

ORIGINAL ARTICLE

The experience of postpartum bleeding in women with inherited bleeding disorders

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Abstract

Introduction: Postpartum hemorrhage (PPH) affects 6% of all deliveries and is the leading cause of maternal death worldwide (19.7%). The incidence of PPH in women with inherited bleeding disorders is substantially greater than in unaffected women; however, estimates of relative risk are highly variable. To date, their experience with postpartum bleeding has not been well studied.

Objective: We set out to explore the experience with, understanding of, and attitudes regarding postpartum bleeding among women with inherited bleeding disorders.

Methods: This qualitative study involved focused interviews of women with inherited bleeding disorders about postpartum bleeding. Women followed at a multidisciplinary clinic for women with inherited bleeding disorders who have experienced childbirth within the last 5 years were included in the study. The interview style was semistructured. Interviews continued until the point of saturation of themes. All interviews were transcribed and then analyzed using qualitative descriptive analysis.

Results: We interviewed 10 women with inherited bleeding disorders. Themes that emerged were normalization of excessive vaginal bleeding, difficulty distinguishing normal from abnormal postpartum bleeding, and empowerment of women by having a clear delivery care plan.

Conclusion: In this study, women with inherited bleeding disorders were desensitized to heavy vaginal blood loss. As a result, excessive postpartum bleeding was not recognized by many of the women we interviewed. Results highlight the importance of a multidisciplinary delivery care plan for these women. Findings revealed key areas for targeted multidisciplinary intervention.

KEYWORDS

blood coagulation disorders, female, inherited, postpartum hemorrhage, postpartum period, pregnancy

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Essentials

- Women with inherited bleeding disorders are at high risk of excessive vaginal bleeding after delivery (postpartum hemorrhage).
- We interviewed 10 women with inherited bleeding disorders about their postpartum experiences.
- Heavy menstrual bleeding desensitizes these women to excessive postpartum bleeding.
- We need to empower women to recognize abnormal postpartum bleeding, which should improve care.

1 | INTRODUCTION

Postpartum hemorrhage (PPH) affects 6% of all deliveries¹ and is the leading cause of maternal death worldwide (19.7%).² Even in the developed world, maternal mortality from PPH occurs in 2 per 100 000 live births.³ PPH can be either primary or secondary. Primary PPH is defined as >500 mL of blood loss within the first 24 hours after delivery,⁴ while secondary PPH occurs between 24 hours and 12 weeks postpartum.⁵

PPH is of particular importance for women with inherited bleeding disorders. Von Willebrand disease (VWD) is the most common inherited bleeding disorder, affects approximately 0.1% to 1% of the population,⁶ and is characterized by excessive mucosal bleeding.⁷ Hemophilia A and B are X-linked disorders affecting heterozygous males and homozygous females.⁸ Females that are heterozygous for the mutation, historically referred to as hemophilia carriers, experience a variable phenotype ranging from asymptomatic to excessive bleeding.⁸ Inherited platelet disorders encompass a variety of quantitative and qualitative platelet abnormalities.⁹ Factor XI deficiency is a rare autosomal recessive disorder affecting 1 in 1 million individuals. Symptomatology can be variable and does not reliably correlate with factor levels.¹⁰ A variety of other coagulation factor deficiencies (eg, factor XIII deficiency) exist; however, these are much less common. VWD, hemophilia carriership, quantitative and qualitative platelet disorders, and factor deficiencies can all manifest with heavy menstrual bleeding and a higher risk of postpartum hemorrhage in affected women.

The incidence of PPH in women with inherited bleeding disorders is greater than that of unaffected women, although estimates of their relative risk are highly variable.¹¹⁻¹³ It is known, however, that these women have a maternal mortality rate nearly 10 times that of unaffected controls.¹⁴ While heavier and prolonged bleeding are more common in women with inherited bleeding disorders, this bleeding can also represent a magnified response to other unrelated etiologies such as uterine atony, endometritis, and retained products.

There is a growing body of evidence to support the importance of multidisciplinary care for patients with inherited bleeding disorders.^{15,16} The Multidisciplinary Clinic for Women with Bleeding Disorders (MCWBD) at St. Michael's Hospital in Toronto has cared for approximately 260 women since its inception. The care provided by this specialized team is particularly important when patients face the unique hemostatic challenges of pregnancy and delivery. This clinic consists of a specialized nurse, obstetrician, anaesthesiologist, pediatric hematologist, and adult hematologist, all of

whom collaborate to manage these women throughout pregnancy. Importantly, the MCWBD at St. Michael's Hospital considers the pregnant patient herself as a critical part of the care team, as she is provided with a hard copy of the peripartum care plan along with educational materials to facilitate awareness, empowerment, and self-advocacy skills.

Developing patient-centered resources requires a critical assessment of patient needs. The value of the patient voice is becoming increasingly recognized in medicine.¹⁷ Von der Lippe et al¹⁸ suggested that by understanding the experiences of hemophilia carriers, health care providers can improve the quality of communication with their patients. Therefore, to advance the peripartum care of women with bleeding disorders, we have to first understand their perspective.

The aim of this study was to describe the postpartum bleeding experiences of women with inherited bleeding disorders and to identify areas for education and improvement in the peripartum care of this high-risk population.

2 | MATERIALS AND METHODS

2.1 | Study design and setting

This qualitative study involved interviewing women diagnosed with inherited bleeding disorders about their experiences with postpartum bleeding. The interviews were semistructured and individual.

All participants are followed at the MCWBD at St. Michael's Hospital in Toronto, Ontario. The MCWBD was founded in 2014 and follows a total of approximately 260 women. It is part of the largest Canadian hemophilia treatment center. Forty-five percent of women followed at the clinic have VWD, 11% are symptomatic hemophilia carriers, 15% have an inherited platelet disorder, 2% are affected by factor XI deficiency, and 1% have rare clotting factor deficiencies.

2.2 | Participants

Patients were identified using the MCWBD research database. This database was developed at the inception of the multidisciplinary clinic and includes longitudinal demographic, clinical, laboratory, and quality-of-life data. More than 90 infants have been born under the care of the MCWBD since its creation (January 2014). Women were eligible to participate in the study if they were 18 years of age or older, English speaking, had a formal diagnosis of an inherited bleeding disorder, and had delivered a child within the past 5 years. Patients were excluded if they were on therapeutic anticoagulation during their pregnancy or within 3 months of delivery.

Patients were approached by a member of their circle of care and, if amenable, were introduced to a research assistant. Consent was obtained by a research assistant. This study was reviewed and approved by the Research Ethics Board at St. Michael's Hospital (Research Ethics Board approval number 17-177).

2.3 | Interviews

Semistructured interviews were performed over the phone by a study investigator (HV). This interview style allowed for a fluid conversation with follow-up questions when appropriate. A female interviewer was selected to facilitate patient comfort. Interviews lasted approximately 30 minutes. An interview protocol was followed to guide the discussion. This protocol was developed by a resident physician (HV), a hematologist (MS), and a qualitative research methodologist (KND). It was revised after the first 2 interviews to cover the topics of interest in more detail. Questions focused on patients' experiences with peripartum care, delivery, and postpartum bleeding. Patients' understanding of normal vs. abnormal postpartum bleeding was explored. Interviews continued until a point of theme saturation, which occurred after 7 patient interviews. At this time, 3 more interviews were completed to ensure that no new themes arose.

2.4 | Data analysis

All interviews were recorded with patient permission, and anonymous voice recordings were subsequently transcribed by Paul M. Garton Inc. Transcriptions were analyzed for themes using qualitative descriptive analysis. We used a 3-phase coding process to identify themes that represented the data. A random selection of interviews was coded by 2 team members (HV, KND) to ensure similar interpretation of the data. From there, the remainder of the data set was coded by the lead author (HV). The coding scheme was developed by analyzing the first 3 interviews in collaboration with a qualitative research methodologist (KND).

3 | RESULTS

A total of 10 participants were interviewed (see Table 1). All interviews occurred by phone. Participants had a range of inherited bleeding disorders including VWD (4 patients), hemophilia carrier-ship (1 patient), factor XIII deficiency (1 patient), and platelet function disorders (4 patients). The median condensed Molecular and Clinical Markers for the Diagnosis and Management of Type 1 VWD Bleeding Questionnaire (MCMDM1) scores was 9.5 (see Table 1). Four of the participants carried a formal diagnosis of primary PPH, and a fifth woman described features consistent with unrecognized primary PPH. Six of the 10 women described excessive or prolonged postpartum bleeding suggestive of secondary PPH, although none carried a formal diagnosis. Using qualitative descriptive analysis, we grouped the data into 4 primary thematic areas.

TABLE 1 Patient characteristics

Age, median (IQR)	34 (2.5)
Bleeding disorder, n (%)	
Von Willebrand disease	
Type 1	3 (30)
Type 2	1 (10)
Platelet disorder	
Gray platelet	2 (20)
May-Hegglin anomaly	1 (10)
Unspecified	1 (10)
Factor XIII deficiency	1 (10)
Hemophilia B carrier	1 (10)
Number of pregnancies, n (%)	
1	5
2	4
≥3	1
Family history, n (%)	7 (70)
Condensed MCMDM1 score, n (%)	
6	1 (10)
7	1 (10)
8	2 (20)
9	1 (10)
10	1 (10)
12	2 (20)
13	1 (10)
18	1 (10)

MCMDM1, Molecular and Clinical Markers for the Diagnosis and Management of Type 1 VWD Bleeding Questionnaire.

3.1 | Discomfort in defining and recognizing abnormal postpartum bleeding

We asked women about their knowledge of postpartum hemorrhage and abnormal postpartum bleeding. While all interviewees had heard of postpartum hemorrhage, none could clearly define it.

When asked to describe her understanding of the term *postpartum hemorrhage*, a participant replied:

"I know the words but ... I don't know much about it. ... I know what a hemorrhage is, but I can't say that I know what a postpartum hemorrhage is, other than being excessive bleeding." [P3]

Most women's conceptions of PPH addressed the amount of blood lost rather than the duration of postpartum bleeding. Eight of 10 women did not address the duration of bleeding in their definition of postpartum hemorrhage. Patients had a clearer understanding of how to identify abnormal menstrual bleeding than how to identify abnormal postpartum bleeding. As one woman explains:

"I can understand [what heavy menstrual bleeding is], but in terms of what would be normal post delivery, I don't know the answer." [P4]

We identified that 6 of the 10 women that we interviewed described symptoms consistent with secondary postpartum hemorrhage without recognizing it. Multiple women referenced education they received before being discharged from the hospital, in which they were told to watch for golf ball-sized clots. To women with bleeding disorders this provided false reassurance. A woman who subsequently described symptoms consistent with secondary postpartum hemorrhage said:

"The education that they teach you is if you have any lemon-sized clots or golf ball-sized clots that you're passing, if you're soaking a pad within an hour or two, then I should be going back to the emergency department. I didn't have any of that, so that's why I thought it was normal." [P10]

3.2 | Normalization of bleeding

Many women with inherited bleeding disorders have grown up with an affected family member. In our study, 7 of the 10 women had family members with a diagnosed bleeding disorder. They identified that their mothers had experienced heavy vaginal bleeding, and this minimized their perception of heavy or prolonged postpartum bleeding. These women also described lifelong menorrhagia and other types of mucocutaneous bleeding. As one woman said of her menstrual bleeding, "What I thought was normal was obviously not normal." Many anticipated their postpartum bleeding would be similar to their menstrual bleeding. When asked what would be considered abnormal postpartum bleeding, one patient with a history of menorrhagia said:

"If it's heavier than a heavy period, that to me would be worrisome." [P5]

After a caesarean section, a symptomatic hemophilia B carrier said she "would be more likely to call the clinic right away if I'm bleeding from my incision than I would if I was bleeding vaginally." Perhaps due to the familiarity of excessive vaginal bleeding, many patients did not label their heavy or prolonged postpartum bleeding as abnormal. Women frequently used their menstrual periods as a reference for normal, and postpartum bleeding would need to be "much heavier" than their menstrual bleeding to raise concern.

One woman stated:

"As far as I'm concerned it's completely normal to have heavy bleeding after a delivery." [P4]

Their threshold to seek assessment was also higher, since they did not identify their bleeding as true "hemorrhage."

That same patient explained:

"I didn't have to call an ambulance, I wasn't in and out of consciousness—those are my opinions of true hemorrhages, but it wasn't like that with my delivery." [P4]

Another said:

"Comparing to my periods ... [postpartum hemorrhage] is much heavier ... it feels like feeling faint, the heart rate increasing ... going pale." [P1]

Five women sought assessment for their postpartum bleeding; however, only 3 of 6 women who described symptoms suggestive of secondary postpartum hemorrhage contacted a health care provider.

We also noted that the way participants spoke about their postpartum bleeding changed if their child was affected by a bleeding disorder. Women whose children also had a bleeding disorder further downplayed the impact of their bleeding symptoms, yet they were still able to identify and act upon abnormal bleeding in their children. A woman whose son is affected by VWD described:

"Last night we spent 7 hours in [the emergency department] for a severe nosebleed. [My son] was vomiting blood. It's those types of things that are a bit stressful." [P1]

3.3 | Access to care

Numerous women with relatives affected by an inherited bleeding disorder commented on the differences in care between their pregnancies and those of their affected family members. Commonly, women described their deliveries while being followed at the MCWBD as more organized than those of their sisters or mothers who lived in more rural settings and did not have access to a specialized bleeding disorder team. They also perceived that their health care providers were better informed about their bleeding disorder and their risk for excessive peripartum bleeding. A patient with VWD compared her experience with pregnancy to that of her affected sister:

"She had no plan. She wasn't overseen by a good clinic. My mom was the one who was in the room administering Humate-P. ... Her hemoglobin dropped to 80 and she had hemorrhaging afterwards. ... She couldn't breastfeed either of her kids because she was just too lethargic. ... She has a totally different story than I do. It's very unfortunate. It's just because I have the luxury of living in Toronto." [P1]

One woman who is a symptomatic hemophilia carrier described the difference between her affected sister's experience and her own:

"My sister is actually pregnant as well, and she's a hemophilia carrier. Unfortunately, she lives [farther away] and she's not followed by a ... bleeding disorder team. ... It's much more comforting coming to the clinic and knowing that they're well aware of any complications that I could be experiencing. I was able to meet with a team ... and discuss my birthing plan and ... how to prevent a bleed afterwards ... whereas my sister was like, 'I don't understand, I'm scared. How is this okay for you but not for me? My doctors are not taking me seriously.'" [P4]

Another woman explained that her diagnosis of a platelet function disorder was delayed by poor access to primary health care:

"Many people ended up without a family doctor, and I was one of them. ... All the care I had was from the emergency department, and you don't go to the emergency department for menstruation unless it's really, really bad." [P7]

One interviewee who moved 1 hour away from the MCWBD expressed the following concern about accessing care:

"Especially now that I'm living [farther away] I probably should know [how to recognize postpartum hemorrhage], because I would be going to one of the hospitals here." [P1]

When asked where they would seek help for concerns about excessive postpartum bleeding, 6 patients stated that they would contact the MCWBD, 3 said they would present to the emergency department, and 1 said she would contact her midwife.

3.4 | Empowerment with a clear plan

The multidisciplinary team at MCWBD consists of a specialized nurse, obstetrician, anesthesiologist, pediatric hematologist, and adult hematologist, who collaborate to develop a clear delivery plan for women; this includes detailed instructions about how to approach peripartum bleeding. Many women alluded to a sense of control when provided with a thorough multidisciplinary plan. The MCWBD gives them access to multiple health care providers with varying perspectives who can inform them about peripartum bleeding risks for both themselves and their infants. For many, this information allowed them to prepare and gave them a sense of empowerment.

A woman with VWD said:

"I'm having a son this pregnancy, so it was also very helpful for me to talk to the multidisciplinary team. We ultimately have decided we're not going to circumcise our little guy anyway, but if we were to, that

could have had a really negative impact if we didn't know about my bleeding issue for him." [P2]

Women often described a sense of relief and empowerment that came with having a clear plan in place to manage their own peripartum bleeding. As one participant described:

"I was able to leave with something, a hard copy in my hand of what I was going to need to do if something happened. ... I had a plan in case I wasn't able to make it downtown, because I do live [1 hour away] ... in case my labor progressed really quickly, I would still be able to go to my local hospital and say this is what I need." [P10]

Speaking of the MWCBD, another woman said:

"They allayed my fears that if I did need a C-section, the bleeding could be controlled." [P2]

Others commented on the importance of having clear communication among the various health care professionals involved in their care. Of the 10 patients interviewed, 8 delivered at the hospital associated with the MCWBD. Particularly for women who delivered at other institutions, the obstetric and anesthesiology teams required clear instructions on how to safely care for them and their babies. In one patient's experience, the MCWBD staff prepared "the team of doctors for any possible scenario during the pregnancy, delivery, and postpartum period."

A recurrent concern for women was the ability to receive regional anesthesia (eg, an epidural) at the time of delivery. This issue is continually reassessed by the hematologist and anesthesiologist at the MCWBD leading up to delivery and is included as part of their care plan.

A woman with type 2A VWD stated:

"During the delivery, there was a well-thought-out plan. We had it written down; they briefed the labor and delivery floor. ... There were no surprises." [P1]

4 | DISCUSSION

To our knowledge, this is the first qualitative study to explore the experience of postpartum bleeding among women with inherited bleeding disorders. We have chosen 4 primary themes to represent the data collected in the interviews: discomfort in defining and recognizing abnormal postpartum bleeding, normalization of bleeding, access to care, and empowerment by having a clear plan.

Some of the women we interviewed were uniquely positioned to compare their care to that of their affected family members who were not followed by a multidisciplinary hematology team during

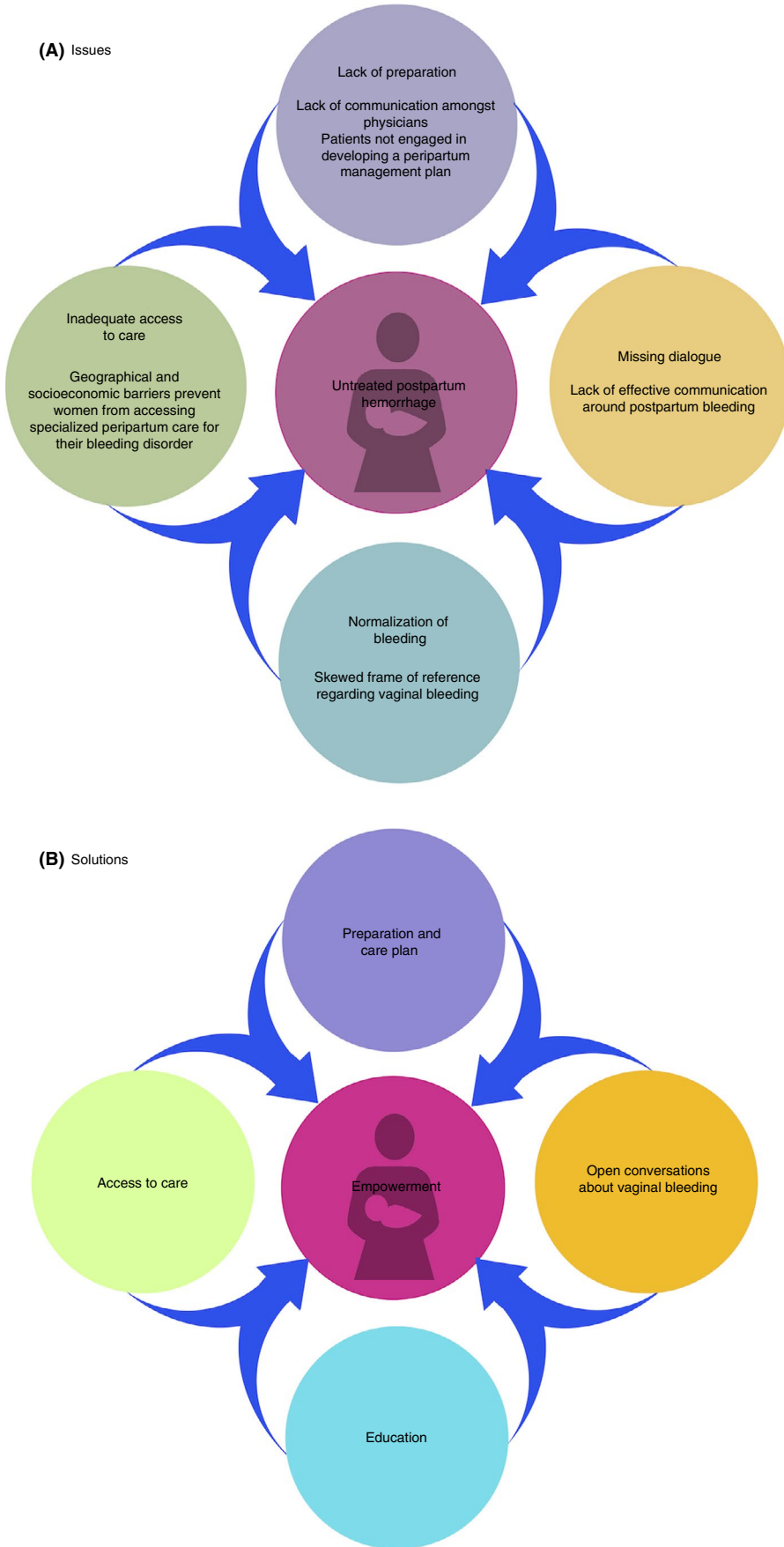


FIGURE 1 Issues identified during interviews with women affected by inherited bleeding disorders about their postpartum bleeding and proposed solutions

pregnancy. They perceived major differences in their experiences based on their access to care. The peripartum management of these women can be very challenging and warrants expert input to prevent catastrophic bleeding. This highlights the importance of connecting these patients with specialists before pregnancy to facilitate accurate diagnosis and preemptive care planning.

Given that specialized care is not always readily accessible, it is particularly crucial to engage and enable patients to advocate for their own best health care. For example, giving women a printed copy of their birth plan can empower them to advocate for appropriate care even if they are unable to reach their planned delivery site in time. Another important way to empower these patients is to include them and their care providers in developing and implementing a clear delivery plan. Involving patients, anesthesiologists, and pediatric and obstetric teams also helped allay much of the anxiety felt by the women we interviewed. The complexity of managing these cases requires carefully considered antenatal multidisciplinary care.

Despite the popular anecdotal belief that women with inherited bleeding disorders overreport bleeding symptoms, we demonstrate the opposite: heavy bleeding was considered “normal” by many of these women and, in fact, they tended to underreport worrisome bleeding. We label this “normalization” of bleeding, by which we mean that these women become desensitized to heavy vaginal bleeding. This is in keeping with Kulkarni’s¹⁹ observation that women with heavy menstrual bleeding underreport their symptoms, delaying their diagnosis and access to treatment. Care providers need to ask directed, unbiased questions to screen for abnormal bleeding in all peripartum women, but especially in those affected by inherited bleeding disorders. What many of these women perceive as “normal” is in fact quite abnormal.

This emphasizes the need to reframe our vernacular around vaginal blood loss. The common idiom advising women to watch for “golf ball–sized blood clots” oversimplifies abnormal postpartum bleeding. Rather, the concept would be best defined to patients not only by the quantity of bleeding but also the duration. Exploring a woman’s usual menstrual bleeding history can help a health care provider quantify abnormal bleeding in relative terms for the patient. Thoroughly assessing a woman’s bleeding at their postpartum visit and providing a nursing help line may also help avoid undiagnosed and untreated secondary postpartum hemorrhage. Reframing our conversations with patients about abnormal bleeding will help address its underrecognition. Our findings suggest that the dialogue around postpartum bleeding needs to evolve to facilitate accessible and patient-centered conversations.

We highlight a large knowledge gap in identifying secondary postpartum hemorrhage, and this is important because an estimated 1 in 10 women who deliver vaginally experience undiagnosed abnormal postpartum blood loss.²⁰ While health care professionals should be screening for this, many women do not see a physician in follow-up until 6 weeks after delivery. Therefore, it is important to empower these women to identify abnormal bleeding after they leave the hospital, and we have identified a significant opportunity to educate women about the objective signs of abnormal postpartum bleeding.

In fact, we found that a multitude of factors interact to affect the perception and management of abnormal bleeding among women with inherited bleeding disorders (see Figure 1a). Moreover, we suggest targeted solutions based on these identified issues (see Figure 1b).

Next steps include exploring the experience of women without inherited bleeding disorders and the development of knowledge translation and exchange tools to help these patients recognize abnormal bleeding in the postpartum period.

4.1 | Limitations

We recognize that this study is limited to the experience of women cared for at a hemophilia treatment center in a high-resource setting. The bleeding scores of these women are also high, representing women with more severe bleeding disorders. Further research is needed to expand our understanding of women’s experiences of postpartum bleeding in settings with less access to care and the experiences of women with milder symptomatology. This study also does not include the perspective of women with acquired bleeding disorders such as immune thrombocytopenia.

RELATIONSHIP DISCLOSURE

The authors have no relevant disclosures.

AUTHOR CONTRIBUTIONS

HV contributed to study design, performed interviews, analyzed data, and drafted the manuscript. JP recruited and consented patients and helped analyze data. KD contributed to study design, refined the research methodology, and edited the manuscript. GF recruited patients and helped facilitate patient interviews. FM contributed to study design and provided content expertise. MS contributed to study design and data analysis, provided content expertise, and edited the manuscript. The authors acknowledge the following contributions: Nicole Veloce for her help with patient recruitment, and Amy Skitch for her assistance with coordinating the study.

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