | Study design and setting

We enrolled adolescents from the multidisciplinary Young Women's Blood Disorders (YWBD) Program at the University of Texas Southwestern between July 2020 through August 2021, presenting for annual visits. The YWBD program was established in 2014 and is multidisciplinary, staffed by a pediatric hematologist and obstetrics-gynecology or adolescent medicine based on campus location.[13] The program manages patients with HMB without a confirmed BD diagnosis until a diagnosis is established or ruled out and those with an established BD after menarche or HMB. Patients were eligible for the study if they had a confirmed BD diagnosis, were English speaking, within 3 years of menarche, and had been seen within the program at least once. We focused on BD patients within 3 years of menarche to learn about early experiences. A care team member approached patients, and, if interested, consent was obtained (M.H.). University of Texas Southwestern's institutional review board approved the study (institutional review board number: STU-2020-0772). All procedures in this study were conducted following the highest ethical standards as contained in the Helsinki Declaration. All participants provided informed consent. We collected demographic (age, race, ethnicity) and clinical information (age at menarche, age at BD diagnosis, type of BD diagnosis, pictorial bleeding assessment chart score, and the ISTH-bleeding assessment tool score at initial evaluation in the YWBD program).[2,13]

2.2 | Interviews

The study team (M.P., M.H., and A.Z.) developed an interview guide structuring the interview process while allowing other questions to emerge (see Supporting Information). We conducted individual semistructured interviews virtually using the Doximity platform (Doximity, Inc.). One interviewer (M.P.) completed all the interviews. The semistructured nature of the interview allowed for guided conversation and additional probing while preserving conversational aspects. The virtual video permitted mindful attention to verbal and nonverbal communication. We reviewed interview questions after conducting the first three interviews to include questions that best capture the interviewee's experience and modified or eliminated questions that proved to be unclear or did not elicit necessary information. The interviews were designed to last approximately 30 min. Interviews were continued until theme saturation, defined as the point when each additional interview did not reveal any new themes that were not identified in previous interviews.[23] The interviews were recorded, and anonymous recordings were transcribed with permission.

2.3 | Data analysis

Meaningful data from the interviews were analyzed using a multiphase coding process.[24] We used the qualitative descriptive

analysis software Quirkos v1.6. The coding scheme was developed by analyzing the first three interviews and modified as needed. All transcripts were coded by the first author (M.P.) and reviewed by the lead author (A.Z.) to ensure consistent interpretation. We divided data into categories and subcategories, identifying links between categories and concepts.[24-26] Analytic notes about possible themes were written throughout the study and maintained via an electronic trail. Each theme was continually refined until its meaning fit the experience it represented.[27] The final themes were developed through validation in multiple interviews, using interpretative refinement.

3 | RESULTS

During the study period, 92 postmenarchal adolescents were seen within the YWBD program. VWD comprised 49% ($n = 45$); qualitative and familial platelet defects, 7% ($n = 6$); clotting factor deficiencies, 8% (mild FVIII deficiency and FVII deficiency, $n = 8$), Bleeding of unknown cause, 2% ($n = 2$), and patients undergoing a workup of a BD, 34% ($n = 31$). A clinic member introduced the study to consecutive eligible patients irrespective of the type of BD, and if they agreed, a study member obtained consent. Enrollment and data collection occurred in parallel until theme saturation.

We interviewed nine adolescents (median age: 17 years; range: 16–18) with an inherited BD, including VWD type I ($n = 5$), VWD type 2B ($n = 2$), VWD type 3 ($n = 1$), and inherited thrombocytopenia ($n = 1$; Table 1). The median Pictorial Bleeding Assessment Chart score was 465 (range 250–840), and the median ISTH-BAT score was 5 (range 3–11). All participants were on hormonal menstrual suppression ($n = 9$) and as-needed antifibrinolytics ($n = 7$). The participants with type 2B and 3 VWD were receiving von Willebrand factor replacement for prophylaxis for sports participation and joint protection, respectively. At the interview, none of the participants were iron-deficient or anemic. Four had a previous or current diagnosis of depression, and one had a diagnosis of anxiety; all were receiving medical management. The median duration of each interview was 32 min (range 20–55 min). Theme saturation occurred after six interviews, after which we conducted three additional interviews to ensure no new themes emerged. Through our qualitative analyses, four thematic areas emerged (Figure 1). Direct participant quotations for each theme and subtheme follow below.

3.1 | Heavy and unpredictable bleeding: stressful and anxiety-provoking

When asked to describe what being on their period is like, the participants overwhelmingly quoted it as stressful and anxiety-provoking. Participants constantly worried about the timing of the period, heaviness, and whether manageable without soiling clothes. One participant described:

> [My period] has been pretty much a huge impact on my life, because I've been dealing with it for a while and then just the "out of blue" kind of periods and the heavy periods. Like I don't know if it's going to be a heavy period, a light period, like a heavy period lasting over a week or a light period lasting like a couple days.
>
> (P2)

Another participant described the result of the unpredictable, heavy bleeding on her emotional state:

> [I felt] really on-edge. It put a lot of stress on me whenever it came because I was always "oh it's going to leak," or "oh what if my period comes right now?" Because whenever I get like these little like things of pain in my abdomen, I'd be like "Oh My God is it coming right now," and it always put me on edge and stressed me out.
>
> (P4)

One unique challenge adolescents with HMB face is attending school while on periods. All participants responded that periods made attending or participating in school challenging. Periods required going to the restroom to "check" and ensure they had not bled onto their clothes. Participants felt distracted in class and had less energy. One participant described it as "the week I dreaded the most" (P5). Another participant stated:

> It's always like a conscious thing, like "oh, am I leaking" or "what if I'm stained?" It's always in like the back of your head. For me, I can't really go to school comfortably when I'm on my period because I always have to go to the restroom, like between every single period to like check if I'm not stained.
>
> (P4)

The anxiety and embarrassment resulting from HMB caused a significant negative emotional impact. Participants felt shut down or closed off during their periods. Although all participants were on treatment for HMB, they look back on their experience of heavy bleeding as a challenging time. The oldest participant in our study described:

> I definitely can remember quite a few times where I just cried myself to sleep at night because I just didn't know what to do. It was just so hard, and so stressful to deal with, and so exhausting, and I just wanted it to stop… And still, every time I even have a glimpse of recall, I'm almost brought to tears because it was just so difficult. It was a lot of emotional pain I had to go through.
>
> (P9)

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TABLE 1 Clinic and demographic characteristics of study cohort

Participant	Age, year[a]	Race/ethnicity	BD	Age at menarche, year	Age at BD diagnosis, year	PBAC score	ISTH -BAT Score[b]	ISTH-BAT score breakdown
1	17	AA Non-Hispanic	VWD type 1	14	16	380	4	3 for HMB; 1 for bruising
2	16	White Hispanic	VWD type 3	13	5[c]	450[c]	10	4 for HMB; 2 for epistaxis; 1 for bruising; 3 for hemarthrosis
3	18	White Non-Hispanic	VWD type 1	15	15	450	3	3 for HMB
4	16	White Hispanic	VWD type 1	13	16	250	4	3 for HMB, 1 for epistaxis
5	16	White Non-Hispanic	VWD type 1	13	15	480	5	3 for HMB, 2 for epistaxis
6	16	White Hispanic	VWD type 1	13	13	560	8	4 for HMB, 3 for epistaxis, 1 for bruising
7	17	White Non-Hispanic	VWD type 2B	14	9[c]	180[c]	6	2 for HMB, 3 for epistaxis, 1 for bruising
8	17	White Non-Hispanic	VWD type 2B	14	9[c]	210[c]	4	2 for HMB, 1 for epistaxis, 1 for bruising
9	18	Asian Non-Hispanic	Inherited thrombocytopenia	15	4[c]	840	5	4 for HMB and 1 for bruising

Note: The PBAC and the ISTH-BAT scores are routinely collected at the first evaluation in the multidisciplinary Young Women's Blood Disorders Program Clinic visit. The care of female patients with established bleeding disorders is generally transferred to the Young Women's Blood Disorders Clinic at the onset of menarche and/or heavy periods.

Abbreviations: AA, African American; BAT, Bleeding Assessment Score; BD, bleeding disorder; HMB, heavy menstrual bleeding; ISTH, International Society of Thrombosis and Haemostasis; PBAC, Pictorial Bleeding Assessment Chart; VWD, von Willebrand disease.

[a]Represents the age at study enrollment.

[b]The normal range for the ISTH-BAT score is 0–2 in children for both males and females and 0–5 for adult females; therefore, the cutoff for a positive or abnormal bleeding score is >2 in children and >5 in adult females. In adolescents with HMB, an ISTH-BAT BS of >4 instead of the established cutoff of >2 in children is highly specific in predicting a bleeding disorder (Jain et al. J Thromb Haemost. 2020 Oct;18 (10), but this work has yet to be validated).

[c]Participants had a period plan in place, and period interventions were instituted with menarche; therefore, their reported PBAC is postintervention, whereas, for others, it was calculated before any period intervention was undertaken. Of note, participants 7 and 8 are twins.

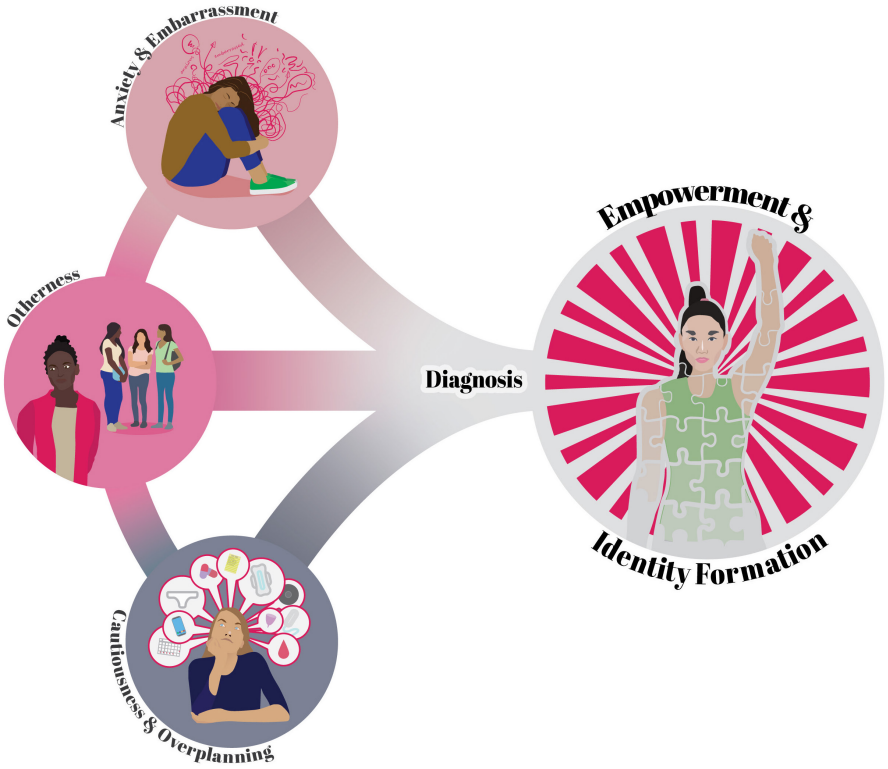

FIGURE 1 Themes from descriptive qualitative analysis in the study cohort

3.2 | Heavy bleeding and missed activities lead to feelings of "otherness" and isolation from peers

All participants reported a limitation of daily activities while on periods. They could not participate in activities, such as swimming, physical exercise class, or rough play with siblings. Reasons for missed activities included fatigue, fear of soiling clothes, pain from cramping, or fear of bleeds. They felt "left out" and different. One participant described:

> I mean, obviously [I felt] sad, no one really wants to feel left out, no one wants to feel like they're missing something, and that's how it felt missing sports or even missing school. I like school, I enjoy it a lot, but whenever I had to miss, I felt like I was missing something important, even though it was just a practice… But I wish I could be there, and some girls wish they could be home and I'm like "I don't, can we trade places?"
>
> (P7)

This limitation of daily activities negatively impacted social quality of life with HMB. Many regretted having to say no to their friends. As one participant described:

> There were times when my friends invited me places, but I just didn't feel like going those days because that's when I was on my period and the cramps were really bad and stuff. But then I feel really bad about not going with them. Like, after when it's over, I'm like "oh I should have gone with them, it looks like they had so much fun," so that made me feel bad because I was like "now I regret it I should have just put up with the pain," but then I remember the pain was pretty bad not to go out.
>
> [P4]

The participants described that teenagers often connect over the shared experience of menstruation; however, they felt isolated. Their friends could not relate to their experiences with HMB. Two different participants described this feeling:

> Sometimes you talk to your friends and they're like "oh, yeah, it's not that bad, it's just like once a month" and I'm over here like "oh, I had my period twice this month, and like one time it was really heavy and one time it was really light." I guess it just kind of makes you feel different, like not in a bad way, just that is not normal for everyone else, and I have something different. It's like kind of separating, almost, or like isolating, that's the word I'm thinking of. Cause like other than my sister really, I don't know anyone else who has this disorder, so no one else really understands what's happening other than her.
>
> (P3)

> Obviously, it's like a different experience than everyone else and like it wasn't like something I wanted

> to tell other people… You hear other people talking about their experiences and you realize how much harder your experience is, and that can make you sad, you're like "oh I'm going through all this, and they don't have to."
>
> (P9)

One protective factor against these feelings of isolation for some participants was having a family member with HMB. Seven of the nine participants had a family member with HMB or a BD. One participant with an affected sister described her experience:

> I think my sister and I, it brought us closer together just because it's something that we're both going through and it's like my mom and my dad are both really supportive and they understand what's happening. And having someone who actually like knows what it's like and know what it feels like is a lot better, so I think it brought us together more.
>
> (P3)

This was not a universally described experience, however. Some participants described neutral feelings or did not feel it affected their experience.

3.3 | A bleeding disorder diagnosis contributes to increased cautiousness and planning

Few participants experienced other types of bleeding. Five participants reported other bleeding episodes, most commonly epistaxis and bruising. Most participants described an awareness of possible severe bleeding in the case of an accident. Consequently, they developed increased cautiousness in their daily lives. One participant described:

> I have to be aware of the situations I'm in if they could cause a lot of bleeding or if something could go wrong, so I think that's like one of the main ways [it affects me]. I just always have to be like processing what I'm doing… It interrupts my thought process, like there's always just something there that you have to focus on.
>
> (P3)

All participants described excessive planning because of HMB or BD, often described as a "hassle" or "annoying."

One participant described the change she experienced after receiving her diagnosis of VWD:

> I just have to be more cautious, like if I'm bleeding too heavy, I tell my mom. If I'm not bleeding at all like if I go a month or two without a period, I tell her. I just make sure like if something's different or something seems different, I just make sure to tell my mom or we call the doctor to see what they want to do.
>
> (P1)

Another described the increased planning and precautions she must take:

> It's just the way I see, just the way I take precautions in my daily life to just move on to the next day is just kind of crazy. Cause like most people, they don't have to think about when they need to do an infusion or if they go out of town to make sure they have all their infusion stuff, so I like to make sure I don't get hurt in the future, it's just a lot of planning.
>
> (P8)

Overall, the participants seemed to develop a mental awareness of their BD, which led to cautiousness and planning. One participant highlighted the overall impact of a BD on her life solely because she was female in a quote adapted as the title of this work:

> I don't think my bleeding disorder would have had an impact on me if I wasn't a girl. Because everything else in my life is pretty normal… In my daily life, I don't have to be cautious outside of my periods.
>
> (P6)

Another uniquely female concern noted was in thinking of future childbearing. Many participants spoke of their fears and considered childbearing another area requiring increased planning. One described:

> I have always wanted to be a mom and so knowing that that is like a possibility or something that could cause complications has always stressed me out. And also, because it's like genetic I don't want to give it to a kid. I don't know I haven't thought through that all the way but that is something that does worry me.
>
> (P3)

3.4 | Unique journeys to diagnosis impacted identity formation and resulted in empowerment

Participants had unique experiences in receiving the diagnosis of their BD. Two participants experienced significant delays in diagnosis, causing fear and anxiety. Participants, especially those with delayed diagnosis, formed identities around their bleeding symptoms and diagnoses. Before VWD diagnosis, one participant described this identity formation:

> I think that anemia was my first identity when people ask me, "why do you bleed so much?" … I could just tell everybody, "hey I'm anemic," instead of saying, "yeah, I don't know what's wrong with me." And so, I think it just gave me kind of my first identity on what was going on with my blood, and I think it was just comforting to know that it was probably anemia, but at the same time it just wasn't enough at some point when it came to my menstrual bleeding.
>
> (P6)

After receiving a diagnosis, many participants felt less scared of their symptoms. A BD diagnosis empowered them to know what to do in situations where they are bleeding or could bleed. One girl said,

> It always helps to know why something is happening. To me, it's not that big of a deal because, luckily, I have a very mild form of it. But it's just nice to know, like okay this is what is happening. And also, it's just kind of good knowing that if an emergency happens, I will now know what to do in order to protect myself better, so that was helpful.
>
> (P3)

The feeling of "safety" also meant that friends and family could better support them. One described that her diagnosis makes her feel strong (P2). Another described the emotions before and after the diagnosis of VWD:

> I was really angry for a long time, like I'm really angry that nobody can figure out what's going on with me. But now that I know, it's so much easier. And I feel like I couldn't be happier
>
> (P6)

Having a diagnosis of a BD that explained the participants' HMB was, overall, positive, resulting in identity formation and empowerment and looking forward to their futures.

Two participants with VWD stated,

> I feel like now that I can love myself, and now that I can be more positive. Now I'm happier.
>
> (P6)

> I feel like I have moved past an old self, like the weight on my shoulders is gone. Like I can move on, and I can keep on living, and it doesn't feel like I have to turn my head every two seconds, like maybe they're going to try to give me another diagnosis, or maybe they're going to run some more tests. It feels like now I'm going to move past what had kept me angry for so long.
>
> (P6)

> Like as I grow up, it's going to be different, like going to college, and then adulthood, it's going to be different. Having good people work with me on that, is really nice… Like if I were to get hurt or something, I would know what to do.
>
> (P6)

4 | DISCUSSION

We report the experiences of adolescent girls with HMB and a BD through one-on-one interviewing. Four major themes represent the data collected: feelings of anxiety and embarrassment, especially related to school; isolation and "otherness"; increased cautiousness and planning because of HMB; and empowerment and identity formation due to the diagnosis of a BD. Our findings reaffirm and highlight the impact of early BD diagnosis in adolescents with HMB. HMB is an isolating and stressful experience in adolescents, but a BD diagnosis results in identity formation and empowerment. Addressing psychological concerns, providing support, and facilitating connections to others with similar life experiences represent key areas for targeted interventions.

Anxiety about school and sports participation and the need to be prepared for school were recently described in adolescents with HMB and dysmenorrhea without BDs.[28] Specific experiences of adolescent girls with inherited BDs have been limited to hemophilia carriers.[12] Khair et al.[12] showed that adolescent carriers of hemophilia suffer an information gap, rarely met others with BD, and had unmet concerns about fertility, contraceptives, and pregnancy. Since this study was published in 2013, there has been an expansion of young women's hematology programs and a substantial shift in the evaluation and care of women with suspected or diagnosed BD, with pediatric hematologists leading the charge. Therefore, the themes in our study align with the recent literature on the experiences of adult women with inherited BDs.[20,29,30] For example, Arya et al. illustrated that adult women with BD experience severe bleeding symptoms, including HMB.[29] They feel different from their peers, and HMB significantly affects their daily lives. The complications they experienced, such as anemia, iron deficiency, embarrassment, and decreased quality of life from HMB, were also similar. The unique theme in our cohort was the sense of empowerment from receiving a diagnosis of a BD. For adult women with BD, the context for diagnostic clarity and empowerment came through allyship to the BD community; in other words, through external sources such as family bleeding in carriers and other women in the community rather than themselves. Misdiagnosis and delayed diagnosis in adult women may explain the empowerment through community affiliation.[20] Most girls in our cohort without a known BD were diagnosed within 2 to 3 years of menarche compared with the historical 16-year delay in adult women.[9]

Adolescence is a critical time of identity formation, and menstruation is closely tied to the concept of female identity.[31] The negative impact and psychological trauma of HMB were captured by the title

of our work, a direct quote from a study participant. Our participants described fears of soiling clothes at school, inability to participate in social activities, struggling with wanting independence yet still being dependent on parents to manage bleeding, and fears about important life milestones such as college and childbearing. Despite these challenges, empowerment and developing identities around the BD diagnosis suggest that participants' lived experiences were also positive. Many participants expressed hope and resilience. The positive experiences are contrary to previous studies where the experiences of adult women with inherited BD were largely negative.[20,29,30] Whether advancement in the medical care and early identification of women with BD over time has contributed to positive experiences is unknown.

Our study has many strengths: we focused exclusively on experiences related to HMB in the context of a BD; therefore, our themes are relevant for devising HMB-specific patient-centered interventions. The utilization of video interviews allowed for attention to verbal and nonverbal communication. The one-on-one interviews facilitated in-depth responses to interview questions. The homogeneity of age for inclusion allowed insights into early HMB experiences. Last, we provide semiobjective data supporting HMB and bleeding severity in our participants. The limitations of our study include conducting interviews when all participants' menses were well-controlled and following a formal diagnosis of a BD. Patient experiences are likely to be different if interviewed earlier in the BD journey or if the HMB was not controlled. This nondifferential bias, however, affected all participants equally. Further, we cannot rule out recall bias as the time between HMB onset and interview was 3 years. The study cohort was weighted toward VWD; therefore, the experiences noted exclude adolescents with other BD. Participants with non-type 1 VWD in the cohort were receiving prophylaxis with von Willebrand factor replacement before HMB onset, and the impact of varying bleeding phenotype, socioeconomic factors, scholastic achievement and concomitant depression and anxiety on patient experiences cannot be ruled out. Last, we captured the experiences of adolescents treated at a tertiary care center in a high-resource setting. Adolescents' perspectives in other settings are likely to differ. We conducted interviews in English, which may have limited our capacity to capture experiences among non-English-speaking adolescents. Serving as a call to action, we propose that other investigators conduct similar qualitative studies in their settings, including schools and in languages that capture diverse perspectives enabling the BD community toward standardized practices to meet the needs of adolescents with BD.

In conclusion, our study represents a continuation of efforts to understand the adolescent voice with BD. The key implications of our findings include (1) improved access to care for earlier BD diagnosis and (2) tackling negative experiences head-on by implementing formal early psychosocial support in clinics and creating support groups or a buddy system to foster a connection to other with long-standing BD.

AUTHOR CONTRIBUTIONS

A. Zia and M. Parker conceptualized and designed research. M. Parker and M. Hannah enrolled participants. M. Parker and A. Zia analyzed the data and wrote the manuscript, and all other authors edited the manuscript.

RELATIONSHIP DISCLOSURE

The authors state they have no conflict of interests or relationship disclosures.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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