



# Uniting Voices for Change

## Listening to the healthcare challenges women with bleeding disorders face

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**H**emophilia Federation of America (HFA) has been working to better understand barriers and potential gaps in care for women with diagnosed bleeding disorders. As part of this effort HFA invited women, aged 18 and older, with a diagnosed bleeding disorder, who are members of its Blood Sisterhood and/or Moms in Action programs, to participate in discussion sessions. These discussion sessions occurred at HFA's 2019 Symposium in San Diego, California. The purpose of these discussion sessions was to better understand participants' experiences with their symptoms, diagnosis, treatment and overall care for their bleeding disorder.

Twenty-three women attended one of three discussion sessions. In the discussion sessions the women were asked a series of prepared questions designed to engage participants in sharing their experiences. The questions and conversation were guided by a trained facilitator. Each session lasted 90 minutes and was recorded with permission from each attendee. There was also a professional notetaker in the room, taking notes of the discussion, and an HFA staff person providing oversight of the group discussion and available to provide support to the women. All persons in the room were female. From the compilation of these discussions, we identified a number of themes that were shared among participants' experiences.

### Identifying their symptoms, obtaining a diagnosis, and receiving adequate care remains a challenge.

Overall, participants believed the most significant barrier to identifying, diagnosing, and treating women's 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. Participants talked about their challenges in obtaining a diagnosis and receiving adequate treatment, related to providers. Many participants felt this was due to the absence of established guidelines for diagnosis and treatment for women, along with healthcare providers' lack of empathy or interest



Word cloud summarizing feelings currently experienced by discussion group participants.

in listening to their concerns. Participants specifically mentioned that they felt women are being treated with protocols developed based on data collected from men and the male experience, which may not be applicable to women. During the discussion, participants identified a persistent and generalized belief within the medical community that women are not affected by bleeding disorders and that doctors do not have enough information or show an interest in listening to their female patients. Participants believe this lack of diagnosis and acceptance by the general provider community is a direct result of:

-  an absence of adequate testing criteria for diagnosing women (or lack of criteria developed based on data collected from females)
-  the absence of a standardized protocol that is sensitive and inclusive of women's needs



 the lack of communication between different medical specialty providers

Participants also discussed the lack of knowledge and awareness among the general public about bleeding disorders in women and the corresponding signs and symptoms among women, that contributes to a strong challenge in obtaining a diagnosis. Participants felt this lack of awareness and information delays or prevents women from seeking medical attention and/or sharing their concerns with the right specialists, thinking what they were experiencing was normal or not serious enough for a medical consultation.

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

From a physical standpoint, a diagnosis and corresponding treatment help women control or better manage their pain and bleeding episodes. From an emotional standpoint, a diagnosis provides women with validation and empowers them to take control over their treatment. We created a word cloud that summarized the feelings experienced by the participants of these discussion sessions about the impact of receiving a diagnosis. Twelve unique responses were provided by the participants. The larger, bolder words are those that were shared by multiple participants. In other words, those feelings were more common among the participants.

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

Most participants indicated they continue to deal with anxiety about knowing what to do if they experience a bleeding episode and what steps to take to deal with the symptoms and stop the bleed. Additionally, participants felt they live with the stigma of having a bleeding disorder, which limits their ability to perform daily activities and responsibilities. Some of the challenges included missing school or work because of heavy periods and not being able to take care of their children because of pain and weakness. Other challenges were related to their social interactions, such as missing out on social events when on their periods, staying home to avoid having people question them about their bruises, and limiting their participation in physical activities and/or playing with their children because of fear of having a bleeding episode and getting injured. Another word cloud was created that summarizes the emotions that women with a bleeding disorder experience in relationship to their diagnosis. Fifteen unique responses were provided by the participants. The larger, bolder words are those that

knowledgable  
that i'm not crazy  
connected  
alleviated informed  
empowered  
validated  
believed confident  
empowered to make a difference for self  
vindicated  
that i'm not exaggerating

*Word cloud summarizing feelings experienced by discussion group participants after being diagnosed.*

were shared by multiple participants. In other words, those feelings were more common among the participants.

**Support provides benefits for women**

Based on both their positive and negative experiences in the identification, diagnosis and treatment of their bleeding disorders, the general consensus among women who participated in the discussion groups was that they could have benefited from a variety of things: being better educated themselves; having their health care providers be more empathetic, compassionate, and open to the idea of women being affected by hemophilia and other bleeding disorders; having access to support groups or connecting with other affected women. These things could have helped the participants receive earlier diagnoses, 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 what participants believed could be done to improve the experiences of undiagnosed and diagnosed women:

 **Information is empowering.** Participants felt that had they and their parents/families been better informed about the possibility of women in the family being affected by a bleeding disorder, they would have been better prepared to recognize the symptoms and advocate for diagnosis or treatment. More education and awareness among the general public about bleeding disorders, the signs and symptoms of abnormal bleeding, and incidence rates could help identify women and girls affected sooner and at a younger age prior to issues related to uncontrolled bleeding.

**“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 consensus among discussion group participants was that the medical community still operates under the assumption that only men are affected by hemophilia and other bleeding disorders.

**“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 accessing adequate treatment was that their doctors paid attention to their symptoms, instead of simply basing their decision on current diagnostic criteria.

**“That might be the standard of care. The standardized care may be for them to understand that they have to look at us individually.”**

**“He (the provider) 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.”**

 **Raising awareness among providers that women are not just carriers but can have a bleeding disorder themselves.** While all of the women found doctors who listened to them and received a diagnosis, many of these women had past experiences with doctors who were dismissive of their symptoms and not open to being “educated” by the patients.

 **Education and comfort of self-treating at home.** The discussion group participants valued the information and services available to them at hemophilia treatment centers (HTCs) and being able to treat at home which provides more freedom and flexibility, although they recognize it is not always easy to self-treat. However, more education and guidance on treating at home, how to do it, and when to do it would help self-treatment at home become a more comfortable practice and reduce women’s stress.

**“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.** The support and information provided through support groups has been extremely helpful for discussion group respondents and helps prevent them from feeling isolated and alone.

**“Fifteen 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!”**

The information collected in these discussion groups provides HFA with a better understanding of the experiences of the women who participated in them. The experiences shared in our discussion groups are not meant to be reflective of the experiences of all women with bleeding disorders, or even the diagnosed adult women participating in HFA’s Blood Sisterhood and Moms in Action programs. However, the themes identified provide HFA with a better understanding about barriers and potential gaps in care for women with diagnosed bleeding disorders. HFA plans to continue these conversations with women, so that it can develop programs and activities to better address the needs of women with bleeding disorders more directly and ultimately improve their quality of life. 🩸

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