



CULTURATI
Research & Consulting, Inc.

REPORT

**US Qualitative
Hemophilia Symposium
Discussion Groups**

Prepared for



April 26, 2019 – June 19 revision

TABLE OF CONTENTS

BACKGROUND	3
OBJECTIVES & SUCCESS CRITERIA	3
DESIGN, SEGMENTATION & METHODOLOGY	3
QUALITATIVE CAVEAT	4
CONCLUSIONS	5
DETAILED FINDINGS	6
FIRST SIGNS & SYMPTOMS EXPERIENCED	6
CHALLENGES & BARRIERS TO BEING DIAGNOSED	7
CHALLENGES & BARRIERS TO ADEQUATE TREATMENT	8
IMPACT ON THEIR PHYSICAL & EMOTIONAL WELLBEING.....	10
IDEAL CARE PLAN & SUPPORT NEEDED	12
IMPLICATIONS	15
APPENDIX	16

BACKGROUND

The Hemophilia Federation of America (HFA), a national non-profit organization that assists, educates and advocates for individuals with bleeding disorders was interested in assembling women from across the country participating in their 2019 Hemophilia Symposium, to share their experiences with their health care in dealing with their bleeding disorder.

OBJECTIVES & SUCCESS CRITERIA

Specifically, HFA was interested in conducting a needs assessment to identify perceived gaps in care for adult women aged 18 and over, with a diagnosed bleeding disorder, who participate in their Blood Sisterhood and/or Mom’s In Action programs through collecting anecdotal data about their experiences with symptoms, diagnosis, treatment and overall care of their bleeding disorders.

Insights gleaned from these groups will help HFA develop plans and programs to address the barriers to diagnosis and care that women with bleeding disorders experience.

DESIGN, SEGMENTATION & METHODOLOGY

A total of three (3) 90-minute discussion groups were conducted in San Diego, CA during the HFA’s 2019 Hemophilia Symposium among adult females aged 18+ with a diagnosed bleeding disorder.

- 10 – 12 respondents were recruited per group
- Respondents were recruited from HFA’s Blood Sisterhood and/or Mom’s In Action programs.

All groups were conducted by the same tenured female Culturati Moderator. Additionally, one female Culturati note-taker and one female HFA staff member participated in all three sessions.

Groups were conducted in the course of three days according to the following schedule:

	Thursday, April 4 3:00 pm – 5:00 pm	Friday, April 5 9:00 am – 10:30 am	Saturday, April 6 12:00 pm – 1:30 pm
Discussion Group 1	7 respondents	---	---
Discussion Group 2	---	7 respondents	---
Discussion Group 3	---	---	9 respondents
Total: 23 respondents			

The sessions were audio-taped by HFA and transcripts were generated from the audio recordings.

The Moderator was responsible for the analyses and reporting of findings using notes and transcripts. Transcripts were uploaded to NVivo for analysis. Data was coded and analyzed using a deductive approach* per the following list of pre-determined topics (a more detailed list is included in the Appendix):

- Barriers and Challenges to Adequate Treatment

- Barriers and Challenges to Being Diagnosed
- Condition and Age at which Diagnosed
- Desire to Make a Difference or Have their Voices Heard
- First Signs and Symptoms
- Impact of the Diagnosis
- Negative Experiences – Treatment
- Positive Experiences – Treatment
- Treatment and Medications

(*) The deductive approach to qualitative data analysis involves analyzing data based on a predetermined structure. In this case, the questions and topics outlined in the Discussion Guide were used to group and analyze the data. The analysis took into account the number of mentions per question/topic and the nature of the actual comment regardless of where in discussion the comment was made (i.e., the analysis was not limited to the comments made in the section of the Discussion Guide where the question/topic was explored.)

QUALITATIVE CAVEAT

As with all qualitative data collection, the findings described in this summary are intended solely as diagnostic insights for planning purposes. The small sample and non-scientific manner of information collection limits the degree to which it can be presumed this information is necessarily representative of or projectable to the larger universe of system and disposable users.

CONCLUSIONS

Based on the anecdotal information shared by discussion group participants, the most significant barrier to identifying, diagnosing and treating their bleeding disorders is a generalized lack of awareness and information regarding these types of conditions in females, among both health care providers and the general public. In addition, the absence of established guidelines for diagnosis and treatment based on female data, along with health care providers' lack of empathy or interest in listening to the concerns of their female patients make obtaining a diagnosis and receiving adequate treatment particularly challenging. More specifically:

Women are being treated with protocols designed based on male data and specialists are following different approaches to treatment.

- According to these discussion group respondents, the greatest challenge to obtaining a diagnosis is the lack of awareness and information among the general public, regarding bleeding conditions and the corresponding signs and symptoms. This lack of awareness and information prevented them from seeking medical attention and/or sharing their concerns with the right specialists thinking that what they were experiencing was normal or not serious enough for a medical consultation.
- Furthermore, in these discussion group respondents' opinions, there is a persistent and generalized disbelief within the medical community of women suffering from bleeding disorders, and doctors not having enough information or showing interest in listening to their female patients. This lack of diagnosis and acceptance by the general provider community seems to be a direct result of the following:
 - An absence of adequate testing criteria for diagnosing women (or criteria developed based on tests conducted among females).
 - The absence of a standardized protocol that is sensitive and inclusive of women's needs
 - The lack of communication between the different specialties.

Once obtained, a diagnosis seems to have a positive impact on the quality of life of female patients.

- From a physical standpoint, the diagnosis and corresponding treatment help women control or better manage their pain and bleeding episodes. From an emotional standpoint, it provides them with validation and empowers them to take control over their treatment.

Yet, living with a bleeding disorder takes a significant emotional toll on female patients.

- Most continue to deal with anxiety of treating and knowing what to do if they experience an episode. Additionally, they feel they continue to live with the stigma of bleeding disorders that limits their ability to perform every-day activities and responsibilities (participants reported missing school or work due to their heavy periods, not being able to take care of their children due to pain and weakness), as well as interfering with their social interactions (e.g., missing on social events when on their periods, staying home to avoid having people question them on their bruises, limiting their participation in physical activities/playing with their children due to fear of getting injured.)

DETAILED FINDINGS

FIRST SIGNS & SYMPTOMS EXPERIENCED

While discussion group participants experienced signs and symptoms of a bleeding disorder at an early age, in almost every case, these were not immediately recognized as indicative of a bleeding disorder by the patients, their families or their health care providers, which caused a significant delay in the diagnosis.

Lack of Ability to Identify the Problems Experienced Know

- Respondents reported having experienced the most common signs and symptoms of a bleeding disorder at an early age. More specifically:
 - Frequent nosebleeds that were heavy and/or hard-to-stop;
 - Easy and frequent bruising (mostly in arms and legs);
 - Joint pain and/or swelling;
 - Heavy bleeding from small cuts; and
 - Unusually long and heavy menstrual periods (most starting at around the age of ten).
- Yet, even among those with a history of hemophilia or a bleeding disorder in the family, the signs and symptoms were not automatically recognized or linked to a bleeding disorder due to the following:
 - A generalized lack of awareness regarding bleeding disorders: In most cases, respondents and their families were not as familiar with bleeding disorders and/or what to look for as a sign or symptom. Furthermore, some reported not being offered information by their health care providers in the instances in which they were consulted.
 - *“(Nothing really happened) after my diagnosis. I just went on with life... I didn't have (much) support... When you have parents that are not informed, you're not going to be informed. If you have parents who are not connected, you're not (going to be) connected. If you have parents that are ignorant to what's going on, you grow up in ignorance.”*
 - *“They told me I was a symptomatic carrier because of my bleeding. But that was it: You're just a symptomatic carrier.”*
 - *“(My mom's) doctors never said anything back then. And then, they never said anything when she had a surgery that didn't heal, and she ended up having to have multiple transfusions. They never said anything. So, by the time I was born, and I had problems... it was really dismissed.”*
 - The generalized belief that women can be carriers of the hemophilia gene but not affected: In the few instances in which a bleeding disorder was suspected, the idea was dismissed thinking that women cannot be affected or could only be symptomatic carriers. Furthermore, being a symptomatic carrier was often considered a “not-so-serious” condition and as such, not often treated.
 - *“This is a deep-seated cultural issue. And it's not just hemophilia. It's worse for us (women) because of all of the doctors being taught in medical school that only men get hemophilia.”*
 - *“They discovered it when I had a surgery, because I am a carrier. But every (doctor) in Puerto Rico said that hemophilia is for men, not for women.”*
 - *“It's still believed to be X-linked recessive. So, it's a problem.”*

Tendency to Normalize the Problems Experienced

- A prevalent theme among participants was the signs and symptoms of their bleeding disorders systematically dismissed or minimized by both family and health care providers.
 - The bruises, joint pain, nosebleeds and even the prolonged and heavy menstrual periods were consistently considered to be “normal,” “not serious enough to require a doctor’s visit” or, in the case of joint pain, attributed to “growing pains.” This, once again, due to a lack of awareness and/or information regarding bleeding disorders.
 - *“My mom would normalize my symptoms, she would say ‘everybody bruises... (just) some more than others...”*
 - *“I’d be up all night in excruciating pain and all my mom would say was ‘it’s just growing pains, it’s normal...’ but I wouldn’t see any of my siblings going through that... it was just me.”*
 - *“My mom would tell me that her periods were the same; that it was normal, and I’d believe her even though it didn’t feel normal to me.”*
- The constant dismissal or “normalization” of their symptoms made participants feel mistrusted, belittled, and disrespected which was (and continues to be), particularly discouraging for them. For most, the persistent dismissing of their symptoms made them question their own judgment and believe that what they were experiencing was in fact normal. Having to consistently fight and advocate for an answer or diagnosis was particularly draining.
 - *“It’s that culture of, oh you’re just a bleeder... your periods can’t be that bad... all women bleed anyway.”*
 - *“When you have women who get their diagnosis in their 30’s, 40’s, 50’s, we have been taught to learn how to ignore all that pain for so long... That is our normal, so we don’t think to treat. And I think we’ve all been told that we’re wasting expensive medication. The men are told, and we’re told with (our) kids, ‘when in doubt, treat.’ But for women, we need that same message. We’re not getting the ‘when in doubt treat’ message.”*

CHALLENGES & BARRIERS TO BEING DIAGNOSED

Diagnosis Incidental to other Medical Procedures or Life Events

- Although respondents experienced signs and symptoms at an early age, most were not actually diagnosed until they were teenagers (once they started to get their menstrual periods), or as adults, after experiencing heavy bleeding after surgery or childbirth (several mentions), or a dental procedure (mentioned by five respondents). In most cases, a traumatic experience was the only way they were able to get their health care providers to pay attention and eventually make a diagnosis.
 - *“I was diagnosed as a carrier but it was not until I had my first baby that I got diagnosed with the condition because I bled too much and for too long.”*
- While in some cases the diagnosis happened sequentially, for most participants, it had required active and persistent advocating.
 - *“My brother had hemophilia, and it was his doctor who noticed the bruises and had me tested... had he not done this, I think it would had taken me long to get a diagnosis because no one believed me or even suspected I could have a bleeding disorder.”*

Lack of Diagnostic Criteria Based on Symptoms Experienced by Women

Similarly as with identifying the signs and symptoms, for the discussion group participants, the main challenge to obtaining a diagnosis was a lack of awareness and information regarding bleeding disorders in women, as well as the perceived notion of hemophilia only affecting men.

Main Barriers

- The following were identified by participants as additional key challenges or barriers to obtaining a diagnosis:
 - Health care providers still believing only men are affected by hemophilia and/or bleeding disorders;
 - Doctors focusing more on tests and “numbers” vs. symptoms;
 - Testing and classification still based on male parameters and/or a lack of clinical knowledge based on research among females; and
 - No adequate clinical knowledge across different medical specialties.

Additional Cultural Barriers

- In addition to the above, there were cultural barriers that prevented participants of Hispanic, Asian and Middle Eastern descent from seeking help and obtaining a diagnosis. Because their cultures considered the condition or the symptoms taboo or something shameful, it took them longer to communicate the situation to family members. In addition to minimizing the symptoms, family members encouraged respondents to hide or not discuss the condition outside the immediate family.
 - *“As Hispanic women in particular, we just don’t talk about this.”*
 - *“My mom would tell me not to mention (my symptoms), or discuss them with anyone outside the family.”*
 - *“Growing up in Mexico, I was taught to be quiet about this, to not say anything, there was shame around it...”*

Conditions Respondents Were Diagnosed With (in descending order and as identified by respondents)
<ul style="list-style-type: none"> ▪ Symptomatic Carrier ▪ Von Willebrands Disease ▪ Mild/Moderate Hemophilia A ▪ Hemophilia B ▪ Factor VIII Deficient ▪ Platelet Storage Pool Disorder

CHALLENGES & BARRIERS TO ADEQUATE TREATMENT

The general consensus among discussion group participants with regards to adequate treatment included health care providers not having enough or the right information or basing their treatment on male protocols, but more significantly, not being open-minded or willing to listen to their female patients.

No Standardized Treatment and Women Being Treated Based on a “Male Mold”

- The following challenges/barriers to adequate treatment were shared by participants across the three sessions:

- Extremely low awareness and/or a lack of knowledge within the medical community regarding bleeding disorders in women.
 - *“During my pregnancy, I was my doctor’s first patient with hemophilia – he had no idea on how to proceed or treat my pregnancy.”*
- No standards based on studies conducted among women. Generally speaking, the overall perception seemed to be that they are being treated using male as opposed to female standards and protocols.
 - *“It’s like they are trying to fit us into a male mold... a mold created for men.”*
- The lack of a standardized approach to treatment across specialties.
 - *“One doctor says one thing and another doctor says a different thing; no one knows what to do or how to treat women with bleeding disorders... there is no consensus, no communication across the different specialties.”*

Not Being Believed or Listened To

- Most participants had at some point or another, lived through a negative experience with health care providers not believing them, not demonstrating interest or being open to listen to them, questioning their diagnosis, or dismissing the condition as not serious enough. As such, participants felt they had not benefited from more adequate care and had instead been forced to “learn to live with the problem or the symptoms.”
 - *“When I was finally referred to a hematologist, he would not even see me. I was in the waiting area and he came out to tell me (that) he would not see me; he was actually screaming at me, saying that I was lying and would only be wasting his time because women do not get hemophilia.”*
- What had made the difference for some, was having a doctor who had been either better informed, more open to or willing to listen to them and for some, being treated by a female doctor (who was able to understand what was “normal vs. not normal,” specifically when discussing the menstrual periods).
 - *“It was finally my gynecologist, a female gynecologist, the one that suspected the condition after I told her how long my menstrual periods were; she said ‘that is not normal’... I think because she was able to compare it to her own menstrual periods.”*
- A common theme among these women was their doctors not showing interest in listening to them, not being interested in giving them an opportunity to explain themselves and their symptoms, telling them they were exaggerating and saying or making them believe it was all a part of their imagination or a fabrication.
 - *“They (would) pretty much look at me like I (was) crazy, I almost started to feel crazy; like ‘am I making this up in my head?’ But no, like, my ankle is bleeding, and I didn’t do anything to it.”*
 - *“After hearing this so many times I started to question myself, started to believe that in fact, it was all part of my imagination... that perhaps somehow, I was doing this to myself.”*

Obtaining a Diagnosis Is Half the Battle

- Furthermore, the general experience among respondents was that a diagnosis had not guaranteed being believed or receiving proper treatment; that doctors would question the diagnosis or would not know how to treat them.
 - *“We’re all taught to respect doctors, but when you go to them, they look at us like we’re idiots. We know there’s something wrong with us and (all they do) is disregard us.”*

Moms Prioritize the Treatment of Their Affected Children over Their Own

- In addition, some women who had children diagnosed with a bleeding disorder, talked about prioritizing the treatment and care of their children over their own.
 - *“When women find out their kids have hemophilia, they don’t worry about themselves they only worry about their kids.”*
 - *“I didn’t really start paying attention to my symptoms, focusing on me, until my kid was an adult and I did not have to care for him.”*

IMPACT ON THEIR PHYSICAL & EMOTIONAL WELLBEING

While most discussion group participants believed that obtaining a diagnosis had positively impacted their physical as well as their emotional wellbeing, they also felt living with a bleeding disorder has taken a significant emotional toll on them.

A Diagnosis Represents Vindication and Peace of Mind

- From an emotional standpoint, they reported feeling validated and/or vindicated. Being able to prove that in fact, there was something wrong with them, something worth looking into and treating accordingly was particularly powerful for these women because being believed or taken serious had been their most significant challenges.
 - It should be noted that most respondents consistently talked about the positive impact on their emotional wellbeing before mentioning the impact on their physical wellbeing which indicates the emotional aspect being a more top-of-mind concern for them.
 - *“You know what it gave me? Vindication!”*
 - *“Validation, for me.”*
 - *“Now I know that I’m not lying. And that makes a difference just by itself.”*
 - *“After a lifetime of ‘oh, that’s normal, ten-day long, 12-ounce a day periods – that’s normal,’ after waking up in pain every day... Having someone say ‘no, that’s a thing. Like yeah, you got a thing. You got a disease.’ (It was really powerful).”*



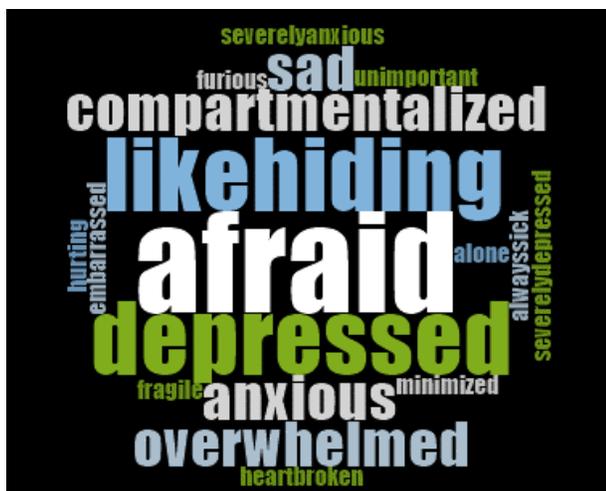
Word cloud summarizing feelings experienced by discussion group participants after being diagnosed.
 (Created based on 12 comments – although more than 12 reported having experienced the same feelings and emotions)

- From a physical standpoint, the diagnosis allowed them access to treatment and/or medication which helped eliminate or alleviate their pain and/or allowed them to minimize or better control their bleeding episodes. They also felt less weak and more energized, which greatly improved their quality of life. For instance, they were able to better take care of their families and lead a relatively more active social life.
- Treatment and medications being used by respondents included:

Treatment & Medications (in descending order)	
Birth control	<ul style="list-style-type: none"> ▪ Most were or had been on the pill ▪ Some were using an IUD ▪ A few had undergone a hysterectomy
Factor replacement therapy	<ul style="list-style-type: none"> ▪ Clotting factor VIII, IX and von Willebrand
Clotting promoters	<ul style="list-style-type: none"> ▪ Lysteda/tranexamic acid, Stimate
Other medications mentioned	<ul style="list-style-type: none"> ▪ Advate, Novel, Proflex

A Diagnosis Does Not Guarantee Emotional Wellbeing

- Living with a bleeding disorder meant experiencing constant anxiety (about treating oneself and about never knowing when they will have a bleeding episode, among other scenarios.)
 - *“I’m great in everything else in my life, but I know that my bleeding disorder causes me pain and limits my options, and... it’s exhausting. And it’s very frustrating.”*
- Some also talked about experiencing shame or “living in shame” of feeling stigmatized because people “do not understand the condition.” They often felt judged based on the physical signs and symptoms of the condition.
 - *“Once a group of moms (at my son’s school noticed the bruises on my arms as I was volunteering in the classroom) and reported me to the office; they said they were not comfortable with me being around their children because I was using drugs... all these things bring you down. (Or they say things like) ‘Oh, you’re fragile,’ or ‘you’re always sick – doesn’t your husband get tired of that?’ That kind of stuff.”*
 - *“I just feel like avoiding people altogether because I don’t want to have to explain myself or have to let people know what is wrong with me...”*
- Additional emotions reported by these women included feeling depressed, withdrawn, alone, and like “they do not matter” or like their lives are “not important.”
 - *“(I experienced) severe depression... people would come to the house (to visit) and I’d hide under the bed. I ended up seeing a psychologist (and) a psychiatrist.”*
 - *“For me... my feeling alone is because I’m (typically) the only (factor) seven (deficient) there.”*
 - *“My depression is huge. Like, I fight with it every day. I just don’t feel that I’m important.”*
- One of the biggest issues for these women was feeling like they are a burden for their families and/or not being able to meet their responsibilities as parents.
 - *“My saddest moment now (is that) my son is a really good caregiver... it breaks my heart because he knows (that) when mom is down, there’s food in the freezer that he could microwave. He’s learned to when mom is down to go ahead and self-care... he knows (that) when mom wakes up and she’s hurting, he doesn’t even bother me... he lets me sleep in... I have trained my son (on) how to be a caregiver. He’s only nine and he’s been doing that for I would say at least three years now...”*



Word cloud summarizing feelings currently experienced by discussion group participants.

(Created based on comments from 15 respondents – although more than 15 reported experiencing the same feelings and emotions)

- As such, they considered mental health an important part of the treatment yet something they do not necessarily have access to.
 - *“There is no help out there for mental health...and there needs to be.”*
 - *“Never once did someone say ‘you’re grieving for what you have lost that you thought you were’. I thought I was normal. Never once did someone say ‘let’s talk about this. How has your life changed? How can we move on?’ You know? That’s what I realize now, that’s what I needed. And it probably took me a year, to no longer hide.”*

IDEAL CARE PLAN & SUPPORT NEEDED

Based on both their positive and negative experiences identifying, diagnosing and treating their bleeding disorders, the general consensus among discussion group participants was that they could have benefited from being better educated, having their health care providers be more empathetic, compassionate and open to the idea of women being affected by hemophilia, as well as having access to support groups or other affected women. This could have resulted in an earlier diagnosis, earlier treatment and, more importantly, prevented them from experiencing a traumatic experience.

- *“I wish (the disorder) had been recognized sooner, that doctors (had been) more willing to speak about it... I just thought bleeding was normal, having grown up in a household with it. But you know, quicker recognition, more conversation with the providers, and with other women, groups like this (discussion group) ... we learn more from each other than we do from providers.”*

The following summarizes themes associated with more adequate treatment:

- **Information is empowering:** Participants felt that, had they and their parents/family been better informed about the possibility of women in the family being affected they would have been better prepared to recognize the symptoms and advocate for a diagnosis or treatment.
 - *“For me, it would be to educate (my) family. My brother, who was the reason we were diagnosed, he (didn’t) infuse, he (didn’t) talk about his hemophilia a lot. So, for me, there was always a*

struggle through high school (making them believe I also had an issue). It was ‘are you just trying to stay home or are you really having trouble?’...”

- *“My mother took me to see her OBGYN. I'm really grateful that this woman was familiar with bleeding disorders because she only talked (to me) and my mother for a little while and said, ‘have you ever heard of something called von Willebrand disease?’ And my mom said, ‘oh yes, my mother has that.’ My mom didn't make the connection between her own mother's diagnosis and (the) symptoms I was having... it (wasn't) really her fault, she (just) didn't realize it.”*
 - *“Common knowledge, really. Have information available. Really. (Because growing up), I didn't know that as a carrier there were a lot more risks in having surgery so, had I known ahead of time... then I would (have) probably changed the care I had.”*
 - *“It was a nurse (the one who suggested) a test. The doctor didn't. It was her. She said, ‘you have a history of hemophilia in your family – have you been tested?’ I (knew) I (was) a carrier. I didn't even know that we need to be tested.”*
- Health care providers acknowledging that women are also affected: The general consensus was that the medical community still operates under the assumption that only men are affected by hemophilia and other bleeding disorders.
 - *“(My mom) went to the HTC to take my brother when he was born (to be tested) ... and yes, he had hemophilia. The doctor at that time felt that every girl that was born in a family of hemophiliacs should be tested... That is what needs to be done, today.”*
 - *“I was fortunate to have a provider that understood and... didn't have the mentality that women aren't affected.”*
 - Health care providers truly listening to them: What made the difference for these women in getting diagnosed or adequate treatment was their doctors paying attention to their symptoms vs. simply basing their decision on the standardized criteria and basing their diagnosis on numbers.
 - *“The doctor came into the room and said, ‘I've read your chart’ (and) I was like, wow! Didn't expect that. And she said ‘I don't believe in treating by the numbers; I believe in treating by the chart. If I have clinical background on you, I would rather work with that.’ So, to me, I don't want them to standardize. I want them to do what (my doctor) does. I want them to look at each of us. I'm tired of them saying ‘we don't want to work on women because they're difficult’.”*
 - *“That might be the standard of care. The standardized care may be for them to understand that they have to look at us individually.”*
 - Raising awareness of both the emotional and physical impact of the disease among patients: The experience of these women has been with doctors that are dismissive of their symptoms and that are not open to being “educated” by the patients.
 - *“He wasn't certain what it was, but he felt like historically, that he knew. I had an educated provider. An open-minded and educated provider.”*
 - Education and comfort of self-treat at home: While they value the information and services available to them at HTCs, being able to treat at home provides with more freedom and flexibility, although they recognize it is not easy to self-treat.

- *“Here’s the thing... there are doctors who will say ‘I’ll prescribe you an emergency dose to have at home; and if you have any other issues, you need to come in; you need to come in and show me your owie, prove you have one... then, I will give you more factor; but I’ll dose you here, I’m not sending it home with you’.”*
- *“I was afraid to infuse myself. Is that not the craziest thing? I was scared... I was crying, and I said, ‘what is the matter with me?’ Like, I got my diagnosis, I have my factor, and now I’m afraid to do it.”*
- **Support from a community:** Because of the lack of information and their tendency to feel isolated and like they are fighting this battle alone, discussion group respondents find the support and information provided through support groups extremely helpful.
 - *“15 years (after my diagnosis), we have these meetings, and for the first time in my life, I’m in a group of women that are also in the same boat as me... and we’re not talking about our kids, we’re talking about our symptoms!”*

IMPLICATIONS

Based on these findings, consideration should be given to the following:

- Developing a “Women & Bleeding Disorders” awareness program directed to key specialties and providers (i.e., Pediatricians, Family Doctors, Gynecologists/OBGYNs, ER Doctors, Hematologists, HTC staff, even school nurses). Beyond simply educating, the program should promote openness and showing empathy for female patients’ concerns.
- Focusing efforts in advocating for the development of a standardized protocol that takes into account female data and better coordination and communication between key specialties.
- Making mental health an integral part of the treatment plan to help women better cope with the condition.
- Developing and implementing a plan that takes into account the following:
 - An education program that demystifies the idea of bleeding disorders mainly affecting men and that focuses on educating women on the signs and symptoms of bleeding disorders and helps them understand what is normal and not normal. Education efforts should be directed towards women in general but should include a component directed to families of Hemophilia patients so they are aware of the potential risk for female family members (i.e., mom and sisters). This program should be deployed through medical offices and school nurses as well as mass media campaigns. These are the most effective ways to reach them and make information available to them. Components of the Patient program should include:
 - In-person or over-the-phone support to help patients feel more comfortable self-treating/infusing and ensure they are treating/infusing on a regular basis.
 - Support to help ensure emotional wellbeing by allowing access to mental health professionals (not just social workers).
 - Access to mental health services with providers who specialize in treating women with bleeding disorders.
 - Access to organizations and support groups to help educate themselves (and other women) but more importantly, feel supported.
 - Health Care Provider program should be developed to promote early detection, diagnosis and referral to the appropriate specialties.

APPENDIX

Topics in which the data was organized for analysis. Includes number of groups in which the topic was mentioned and number of mentions (total) analyzed.

	# of groups in which mentioned	# of Mentions
Barriers and Challenges to Adequate Treatment		
▪ Based on Male Mold (Lack of Research among Women)	3	7
▪ Generational & Gender Related	3	6
▪ Insurance Related	1	3
▪ Lack of Information – Health Care Providers	1	3
▪ Lack of Standardized Protocol or Communication between Specialties	2	3
▪ Moms of Affected Children Delay Own Treatment	3	3
▪ Symptoms not Considered Serious Enough	2	3
Barriers and Challenges to Being Diagnosed		
▪ Believed to Be a Male-Only Condition	2	4
▪ Classification Based on Male Numbers	1	2
▪ Cultural Barriers	2	6
▪ Female Patients Not Being Heard or Believed	1	5
▪ Geographic Barriers & Limited Access to Specialists	2	4
▪ Health Care Providers Focusing on Numbers vs. on Symptoms	3	8
▪ Health Care Providers Not Interested in Listening or Learning	2	4
▪ Lack of Awareness – Family	2	6
▪ Lack of Awareness – Health Care Providers	3	5
▪ Signs & Symptoms Considered Normal or Not Serious Enough	2	10
Condition and Age at which Diagnosed		
▪ Diagnosed as a Kid or Teen	3	9
▪ Diagnosed as an Adult	3	15
Desire to Make a Difference or Have their Voices Heard	3	13
First Signs & Symptoms – Multiple	3	16
Impact of the Diagnosis		
▪ Emotional – Negative	2	15
▪ Emotional – Positive	2	12
▪ Functional – Negative	2	7
▪ Functional – Positive	2	5
Negative Experiences		
▪ Diagnosing – Negative	3	4
▪ Treating – Negative	3	17
Positive Experiences		
▪ Diagnosing – Positive	3	7
▪ Treating – Positive	3	14
Treatment & Medications	3	26