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ORIGINAL ARTICLE

"Everything was blood when it comes to me": Understanding the lived experiences of women with inherited bleeding disorders

Sumedha Arya[1] | Pamela Wilton[2] | David Page[2] | Laurence Boma-Fischer[3,4] | Georgina Floros[4,5] | Rochelle Winikoff[6] | Jerome Teitel[4] | Katie Dainty[7,8] | Michelle Sholzberg[9,10]

[1]Department of Medicine, University of Toronto, Toronto, ON, Canada

[2]Canadian Hemophilia Society, Montreal, QC, Canada

[3]Department of Physical Therapy, University of Toronto, Toronto, ON, Canada

[4]Division of Hematology and Oncology, Department of Medicine, St. Michael's Hospital, Toronto, ON, Canada

[5]Department of Nursing, St. Michael's Hospital, Toronto, ON, Canada

[6]Division of Hematology-Oncology, CHU Ste-Justine, Montreal, QC, Canada

[7]North York General Hospital, Toronto, ON, Canada

[8]Institute of Health Policy Management and Evaluation, Dalla Lana School of Public Health, University of Toronto, Toronto, ON, Canada

[9]Li Ka Shing Knowledge Institute, St. Michael's Hospital, Toronto, ON, Canada

[10]Department of Medicine and Laboratory Medicine & Pathobiology, St. Michael's Hospital, Toronto, ON, Canada

Correspondence
Michelle Sholzberg, St. Michael's Hospital, 30 Bond Street, Room 2-007G Core Lab, Cardinal Carter Wing, Toronto, ON M5B 1W8, Canada.
Email: SholzbergM@smh.ca

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Abstract

Introduction: Despite the many symptoms that women with inherited bleeding disorders experience, no study has specifically sought to explore and understand the lived experiences of these women, nor the barriers to care that they may encounter. The primary objective of this study was to describe the lived experiences of women with inherited bleeding disorders.

Methods: Inclusion criteria for study enrollment were the following: age ≥18 years, English speaking, and confirmed diagnosis of an inherited bleeding disorder. Women were recruited across Canada through identification by treating health-care providers and study members of the Canadian Hemophilia Society. Telephone interviews were conducted using a semi-structured interview style, transcribed verbatim, and analyzed using descriptive thematic analysis.

Results: A total of 15 participants were interviewed. Median age was 31 years (24–70 years old). Four primary themes emerged: uncertainties surrounding diagnosis, conceptualization of experience through family bleeding, intensity of bleeding symptoms, and impact of bleeding on identity and daily life.

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Discussion: To our knowledge, this is the first study to thoroughly describe the experiences of adult women living with inherited bleeding disorders. We found that these women experience multiple uncertainties around their diagnosis. They conceptualize their bleeding by examining family histories; experience severe symptoms irrespective of their underlying diagnosis; and create identities around their bleeding symptoms, which influence multiple aspects of their life. Next study steps will involve sharing work specifically focused on treatment plans, barriers to care, and factors affecting care access.

KEYWORDS

hemophilia A, hemophilia B, patient-centered care, von Willebrand disease, women's health

1 | INTRODUCTION

Women with inherited bleeding disorders may experience increased bleeding symptoms due to a variety of hereditary bleeding diatheses, including von Willebrand disease (VWD), platelet function defects, hemophilia A and hemophilia B carrier status, and other rarer coagulation factor deficiencies.[1] Bleeding secondary to these disorders may have a range of adverse consequences including, but not limited to, heavy menstrual bleeding (HMB), post-partum hemorrhage (PPH), iron deficiency anemia (IDA), and reduced quality of life (QOL).[1-5]

VWD, which is the most common inherited bleeding disorder, is an autosomal dominant or recessive genetic condition caused by missing or defective von Willebrand factor (VWF), a multimeric glycoprotein necessary for hemostasis. Due to its inheritance pattern, it is expected to affect men and women equally.[6] Clinically, however, women are more frequently diagnosed due to bleeding symptoms associated with menstruation and childbirth.[3,6-9] Hemophilia, conversely, is an X-linked recessive condition, and has been classically considered a disease of men. Women with hemophilia trait, often referred to as "carriers," are seldom recognized due to lack of disease awareness at both the patient and health-care provider level, despite bleeding phenotype.[1] Platelet function disorders, or other rarer factor deficiencies, additionally remain challenging to diagnose and treat secondary to ill-established epidemiology, limited laboratory assay testing, and scarce management recommendations.[1,10,11]

Recognition and early diagnosis are critical for the management and avoidance of complications for women with inherited bleeding disorders. However, despite the many symptoms that women with inherited bleeding disorders may experience, their lived experiences surrounding diagnosis and treatment have been minimally described. Furthermore, whether they receive timely screening and specialist referral remains unclear. While literature on this topic is sparse, studies specific to VWD have found that, irrespective of the hemostatic challenges women face, they are often unlikely to be referred to hematologists, subsequently remaining undiagnosed and undertreated.[6,7,12] Concerns for diagnostic delay among patients with undiagnosed and rarer bleeding disorders have also been raised; however, it is unclear if morbidity and mortality related to delayed diagnoses differs between women and men.[13,14]

Essentials

- Despite the manifold symptoms that women with inherited bleeding disorders may experience, their lived experiences have been minimally described.
- We conducted in-depth semi-structured interviews with adult women with inherited bleeding disorders in Canada.
- Four major themes emerged: uncertainties surrounding diagnosis, conceptualization of experience through family bleeding, intensity of bleeding symptoms, and impact on identity and daily life.
- Improved tools to differentiate normal and abnormal bleeding, symptom-focused diagnostic language, and early testing and accurate diagnoses are needed.

The objective of this qualitative descriptive study was to describe the experiences of women with inherited bleeding disorders, and to identify areas for improvement in their care. This article focuses on describing the lived experiences of these women; a separate article will detail diagnostic awareness, barriers to care, and potential solutions.

2 | MATERIALS AND METHODS

We conducted a qualitative descriptive interview study to explore the lived experience of women with inherited bleeding disorders. Women were recruited across Canada through identification by their treating health-care providers and by study investigators of the Canadian Hemophilia Society. Inclusion criteria for study enrollment were: age ≥18 years, English speaking, and confirmed diagnosis of an inherited bleeding disorder. Women who agreed to participate were

then contacted by a research team member to obtain consent and arrange the interview.

Semi-structured telephone interviews were conducted by the lead author (SA). A female interviewer was selected to optimize patient comfort. A qualitative interview guide was developed in conjunction with experienced hematologists (MS and RW), patient advocates from the Canadian Hemophilia Society (CHS; PW and DP), and a qualitative research expert (KD; see Appendix S1 in supporting information). Questions focused on patients' diagnosis, associated symptoms and complications, the ways in which living with a bleeding disorder affected their lives, the type of care they have received since their time of diagnosis, and challenges to the care experience. A semi-structured interview style allowed for additional probing utilizing optional prompts, as well as for follow-up questions as needed. Interviews continued until thematic saturation, the point at which no new themes could be extracted from the data.[15] This occurred after 10 patient interviews. Five additional interviews were completed to ensure no new information was being offered.

All interviews were recorded with patient permission and recordings were transcribed by a professional transcription service. Transcripts were analyzed using descriptive qualitative analysis using a multiphase coding process. All transcripts were coded by the lead author (SA). A random selection of interviews was independently coded by three investigators, including a qualitative research methodologist and a patient advocate, to ensure there was a consistent interpretation of the data during analysis (SA, KND, PW). The initial coding scheme was developed by analyzing the first five interviews and modified as needed.

3 | RESULTS

A total of 15 participants were interviewed. The median age of the women was 31 years old (24–70 years old). Their diagnoses included hemophilia A carrier (N = 5), hemophilia B carrier (N = 2), VWD type 1 (N = 1), VWD type 2 (N = 3), disorders of platelet function (N = 2), Glanzmann's thrombasthenia (N = 1), Hermansky-Pudlak syndrome (N = 1), and congenital dysfibrinogenemia (N = 1). One patient carried more than one diagnosis. Mean interview length was 43 minutes (range 30–65 minutes). Data were grouped into four primary thematic areas (Figure 1). Direct participant quotations for each theme and subtheme are provided in Tables 1-4.

3.1 | Theme 1: Uncertainties surrounding diagnosis

3.1.1 | Difficulties differentiating normal from abnormal symptoms

Irrespective of their underlying diagnosis, or how they were diagnosed, women described challenges differentiating normal from abnormal bleeding symptoms, particularly in relation to vaginal bleeding. In the context of these difficulties, they often utilized family history to determine whether or not their menses were abnormal. However, abnormal bleeding histories within families were often normalized, resulting in women believing that their heavy menses were the norm for them. Stigma surrounding menses created additional challenges for women in understanding their bleeding patterns; some participants described a lack of open discussion with both female family members and peers as a barrier. When counseled by health-care practitioners regarding indicators of heavy vaginal blood loss, some women described that certain bleeding symptoms that they were instructed to be observant of (eg, passing clots) did not apply to their personal bleeding experience. While participants did not propose a specific prescriptive solution to the challenge of differentiating normal from abnormal bleeding, they did delineate the importance of having a health-care team that listened to them and helped them understand their symptoms.

3.1.2 | Challenges with diagnostic labels

Women described the various diagnostic labels they had been given throughout their lives; the uncertainty around these labels; and the profound impact that these labels, including the label of "carrier," could impose. Many felt that the label "carrier" was dismissive of their symptoms, and that the language utilized permitted neglect toward their bleeding experiences. Others noted how challenging it was for them not to fit into a clear diagnostic "box," subsequently struggling to understand their own diagnostic identity and its implications. Participants grappled with the lack of clarity around their diagnoses, and subsequently felt misunderstood, judged, or invalidated. One woman shared that she was labeled as a carrier, without the associated terminology "symptomatic." This slight shift in language resulted in perceived under-recognition and undertreatment. For some participants, having a clearly defined label felt validating, because it brought recognition to their symptoms, and acknowledged an underlying diagnosis that felt concordant with their degree of bleeding. Participants described a discordance between labels and bleeding phenotypes; frustration with incorrect labels or lack of diagnostic clarity; and the need for a more open, symptom-recognition–based approach.

3.1.3 | Misdiagnoses and diagnostic delay

In the context of challenges differentiating abnormal from normal symptoms, as well as difficulties with diagnostic labeling, multiple participants also described either misdiagnoses or diagnostic delay. Often women experienced a change of diagnosis, or even the addition of an alternative diagnosis. One woman, who was misdiagnosed as having hemophilia and eventually was found to have a platelet function disorder, shared that she received incorrect treatment for more than two decades. Another described receiving incorrect treatment, while others described years of bleeding without a clear explanation

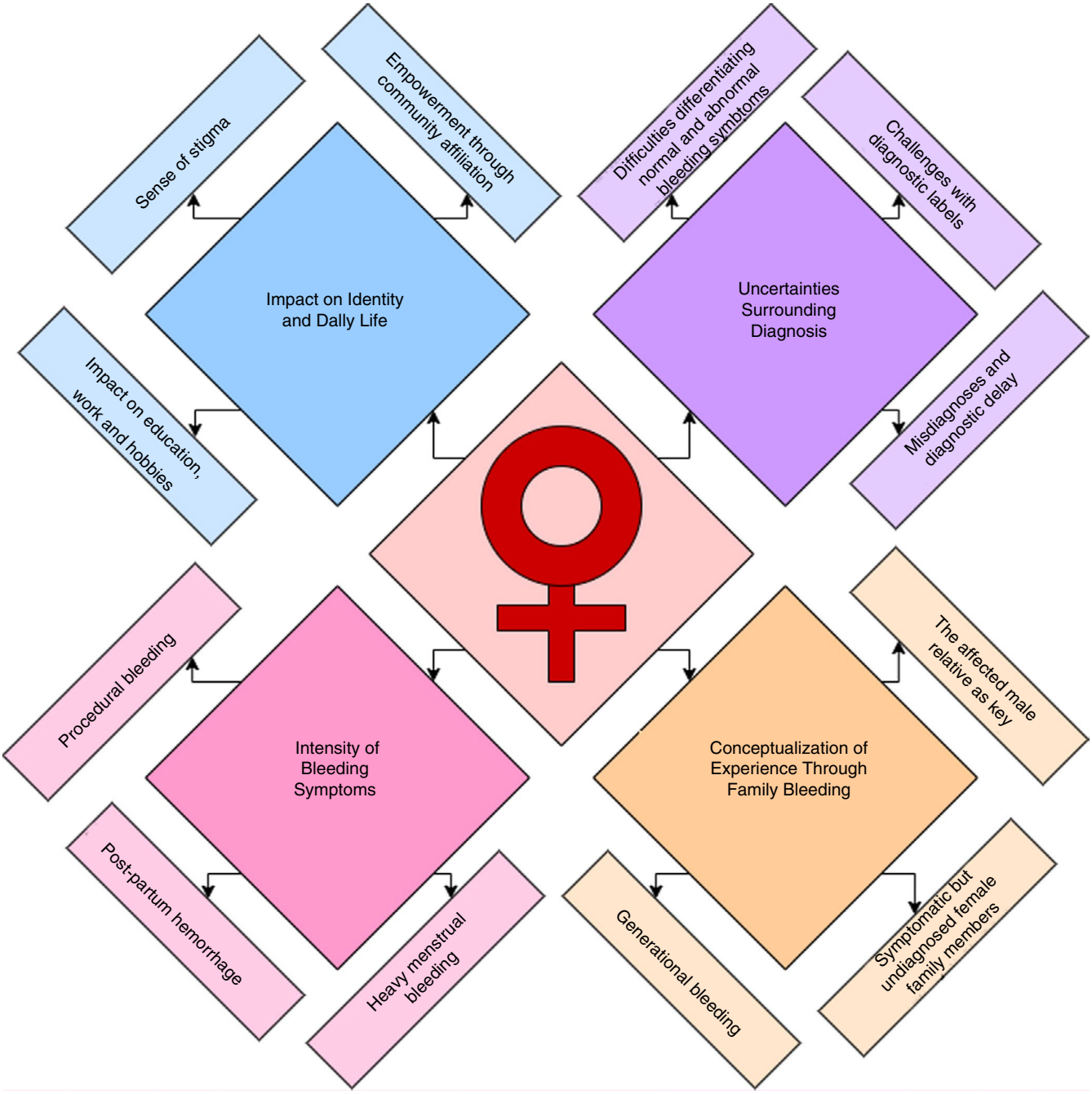

FIGURE 1 Themes and subthemes from descriptive qualitative analysis

and correct diagnosis. For multiple women, reaching a correct diagnosis was not immediate, and often required re-evaluation.

3.2 | Theme 2: Conceptualization of experience through family bleeding

3.2.1 | The affected male relative as the key

Particularly with regard to hemophilia, women often discussed that their own diagnoses were discovered based on their fathers' diagnoses, or the births of their sons; multiple women who were diagnosed with an inherited bleeding disorder had been living with it for years prior to giving birth to their affected sons. The lives of their affected male relatives were inseparable from many women's experiences, particularly as multiple women had loved ones suffer complications from Canada's tainted blood crisis, which affected their own attitudes toward having a bleeding disorder. Women often described learning of bleeding disorders first from their affected father or son, and male relatives created much of the context for women's diagnostic certainty and subsequent understanding of bleeding.

TABLE 1 Representative quotes from participants illustrating subthemes related to theme 1: Uncertainties surrounding diagnosis

Uncertainties surrounding diagnosis		
Difficulties differentiating normal from abnormal bleeding symptoms	**Challenges with diagnostic labels**	**Misdiagnoses and diagnostic delay**
When I started my period, I wasn't sure what was normal or not. [P2]	I've been living with the label of symptomatic carrier. He [the doctor] looked at my file and said "you're a symptomatic carrier." Like the term "carrier" was just thrown around so many times that I was like, "I don't care what you call it. I have hemophilia, and my wrist is broken, and I need an infusion. [P1]	I was probably 26 when I had [my blood] retested and they then finally realized that they weren't quite normal. [P2]
Since I've been with [my bleeding disorders] team, the bleeding disorder is still there, but, on my monthly basis, I now know how to calculate when I'm supposed to bleed or when it's supposed to last. [P5]	When I ask, like, you know, should I be doing this, like, what should my care plan be, there's not really a definitive answer, and I feel like it is because of the label, symptomatic carrier. [P1]	Everything was blood when it comes to me, and they didn't understand me [...] I was born with a bleeding disorder, and before I was advised to go to [my current treatment center], I was misdiagnosed. I was told I had hemophilia [...] So, for the past 23 years, I was taking the wrong medications and the wrong treatment. [P5]
I remember hearing them say, "Where is all this blood coming from?" And of course, I really didn't know what was normal and what wasn't. I just thought, well, you got a – there's a placenta in there. You have to expect some. And so, I wasn't really all that concerned about it. [P6]	I don't really remember them calling me anything besides a carrier. [P2]	It was even after [my geneticist appointment] that I was given the referral to go to [the specialist center]. So, I could probably, it was easily, say, a year before I even saw someone. [P7]
My grandmother and my mother both bled a lot. They just told me, "Well, you're just a redhead like us, so it's normal for you to bleed." [P7]	I don't have hemophilia, but I do have a platelet dysfunction that's – they're still kind of unsure what exactly it is [...] I'm unclear of exactly what it is because the doctors are unclear exactly what it is. [P3]	It wasn't looking like they could figure [my diagnosis] out. Anyways, they ended up doing genetics testing, in which case I was told that I have type 2M and that's probably why in real life I wasn't responding to the DDAVP. [P8]
I was diagnosed with von Willebrand type 1 around the time that my periods were, I guess, newer, and I was learning what was supposed to be normal or not normal. [P8]	I have a platelet dysfunction and it's, like, unidentified or unspecified. I don't know what's wrong with my platelets. [P4]	I wasn't diagnosed until my son was diagnosed with severe hemophilia [...] Nobody [previously] knew anything, and they just finally had to burn my gums shut to stop the bleeding. So, things like that, when I was diagnosed and then it was like, okay, that's why things like that happened to me growing up. It was kind of, you know, oh – it all made sense. [P9]
For the post-partum bleeding I went [to hospital] twice. So, one of the problems was how they asked me to determine if my bleeding was abnormal or not. They would say if you have blood clots the size of whatever they said at the time – the problem is I don't clot. So, I'm looking for these blood clots. Meanwhile, I'm bleeding a lot. [P8]	They're supposed to understand you and be empathetic and compassionate, but then I realized when people don't understand you or don't know what – they can't see where you're going through, they assume, and they label you. [P5]	I bled for 5 days and [my physician] noticed that I had symptoms of a bleeding disorder, so he stepped in and they found out that I had hemophilia A, and they thought I was just a symptomatic carrier. Over the years, I have changed. I've gone from hemophilia A to mild to a carrier, and now, today, I have hemophilia A and von Willebrand 2N. [P12]
A lot of my family is very old school and don't talk about periods or anything, but me and my mom are very open, so when I would tell her about my period, she knew that's not normal. [P12]	They have – they don't call you a symptomatic carrier anymore. And even if you do have bleeds and you report the bleeds, that doesn't seem to count. [P6]	
[My mother] had super heavy periods, which also then kind of led to, not through any fault of her own, but my normalization of my periods, even though I had my diagnosis at that time. [P13]	I was always told that it's mild, and I think that there was a lot of confusion why certain things were happening to my body when there was an injury from sports or reaction to surgeries. People were always explaining to me that it was unusual or they questioned what I was saying, so that was challenging. [P8]	
Women do not talk about [periods]. There's no point during my teenage years or longer did I said to anybody, how many pads do you use in a day? That's not a topic of conversation. So I did not know [if my bleeding was heavy]. [P14]	There's so much in the medical profession that has left to be understood and it's frustrating when people try to force you into a bucket when maybe there's a totally new bucket that hasn't been discovered yet or understood or they don't understand. [P8]	
Especially when it came to menstruation and starting my period, that was something that I really had to navigate on my own [...]it was challenging to sort of use my bleed as a barometer. Talking about blood loss or flow or products or even just handing a product over to another woman is not something that's really done openly. [P15]	No one has ever said to me, "You're a symptomatic carrier," or, "You're a mild hemophiliac," even. They've never said that, ever. [P11]	
	We don't have the science, it's anecdotal, so physicians who work in the science world don't know what to do with carriers like me. You don't fit in the box, you must be nuts. [P11]	
	I felt at the time [of my diagnosis] that I was kind of branded, like I felt that I carried this label around that I was a carrier. I know that, that may sound silly, but, but it was, I'm a carrier, you know, it was almost like a stigma. [P14]	

TABLE 2 Representative quotes from participants illustrating subthemes related to theme 2: Conceptualization of experience through family bleeding

Conceptualization of experience through family bleeding		
The affected male relative as the key	**Symptomatic but undiagnosed female family members**	**Generational bleeding**
I was diagnosed when I was younger, obviously I was an obligate carrier 'cause my father had hemophilia. [P1]	[My undiagnosed mother] hemorrhaged after the birth of my older sister, and she's always had very heavy menstrual bleeding, and, like, her whole life. So, after she had my sister, she hemorrhaged quite badly and was hospitalized for a little bit. [P1]	There was bleeding on both sides of my mom, like, my mother's parents' side. So, my grandmother had an aunt or a great aunt that passed away as a youth because of having just, like, having her period. It was too extreme [...] we've also had, like, experiences with bleeding in both sides of our families, like on my mother's side and my mom's dad's side, so they don't know where it even originated from because my grandmother is not diagnosed. [P3]
My dad, unfortunately, was a tainted blood victim, so he received hepatitis C through blood products and blood transfusions [...] my father passed away when I was 13 turning 14, and I decided then that I was honestly done with hemophilia. I didn't wanna talk about it. [P1]	My mom, she did have a hysterectomy because her periods her whole life were very heavy but she didn't have a diagnosis for a bleeding disorder, and, of course, she was tested for all of them. [P4]	We had no idea that it ran through the family, although when you looked at issues that my [undiagnosed] grandmother in England had had, and issues my own mother had ... they had issues with the bleeding. [P6]
I knew about hemophilia from my father. [P2]	I remember as a child standing in church or in the grocery store with my grandma and she would just start bleeding and it would be on the floor. Her pants would be soaked. Much the same with my mother. [P7]	She is 68, and she's finding out for the first time what the proper bleeding disorder is that she has. [P8]
Our first introduction to hemophilia was when our oldest son was born. [P6]	My mother had a duodenal ulcer, and almost died. She had nine blood transfusions – it wasn't diagnosed, and they called it a silent ulcer, and she almost died. She was in intensive care for a couple of weeks, and she said to the doctor something about her blood pressure, and he said, you don't have one. So she was really sick after that. [P10]	My three daughters all inherited [their bleeding disorder] from me ... [one] had had her period for 120 days. I went in with her, and 22 hours later, they decided they're going to do a D & C [P10].
Our oldest boy was very ill both with AIDS and with hepatitis C-related – the tainted blood. And it was – it was hard to maintain any sort of balance both in our home [...] you know, just trying to stay sane with – was a bit of a challenge at that point. [P6]	You know, my mom has always had very heavy periods. Same with my aunts when I've been asking them about it [...] it's interesting that the pattern is there, although no one has any diagnosis of a bleeding disorder. [P13]	
In the letter that I have from the geneticist it says that my father had a history of increased bleeding when cut and had a lot of nosebleeds as part of his history. [P7]	When my mother found out she was a carrier, it was jaw-dropping. So little was known, and nobody at the time suggested to my mother that maybe she should be tested, as we know that your sister has two hemophiliac sons. [P14]	
I wasn't diagnosed until my son was diagnosed with severe hemophilia. [P9]		
My son, my second born child, I started noticing that he was having some bruises and stuff that was unexplainable [...] so we had gone through some investigation. [P11]		
My father is a hemophiliac. I think he was severe, and they didn't test me when I was born. However, because I didn't stop bleeding, and I almost died from bleeding, [my physician] recognized that it's not normal bleeding. [P12]		

3.2.2 | Symptomatic but undiagnosed female family members

While most participants discussed female family members who were symptomatic, many reflected on how their female family members, unlike their male relatives, remained undiagnosed. This linked back to women's normalization of bleeding symptoms, as many had symptomatic female relatives who never carried a clinical diagnosis irrespective of bleeding severity. Particularly among symptomatic hemophilia carriers, a pattern emerged in which women were often diagnosed with an inherited bleeding disorder after the men in their family were diagnosed, with the diagnosis of other affected female family members following suit. Multiple women interviewed described advocating for their female relatives to seek diagnoses. One woman shared a story in which she encouraged her mother to get diagnostic testing much later in her life, which resulted in her mother's diagnosis.

3.2.3 | Generational bleeding

Participants retrospectively evaluated their family's experiences with bleeding to better understand their own bleeding, or to help them receive context. Often, they examined undiagnosed mothers and grandmothers in their family, reflecting on individuals who may have been affected. Women also described the effect on their daughters.

TABLE 3 Representative quotes from participants illustrating subthemes related to theme 3: Intensity of bleeding symptoms

Intensity of bleeding symptoms		
Heavy menstrual bleeding	**Post-partum hemorrhage**	**Procedural bleeding**
I had an episode in school. I was bleeding for almost 4 months continuous, and I was rushed to the hospital [...] Like, it was hard to be in school. It was hard to concentrate. I used to collapse a lot. I would just be walking down the street, and I would just collapse because I had low iron. [P5]	After giving birth [I bled]. Both times. I remember hearing them say, "Where is all this blood coming from?" And of course, and I really didn't know what was normal and what wasn't. [P6]	I had had bleeding issues as a child. From the time – I had a tonsillectomy at age 5, and that was the main thing. Not a lot of bruising, but more things that were directly related to either a surgical procedure or something, you know, like falling head first off your bike. [P6]
When I'm on my period, I can't go to school. I will wake up with my sheets soaked in blood. I'll be walking down the street, and people would tell me I have blood on my dress. It was coming out, like, you know, when you turn on a tap water, when it's shut off, and you turn it on, and the pressure and the gush, the way it comes, that was how I was bleeding every month. [P5]	I had my daughter and I was bleeding, bleeding, bleeding. ... There was a lot of bleeding. I couldn't see it, but my husband at the time said that they put the big garbage can right under the edge of the bed because it was just flowing into the garbage can like a waterfall. [P7]	I've gone in, and this is when I had the bleed in my face – gone in and – and had to insist on this one to have some DDAVP to get – to get my face sorted out. I could only barely get a teaspoon in my mouth and ate yogurt for 10 weeks when that happened. [P6]
In reality, I had – it was basically like a reverse period. I would bleed for three to four weeks and then I'd stop for one. I did that for the 18 months like a reverse period, so it was very strange. Obviously, that's abnormal, but each time I would try to explain to people they wouldn't be able to understand that what I was experiencing was different. [P8]	It wasn't until after the birth of my daughter that my blood was up for genetic testing, in which case they realized that I have type 2M VWD. [P8]	I had my tonsils and adenoids out and I bled quite a bit during that procedure. I vomited an astronomical amount of blood. [P7]
As a teenager, whenever I had my period, I was in the high school health room every month, and just extensive bleeding, and very heavy, heavy periods right till menopause [...] I had a period of three days that I just had to keep getting in the bathtub, I was hemorrhaging so badly. [P10]	My second child was breech. I hemorrhaged really bad, I was in the hospital for 2 weeks after her birth, and I had a lot of problems at her birth, but it wasn't diagnosed. [P10]	I had a procedure done and actually hemorrhaged from the procedure when you shouldn't bleed at all, so the doctor that I was seeing at that time ordered some blood tests. [P7]
I would have extremely heavy periods that would last for more than seven days when I was nine years old. [P11]	I decided that I didn't want any more kids because I was almost 31 and I'd had some complications after the, during the birth of my third child. [P14]	When I was 17 years old, I had four wisdom teeth out, and I hemorrhaged for a month. I went through a very, very hard time with them, because they wouldn't stop bleeding. [P9]
They used to go for about 8 days, and I think 4 of those, 4 or 5 of those were heavy days, so it was very, very draining. I have very low iron, so I would miss every month, I would miss about a day or two of school because I was so drained. [P12]		I would have long, long nosebleeds when I was a little bit older, and I was having some dental work in preparation for braces, bleeding after dental work. [P11]
My periods were getting to be far too frequent. It started out at 21 days, you know, 21, 22 days, and then it was getting down to every 2 weeks. [P14]		A week after [my tubal ligation], I hemorrhaged and went into our local hospital. They advised me to go back home, keep my feet up and everything. So, I did. I hemorrhaged more, a lot. [P14]
[During my period] my levels were basically in the double digits and in the single digits as far as hemoglobin and ferritin. So, I was very, very low. [P15]		I had a hysterectomy [...] and later on in the evening, I called for the nurse. I said, I'm hemorrhaging. And so they checked and again I was hemorrhaging, so I again had to have blood transfusion. [P14]

All women with family histories of bleeding mentioned their affected family, illustrating that often, bleeding disorders, even if unrecognized initially, are deeply embedded in a family's history, subsequently creating a contextual narrative for the affected woman herself.

3.3 | Theme 3: Intensity of bleeding symptoms

3.3.1 | Heavy menstrual bleeding

Participants universally described HMB, sharing a multitude of experiences related to severe bleeding episodes. The language used to describe the extent of bleeding indicated the severity of bleeds: "soaked sheets," "collapsing," and "hemorrhaging." Women shared very similar complications such as anemia, iron deficiency, embarrassment, missed schooling, and decreased quality of life. These symptoms were not isolated to women with VWD; symptomatic hemophilia carriers and women with platelet function disorders described them as well.

3.3.2 | Post-partum hemorrhage

Irrespective of their underlying diagnoses, several women described experiencing serious issues with childbirth. One participant described not knowing that her extent of post-partum bleeding was abnormal, while another described that her correct diagnosis was only reached after she gave birth and experienced PPH. Yet another participant was not diagnosed despite symptoms retrospectively recognized to be in keeping with PPH. Women frequently described

TABLE 4 Representative quotes from participants illustrating subthemes related to theme 4: Impact on identity and daily life

Impact on identity and daily life		
Sense of stigma	**Impact on education, hobbies, and work**	**Empowerment through community affiliation**
I remember that I had to go to clinic once a year, and none of my other siblings did, which is interesting [....] no kid wants to feel different, especially when it's something as complicated as a bleeding disorder. [P1]	I wanted to try all these sports, and I feel like I don't know if it's from visiting the hospital, but my mom became very, like, apprehensive and, like, worried about, like, me getting hurt, and I just thought it was nonsense [...] I just didn't understand why I had to have all these limitations placed on me. [P1]	I decided to go to camp with my sister and be a counselor, and I was like, oh, there's actually healthy people with bleeding disorders, and there's people who have lost family members to the tainted blood scandal just like we have and understand what that feels like and kind of, you know, provided us some support in that way. [P1]
I remember that, like, I was really confused. I don't know anybody with a bleeding disorder or with any type of disorder that's going to affect them for, like, their whole lives [...] So, for the first year and a half, 2 years, it was just I felt like an outcast. [P3]	It's kind of affected my hobbies in the sense that when I was younger, you know, the doctor said no contact sports, so I only did ballet and swimming until I was, like, 11. [P4]	I had something that my father had, and I could share that with him and my aunt, and it didn't feel like it was a burden. [P2]
Some people wanna put you in a bubble, too, as soon as you tell them [...] They're, like, oh, my gosh. Like, can you do this, and can do you that? [P3]	One semester, I had to defer my exams because I had a sinus infection, and then I got a really bad nosebleed, and I got, several that week, so I had to defer my exams, and then it was just it was a huge mess. It really affected my whole university experience [...] and I wasn't ready for that, and I actually got, like, anxiety and a little bit of depression. [P4]	I went to summer camp, and I learned that there are a lot of other people with the same issues, and, since then, it just kind of empowered me, and it made me more confident in talking about it and not being ashamed about it. [P3]
I'm not a regular person having a nosebleed. [S4]	I never used to go anywhere. I would always stay at home. I stopped schooling. I couldn't play. I couldn't do anything. [P5]	I've been able to travel all over the world. Like, I've been to Scotland this past May for the World Hemophilia Congress. I got to meet people from all over the world and different countries that have minimal care compared to what we have here, and it's amazing. [P3]
People judge you even before they get to know you, even at work, everywhere, you know, where you think people are supposed to understand you [...] my family said I was a witch because of the bleeding, because I would be throwing up blood [...] It was scary. It was hard to look at the future, like, to see even if I had any future. I felt alone and abandoned, and I always questioned myself if I was enough for anything, you know? I used to be scared of the future, and I used to tell them a lot. [P5]	I lost my job, I lost my apartment, I'm still struggling financially, I'm still struggling with depression, so it's not smooth roads [...] I've always lived in a hospital. So, I wanted to give back to the community, and knowing that I wasn't able to do it at certain times made me really depressed. So, I got depression from that. [P5]	I'm like, "But the doctor said that we're not supposed to." They're [the camp mates] are like, "Oh, don't worry about that. You just do it." So, I actually did start playing, volleyball and basketball and doing track and field. [P4]
When I was younger, I actually got bullied a lot because they would say, "Don't touch [her] or she'll bruise" or "We don't want you on our team because you're just going to get injured." [P12]	I didn't feel comfortable doing swimming anymore. I played all of the sports in elementary school that our school offered except for swimming because I was embarrassed about that stuff. [P8]	I've kind of been in the bleeding disorder community for quite a while [...] it was weird until I started going to summer camp, the camp for kids with bleeding disorders. [P4].
	On the first day of my period, I would miss a half day of school or maybe a whole day of school. If I was going to swimming lessons on Saturday morning, there was no way I could do my swimming lessons whatsoever. [P11]	I love it now, and it's one thing that I have in common with my mom, and she's not here with me, but sometimes I feel her around, and knowing that we both share this makes me closer. [P5]
	I wasn't allowed to play sports for it, because my ankles are my site joints. So, I always injured my ankles and I need those to run in most sports, so I wasn't allowed to play most sports. So, I was excluded from a lot. [P12]	[My bleeding disorder] hasn't changed a lot of things that I've done. I still do things like ziplining and diving off of high things. That sort of thing. [P6]
		I think [discussing my experiences with others] most definitely did help in the way that I felt that I could help other people, and I think helping other people helps yourself. [P14]

severe bleeding associated with birth; for some, this had implications for their children, as well as for future family planning.

3.3.3 | Procedural bleeding

Participants noted bleeding after dental procedures, ear-nose-throat procedures, as well as obstetric and gynecologic procedures. Once again, the words that women used to describe their bleeds illustrated their experiences with these severe bleeds: "hemorrhaged," "astronomical amount of blood," or oral bleeding so severe that one woman stated she "could only get a teaspoon in my mouth." Irrespective of whether they were describing menstrual bleeding or procedural bleeding, participants consistently relayed their bleeding experiences to be intense, excessive, and often refractory to regular temporizing measures.

3.4 | Theme 4: Impact on identity and daily life

3.4.1 | Sense of stigma

Women described feeling different from their peers due to their underlying bleeding disorder. One participant described feeling apart from her siblings in context of a desire to fit in, another shared a

sense of alienation secondary to her diagnosis, describing herself as an "outcast," while another described herself as not being a "regular person" experiencing the same symptoms that a peer might encounter. This sense of stigma appeared to be reinforced by the manner in which women were treated, as some described bullying, judgment, or even fear perpetuated by family members. One woman described that there was a taboo around her bleeding disorder, and that she was labelled "a witch." A lack of understanding by both self and others propagated fear and misunderstanding around bleeding disorders for these women, who sought acceptance and peer support.

3.4.2 | Impact on education, hobbies, and work

Given feelings of anxiety around a significant bleeding event, as well as secondary to their degree of bleeding symptoms, women were often unable to participate in school, work, or recreational activities. They specifically commented on missing school or recreational activities secondary to heavy menses. In a circuitous manner, enforced limitations appeared to further amplify women's sense of stigma, with one woman describing people wanting to "put her in a bubble." For some women, living with a bleeding disorder translated into adverse mood symptoms, including anxiety and depression. This was often connected to interference in the achievement of their goals. One participant described anxieties associated with her falling behind in university, while another shared the dismay she felt from not giving back to her community through meaningful work, struggling financially and experiencing depression.

3.4.3 | Empowerment through community affiliation

While participants noted the negative effects that living with a bleeding disorder had on their lives, many also acknowledged positive feelings associated with their bleeding disorder, including a sense of affiliation and community. One participant noted how her diagnosis made her feel closer to her family, while another mentioned how it helped her feel connected to her mother, who had since passed away. Outside of feeling connected with family members, multiple women felt a sense of community through attending camps for patients with bleeding disorders, as well as through advocacy initiatives. Particularly with regard to camp, women described feeling a sense of empowerment, understanding, and acceptance, in stark contrast to the stigma described previously. Advocacy initiatives, group meetings, and conferences were additional avenues through women described being able to feel connected to others like them, subsequently feeling seen, heard, and empowered to better understand themselves.

4 | DISCUSSION

Our study describing the experiences of adult women living with inherited bleeding disorders found that these women experienced multiple uncertainties around their diagnosis, challenges with diagnostic labels, as well as misdiagnoses and diagnostic delay. In the context of these ambiguities, women conceptualized their own bleeding by examining their family histories. They described that they frequently only received their diagnoses after their male relatives were diagnosed, with female relatives often remaining unexamined. By hearing their mothers and grandmothers normalize their bleeding stories, women described difficulties in understanding their own bleeding symptoms, particularly soon after menarche.

Irrespective of whether women recognized their own symptoms, or had these symptoms acknowledged by health-care providers, interviews consistently demonstrated the extent of their symptom severity. Participants discussed the impact of HMB, PPH, and procedural bleeding on their lives, with many characterizing the negative effects that these events could have. For many participants, living with a bleeding disorder contributed significantly to their identity formation, as well as the realities of their daily life. Specifically, women described a sense of stigma and the negative impact that their inherited bleeding disorder had on hobbies, schooling, and work; however, they also described strong ties to the bleeding disorders community, with many finding that allyship empowered them to accept, understand, and even embrace their diagnosis.

While the medical complications of inherited bleeding disorders for women have been well described, the body of literature lending a voice to women's experiences with inherited bleeding disorders has been limited. However, few qualitative and questionnaire-based studies in similar patient populations exist. VanderMeulen et al[16] described the experience of post-partum bleeding in pregnant women with inherited bleeding disorders, and similarly found that these women normalized excessive vaginal bleeding so much as to interfere with the identification of PPH. Khair et al[17] specifically examined the experiences of girls and adolescent women aged 9 to 34 with inherited bleeding disorders, and found that young women often felt isolated, "different," or stigmatized, comparable to our own sample. In concordance with our findings, they also described that a majority of women could not engage in sporting activities, and sought a community of other women with bleeding disorders.[17] Renault et al[18] qualitatively described the experiences of 11 hemophilia A carriers, and found heavy menstrual bleeding to be common and distressing, with hemophilia A carriers often experiencing excessive bleeding. Our work among women with a variety of diagnoses similarly found that symptoms of severe bleeds were not limited to women with VWD, as symptomatic hemophilia carriers and women with rarer bleeding disorders described severe bleeds as well. These findings, coupled with the work of multiple other authors,[1,4,19-22] challenge the notion that hemophilia is a disease entity exclusive to men.

Our study identifies additional phenomena that, to our knowledge, have only been described anecdotally. The first pertains to inherited bleeding disorder labeling. While health-care providers have often acknowledged the term "hemophilia carrier" to be contentious, interviews with women show that they, too, find the diagnostic terminology to be problematic. Symptomatic

carriers expressed a preference be addressed as "symptomatic," as opposed to simply "carriers," relaying that language nuances could lend legitimacy to their experiences. For women with rarer or poorly defined disorders, labeling also made a significant difference; for instance, they felt that, in the absence of a clear label, they were excluded from symptom recognition and clear care plans. While it has been documented that under-recognition of bleeding disorders in women may lead to inadequate treatment,[1] our research specifically demonstrates that women themselves feel uneasy when their diagnoses are ill-established, and are aware of potential gaps in their care. Another uniquely described finding is the manner in which women highlighted the importance of community initiatives that helped them connect with other women with bleeding disorders, whether these be camps, conferences, or research meetings. Despite many women outlining the severity of their symptoms and the negative effects these symptoms could impose on their lives, many also described that a sense of community mitigated feelings of loneliness, shame, and fear. Canada is fortunate to have large patient advocacy groups such as the CHS, and the importance for women to be able to share their lived experiences with one another was underscored. Last, our study illustrates that women with inherited bleeding disorders understand and adapt to their illness by integrating it into their identity, a phenomenon originally conceptualized by Charmaz.[23] While the concept of illness identity has been explored in multiple chronic diseases including cardiac disease, connective tissue disorders, diabetes, and mental illness,[24-27] the ways in which symptoms inform identity have not previously been well explored in the inherited bleeding disorder literature.

In summary, our work aimed at understanding the experiences of women with inherited bleeding disorders suggests that these women experience a diverse range of symptoms, with significant impact on their identity and daily life. Improved tools to differentiate between normal and abnormal bleeding, symptom-focused diagnostic language, and early testing and accurate diagnosis are of utmost importance, especially as women with inherited bleeding disorders may be under-recognized and undertreated. Furthermore, women find benefit in being connected to women with similar lived experiences, particularly if they haven't been provided with the opportunity to talk freely about potentially "taboo" topics. Additional study steps will involve sharing work specifically focused on treatment plans, barriers to care, and factors affecting care access.

4.1 | Strengths and limitations

Strengths of this study include its enrollment of women with inherited bleeding disorders across Canada and our usage of comprehensive one-on-one participant interviews, which facilitated frank and open discussion that may not have been possible through other methods. A limitation of this study is its inclusion of predominantly younger women, perhaps due to participant self-selection; thus, the experience of older women may not be fully captured. Furthermore, this study represents the Canadian point of view, and race and socioeconomic data were not explicitly collected. We aim to better understand how these factors influence patient care through analysis of our group's nation-wide Canadian patient survey, which examines these variables. Heterogeneity and sample size also preclude analysis of the impact of individual conditions on patient experience. Larger cohort data is needed in the future to further investigate what differences in patient experience may exist between bleeding disorders, and how these experiences may differ between women and men. Last, there are language limitations as the interviews were conducted in English; further qualitative research, potentially through the use of interpretation, may capture more diverse experiences.

CONFLICTS OF INTERESTS

The authors have no relevant disclosures.

AUTHOR CONTRIBUTIONS

S. Arya contributed to study design, acquired funding, performed interviews, analyzed data, and drafted the manuscript. P. Wilton and D. Page provided patient-centered expertise, recruited patients, and edited the manuscript. L. Boma-Fischer, G. Floros, and J. Teitel provided health-care provider expertise, recruited patients, and edited the manuscript. R. Winikoff contributed to study design, provided content expertise, and edited the manuscript. K. Dainty contributed to study design, refined the research methodology, and edited the manuscript. M. Sholzberg contributed to study design and data analysis, acquired funding, provided content expertise, and edited the manuscript.

TWITTER

Sumedha Arya @sumedha_arya

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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