

Carrier Perceptions Regarding Care and Resources Elicited from Carriers: Assessment of REsources (CARE) Focus Group

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Introduction and Objectives:

The implications of hemophilia carrier status are increasingly being recognized. Previous studies have found that hemophilia carriers report negative medical care experiences and are unsatisfied with resources available to meet their needs.^{1,2} We conducted a Carriers: Assessment of Resources (CARE) focus group among this patient population at our Hemophilia Treatment Center (HTC). The objectives were to assess care perceptions and experiences, determine availability and perceived effectiveness of existing resources, and understand additional supports desired. We describe the information gathered and outcomes from the CARE focus group.

Methods and Materials:

Following Western Institutional Review Board (WIRB) exempt determination, recruitment flyers were mailed to carriers and potential carriers over age 18 known to our HTC. Participants completed de-identified demographic forms. Two HTC staff members facilitated a 90-minute focus group using 11 pre-determined questions and methods for ensuring confidentiality. Each participant received a meal and \$30 gift card as compensation. Facilitator notes and the session's audio recording were reviewed to compile a summary analysis of the data.

Demographics		Participants (n=8)
Age	18-24	1
	25-34	2
	35-44	3
	45-54	1
	55+	1
Ethnicity/race	White	7
	Hispanic/Latino	1
Education	High school diploma	1
	Bachelor's degree	3
	Master's degree	3
	Doctorate degree	1
Familial diagnosis	Hemophilia A	5
	Hemophilia B	3
Biological children	Yes	7
	Currently Pregnant	1
Carrier status known prior to conception	Yes	3
	No	5

Table 1. Self-reported demographic and personal history information of CARE focus group participants

THEME	EXAMPLE QUOTES
Isolation	<p>"I wanted to speak with other people in my situation to see... if they found out if they were a carrier before they got pregnant and how they made the decision to either move forward with trying to get pregnant or if they decided not to have children..."</p> <p>"The opportunity to get together and hear other stories and experiences is reassuring and validating that you're not... on this island wishing that all these things existed."</p>
Provider interactions	<p>"My OB/GYN was relying on me to tell him information... I was the one who told him... when I found out I was having a boy... we need to get him tested. But I didn't really know anything about carrier status so I wasn't concerned about myself...and he wasn't concerned about it. And I told him I'm a carrier for hemophilia, so the OBGYNs don't know."</p> <p>"My experience at the first [HTC] was when my son was first born... that HTC provided absolutely no education, nothing... At that point [my daughter] had been born. There was no talk about her potentially being a carrier or being tested or anything... It was when I got a second opinion about [my son]'s treatment that [my daughter] was tested... even the support from HTC to HTC varies. It really does."</p>
Impact of family history	<p>"... growing up with a father with hemophilia is so different, the medicine and treatment is so different. So it would have been... nice to have counseling during pregnancy just to know that, because it was very scary after... I had watched what my father went through and how treatments were so different than they are now."</p> <p>"The hemophilia center was familiar to me because my brother grew up coming here, so I knew to come to you..."</p>
Variability of needs	<p>"...as an adult once I turned 18 even if someone could have mailed something to me because then I would have been aware but I was never told and my father was being seen at a hemophilia treatment center very regularly."</p> <p>"I didn't have that luxury... I didn't know I was a carrier and got blindsided."</p>
Implications of diagnosis	<p>"I didn't know there was anything to ask."</p> <p>"I just found out that I was a carrier 3 years ago...even now I hear you guys talk and it's like, 'Oh, I didn't know I was supposed to watch out for this.' So I think what to expect... being a carrier would be helpful."</p> <p>"...Is this an issue that I should be bringing to the HTC's attention or is this something that I should just suck it up and deal with it."</p>
Secondary focus of care	<p>"...I was tested by [a hematologist] that wasn't even in the current HTC that I was at, but [my daughter] was getting her tonsils taken out and so I had no idea that she could have lower levels of factor... then it was presented to me that I could potentially have lower levels of factor... so even after having kids and going through genetic counseling at the time at the treatment center that we were in, that never came up."</p> <p>"There's that disconnect around... how it impacts people outside of my son."</p> <p>"I think we are really proactive with our kids and not with ourselves."</p>
Familial relationships	<p>"My father had hemophilia so I'm relying on him to tell me information... And.... there was definitely a disconnect. Nothing was told to me. I knew I was a carrier, but never, 'Ok, you need to go get tested'. So...did he just ignore things that were being told to him... or was he just never told, I don't know."</p> <p>"There might be some type of disconnect for men... when men are being treated who have daughters, those conversations... pamphlets... the education needs to be occurring with them so that they can pass it on to their daughters, as well."</p>

Table 2. Identified themes and corresponding quotes regarding carrier perceptions and experiences from the CARE focus group.

Results:

Eight individuals participated, all of whom were known to be carriers at the time of the focus group. Table 1 summarizes demographic information and personal history of participants. Seven themes regarding care perceptions and experiences among carriers were identified and are outlined in Table 2. All participants agreed that there is a paucity of resources available specifically for carriers. HTC-based resources reported to be helpful included peer connections, educational programming, and genetic counselor access. Only one participant reported awareness of two non-HTC-based resources. Participants expressed need for validation and requested specific resources for various topics, target audiences, and modes of access, as reflected in Table 3.

Topics	Target Audiences	Modes of Access
1) Implications for carriers	1) OB/GYNs	1) In-person provider
2) Shared experiences	2) PCPs	2) In-person peer
3) Testing options	3) Pediatricians	3) Written
4) Family communication	4) At-risk females	4) Internet/multimedia
5) Implications for relatives/offspring	5) Unaffected relatives	5) Group
6) Psychosocial	6) Affected individuals	
7) Current hematology management		

Table 3. Summary of resources desired by participants from the CARE focus group.

Conclusions:

Hemophilia carriers may experience sub-optimal identification and recognition, negative care interactions, and insufficient availability of resources and support, both within and outside of HTCs. Carrier desires elicited through this focus group will be utilized by our HTC to initiate new local programming/support for carriers and potential carriers. Additionally, this information may be considered by the broader hemophilia community to direct efforts aiming to better meet the specific needs of this patient population.

Bibliography:

1. Khair, K., Holland, M., & Pollard, D. (2013). The experience of girls and young Women with inherited bleeding disorders. *Haemophilia*, 19(5).
2. Renault, N. K., Howell, R. E., Robinson, K. S., & Greer, W. L. (2010). Qualitative assessment of the emotional and behavioural responses of haemophilia A carriers to negative experiences in their medical care. *Haemophilia*, 17(2), 237-245.

