

Balance, falls, and exercise: Beliefs and experiences in people with hemophilia: A qualitative study

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Abstract

Background: Prior research has established that falls are commonplace in adults with hemophilia, and advises that physical therapy and exercise are successful in fall prevention. Recognizing obstacles and catalysts to physical therapy and exercise in people with hemophilia may augment the efficacy of efforts to prevent falls in this population.

Objectives: To learn about the experiences and ideas of patients with hemophilia, especially associated with balance, falls, and exercise.

Methods: Semi-structured interviews with 14 adult patients with hemophilia were performed. The interviews were coded for themes founded on the study aims.

Results: Most subjects described difficulty with balance, often ascribed to joint problems. They believed that staying strong and fit could positively influence balance, but expressed concerns and fear related to falling. Those who exercised regularly did not view exercise as hazardous, while those who did not dependably exercise articulated worry that dangers of exercise may offset the benefits. The most common obstacle to exercise was pain and having someone to exercise with was often described as an enabler. Barriers to partaking in physical therapy included weak proof of its success and distrust in the therapist. Positive physical therapy experiences in the past and the connection with the therapist were reported as facilitators.

Conclusions: People with hemophilia describe some attitudes and experiences that are unique to hemophilia while others are found in the general population. Attending to fear, pain, and support for interventions, while encouraging a robust therapeutic alliance and a plan for routine exercise may aid fall prevention behaviors.

KEYWORDS

balance, exercise, falls, hemophilia, physical therapy

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Essentials

- Exploring exercise beliefs in people with hemophilia may improve efforts at fall prevention.
- Semi-structured interviews of adults with hemophilia.
- Subjects expressed concerns regarding balance, falling, pain, and risks and benefits of exercise.
- Individualized treatment based on patient beliefs may facilitate exercise and fall prevention.

1 | INTRODUCTION

Prior research has established that falls are commonplace in adults with hemophilia,^{1,2} and advises that physical therapy and exercise are successful in fall prevention.^{3,4} Limited exercise and physical activity leads to a decline in balance, increasing fall risk.⁵ Research in geriatric populations has consistently demonstrated that exercise can maintain or improve and decrease fall risk by facilitating independence in mobility and function,^{5,6} and data show that regular exercise is the best single method of fall prevention.⁷ Exercise must be continued over time to maintain these benefits.^{7,8}

Historically, people with hemophilia were encouraged to avoid exercise due to risk of bleeding, but it is currently recommended as a safe and important aspect of health maintenance.^{9,10} There are conflicting data in the literature about the amount of exercise regularly performed by people with hemophilia,^{9,11,12} and boys and teens with hemophilia report barriers to exercise and are unsure of options.¹²

Most existing research regarding exercise beliefs in people with joint disease has been conducted in those with arthritis. Multiple barriers to exercise have been isolated including: pain,^{13–15} concerns about joint damage,^{8,13,16,17} limited time and self-motivation,^{8,18} and lack of knowledge among health-care providers.^{16,17} Commonly identified facilitators to activity in these populations include: relief of pain,⁸ maintaining independence,^{8,13} a trusting relationship with health-care providers,^{8,9} and social and emotional benefits.^{8,13,18–22} To our knowledge, previous research regarding exercise beliefs in people with hemophilia has all been qualitative in nature,^{10,12,23} suggested that people with hemophilia report barriers that are similar to those found in arthritis^{10,12,24} and that men with severe hemophilia want to exercise despite any limitations due to their disease.¹⁰ There has been limited examination of beliefs about fall prevention in this population. Recognizing obstacles and catalysts to physical therapy and exercise in people with hemophilia may augment the efficacy of efforts in fall prevention for this population.

2 | OBJECTIVES

Our objective was to understand more about the views and experiences of people with hemophilia, especially involving exercise, falls, and balance, including why they are driven or dissuaded to exercise consistently or to participate in physical therapy.

3 | METHODS

The Washington Center for Bleeding Disorders (WCBD) at Bloodworks Northwest in Seattle, Washington, teamed with Kaiser Permanente Washington Health Research Institute. An interview guide designed to use open ended questions regarding beliefs about exercise, physical therapy, and balance was created and piloted by the lead author. The first and second authors then collaborated on the final version of a semi-structured interview to address study questions. Qualitative methods were chosen to allow for a deeper understanding of the range of individual experiences, perceptions, expectations, beliefs, and fears around the area of interest.^{8,25,26} Adults with hemophilia who were patients at Bloodworks both with and without a positive fall history were identified by chart review and invited in person and by telephone to participate. The semi-structured nature of the interviews allowed flexibility as new questions were brought up during the interview as a result of participant responses.²⁷ This project was sanctioned by the University of Washington Institutional Review Board. Funding was provided by the WBCD 340B Research Program (approved by the US Health Resources and Services Administration's Maternal and Child Health Bureau).

Interviews took place either at Kaiser Permanente Washington Health Research Institute or at Bloodworks. The interviews were conducted by the second author, who was not previously known to participants. Interviews ranged from 20 to 53 minutes in length, with an average length of 36 minutes. Interviews were recorded and transcribed by a third-party transcriptionist. Qualitative data from key informant interviews were analyzed using a template approach.²⁸ Atlas.ti, a qualitative analysis software package, was used to help code and manage the data (Atlas.ti Scientific Software version 7.1.8, Berlin, Germany).

The first two authors developed a code list for qualitative analysis of the interviews, which included both a-priori codes and emergent codes, created after joint review of three interview transcripts.²⁹ Three interviews were then coded independently by both the first and second author and reviewed together to check for interrater reliability. The codebook was discussed between them until agreement was reached.³⁰ The a-priori codebook was revised to add other themes that emerged in the first three interviews. The second author coded the remainder of interviews using Atlas.ti. Recruitment of subjects, followed by interviews, transcription and analysis, continued until saturation was noted by the second author.

4 | PARTICIPANTS

4.1 | Demographics and hemophilia type/severity

Fourteen subjects participated between January and July 2016. Thirteen identified as cisgender males, while one participant identified as a transgender woman. The average age of subjects was 48 years old (median = 47.5), with age range of 24-77. All reported they had Type A hemophilia; eight had severe disease, three had moderate, and three had mild. Seventy-one percent of the participants reported having at least a Bachelor's degree level education, and 28% had a Master's degree. Less than 20% of participants reported having only a high school or equivalent degree (14%), or some college education (14%). Seventy-nine percent of the participants were employed at the time of the interviews. Of the 21% (three subjects) not employed, two stated that this was due to disability and one reported being "laid off." Five participants reported having physically active jobs, while the other seven had more sedentary positions that generally required a higher level of education.

4.2 | Other medical and surgical history

Forty-three percent of the participants reported a history of Hepatitis B, C, or both. Four participants reported being HIV positive (29%). Forty-three percent reported ankle joint fusions, one reporting bilateral ankle fusions. Twenty-nine percent of participants reported having a total knee replacement (one patient had bilateral replacements). Other medical and surgical history reported included total replacements of hips or ankles ($n = 3$); herniated spinal discs ($n = 2$); abdominal hernias ($n = 2$); and knee joint fusions, rotator cuff tears, knee ligament tears, and mental health conditions (depression, gender dysphoria), all reported by one participant each.

5 | RESULTS

Several recurring themes were noted on analysis; these were grouped into topics and 13 of those are discussed further below. Themes mentioned are representative and were described by the number of participants noted in each section.

5.1 | Topic: Level of daily physical activity, range of types of activity

The majority of participants (11) reported being physically active on a daily basis. Only two participants reported being mostly sedentary. Two participants mentioned that their current level of physical activity was greatly reduced from their normal or desired routine because of current or recurrent injuries. Walking was the most common type of physical activity reported, with seven participants reporting walking as a part of their daily routine. Five participants described physical demanding jobs.

5.2 | Topic: Level of regular physical exercise, frequency of exercise, type of exercise

Six of the interview participants reported a regular exercise routine, while eight reported exercising infrequently or not at all. Those reporting regular exercise exercised an average of 5 days per week, with four reporting daily physical exercise. Types of exercise reported were mostly aerobic and were varied including walking, running, fitness classes, cycling, hiking, kayaking, and martial arts. Three participants reported doing some kind of strength training or lifting weights. Another participant reported practicing yoga and Pilates. In the group of regular exercisers, most participants (5 of 6, or 83%), reported a history of musculoskeletal surgery, while among the infrequent exercisers, a smaller majority (5 of 8, or 63%) reported a history of such surgery.

My family is 'Fit Bit' freaks, so the goal is to hit somewhere between 10 000 and 15 000 steps a day... I can't run at this point, I try to do just do a ton of walking.

5.3 | Topic: Balance issues and beliefs about balance

Ten of the 14 participants described having issues with their balance, with joint problems reported as the primary reason. Participants described difficulty maintaining balance while shifting or getting pushed laterally by an external force. Joint pain, joints "locking up," fused joints, and decreased range of motion, also were reported as a source of balance problems. Five participants mentioned that they are over-protective or hyper aware, or that they make certain modifications to their activities due to concern about potential injury. Three participants specifically expressed the belief that hemophilia puts them at increased risk for balance problems and falling. Two participants mentioned that there is a "cost/benefit" analysis they do to determine whether certain activities are worth the potential risks. Three participants mentioned that for them, mental inattention plays a large role in their balance issues. Interestingly, two of the participants who initially answered "no" to the question "Do you have issues with your balance?" later acknowledged a fall or near fall, demonstrating that for some, the perception of balance "issues" may not align with the reality of their experience or how we define balance "issues."

Well, they're absolutely—if we're talking strictly balance and falling and hemophilia, they're linked inexplicably because if I'm bleeding I have more of a chance of falling. If I fall I will bleed when I land. You know, it's a circle. So the best thing to do is not to bleed.

But it's the cost/benefit kind of thing that you always weigh being a hemophiliac. Sure, you can make muscles work harder but then that almost always increases the possibility of bleeds.

5.4 | Topic: Falls history, frequency of falls

Half the participants (seven) acknowledged a history of falls. Three of these reporting falling in the last year, two recalled falls, but stated they were anywhere from 7 to 9 years prior to the interview and one subject was unsure of the timeframe. The other seven said they had either never fallen (five) or it had been many years since they fallen (two). Of the group that reported regular exercise, a third (2 of 6, or 33%) reported falls, while in the group of participants who exercise infrequently or not at all, almost two-thirds reported falls (5 of 8, or 62.5%). The most common reason given for falling was tripping on curbs, stairs, or other uneven surfaces. Four of those reporting falls described injuries related to falls that ranged from light skin abrasions to joint bleeds, to a head injury that required treatment in the emergency department.

I'll tell you what it was; catching that fused leg. So when my shoe bit, then I went forward. And I was lucky.

5.5 | Topic: Fall prevention and impacts on balance

Strength was the most common response from participants when asked what positively impacts balance, for people with or without hemophilia.

If you don't exercise your muscles are going to atrophy and then you're not going to be able to use them.

Six participants cited joint issues like decreased range of motion, joint injury, or arthritis as having a negative impact on their own balance. Pain was mentioned by three participants as impacting their balance. Three participants also mentioned inattentiveness as impacting them negatively. When asked specifically about what things impact other peoples' (people who don't have hemophilia) balance negatively, the most common responses were aging and weakness.

And so when there's damage in all of the joints... then you have to adjust... so those are all factors in your balance.

5.6 | Topic: Perceptions about what can be done to improve balance

Common themes when participants were asked about ways to improve their balance were building strength and fitness, and staying active. Three participants reported using canes or walkers (as needed) and one anticipated needing to use an assistive device in the future. Three participants said they didn't know how to improve their balance. One mentioned they had been prescribed specific balance-related exercises in the past but was unsure whether they worked.

... I think just repetition and use. I think that's probably the big thing... the more immobile you become, then it mushrooms.

5.7 | Topic: Feelings about falling, how those feelings might impact behavior

The majority of participants (eight) reported worry, anxiety, or fear about future falls when asked "How do you feel about falling?" Participants expressed concern about injury such as causing damage to joints. Five of those who shared this concern reported not exercising regularly. Four participants in the exercisers group said they didn't have any negative feelings about falling or felt fairly confident, while only two non-exercisers reported this confidence, and one of them reported he was confident of not falling because he is so "sedentary," suggesting he didn't allow for as many chances to fall.

The most common adaptations participants reported making as a result of their worry about falling, or in response to their hemophilia-related limitations, were increased attentiveness/mindfulness, for example using caution and listening to their bodies; modifying their physical activities or switching activities, for example, changing types of exercises used depending on current joint pain or injuries; and body compensations, such as using a handrail on stairs, favoring a joint while standing or doing an activity.

Falling is really the only thing I'm afraid of, just because I don't want my knees to give out. So, I'm always paying attention to that.

I get very angry at the fact that I can't control my body, and that, both times [I fell] I'm literally in my mind I'm screaming at my body to respond... and it's like I can't do it.

I'm constantly thinking about the possibility of falling, so I'm often cautious, much more cautious... I'm not in a hurry. I'd much rather take the time, be late, whatever it is, than to fall...

5.8 | Topic: Perceived Relationship between hemophilia and other chronic conditions and balance

When participants were asked to describe the relationship between hemophilia and balance or falling, most described an indirect relationship, ie, they reported that hemophilia is linked to increased risk of falling *only if* there is decreased joint range of motion or joint damage. Nine participants expressed this belief that joint issues lead to a great risk of falling (six in the non-exercising group and three in the exercising group). Three participants mentioned that bleeding leads to falling. Two participants were unsure of a relationship. Two participants reported they don't think people with hemophilia are at any higher risk for falls than those in the general population.

It's one to one—I mean, the hemophilia sort of caused my joints and stuff to be in the situation they're in, which then makes me more cautious about falling.

I think hemophilia has a tendency to coddle the mindset. And that creates you not being physically active, which creates falling.

5.9 | Topic: Perceived risks of exercise and physical activity

Among exercisers there was no feedback about the risks of exercise. Among those who exercise only infrequently or not at all, half of them suggested that the risks associated with exercise or activity may outweigh the benefits. Perceived risks reported by three participants were: causing joint damage, inflicting pain, or causing an injury and/or a bleed. Two participants talked about the negative impact exercise has had on their mental health or body image, because it highlights the limitations that have due to their hemophilia.

In the long run, I think, for me it might do more damage than good.

It can make me feel good, but it can also make me feel bad about how limited I am.

5.10 | Topic: Perceived advantages of exercise and physical activity

The most frequent perceived advantage of exercise, which was reported by half of all participants, was a general sense that exercise “feels good,” and is “enjoyable.” Four of those in the exercise group (four of six) also reported positive benefits to mental health, for example they mentioned stress relief, increased confidence, and improved mood.

It definitely gives you some boost of self-esteem. If you go and exercise, you feel good, you feel like you've done something, accomplished it...

When I don't do it I feel like I really let myself down... it's enjoyable. I enjoy seeing my body get stronger.

Well, it does impact mood. You start kicking the endorphins in.

5.11 | Topic: “Good” and “bad” exercise for people with hemophilia

Generally speaking, participants reported that low-impact exercise (walking, swimming, and cycling) is best for people with hemophilia, while high impact and contact exercise or sports (football, running) are not good.

Among those who exercise regularly, there was less definitive distinction between “good” and “bad” exercise however, with a few participants expressing the idea that it depends on one's age and disease severity. The concept of being mindful of one's body and aware of

symptoms of injury was also brought up. One participant suggested that if you are paying attention to bodily symptoms you can then modify activities to prevent injury. Another participant said that simply accepting that you might experience a bit more pain after a certain activity, allows one to participate in a wider range of activities than patients with hemophilia may have traditionally been limited to.

5.12 | Topic: Perceived barriers to exercise and/or physical therapy participation

5.12.1 | Barriers to exercise

Barriers most commonly cited by participants were illness and pain, cited by half the participants. Three participants also cited fear of pain or injury as a factor. Both regular exercisers and those who did not regularly exercise were equally likely to cite pain as a reason for not exercising. Two non-regular exercisers also cited “other priorities” as a reason for not exercising.

Yeah, after work I'm really sore and I don't really want to do anything.

I mean, it's just finding time... it's just hard to fit it in.

I worry about bleeding. I don't want to bleed. It's like an instinct to avoid bleeding. And so I don't like to overdo it...

...when it comes to exercising, formal exercising...I feel the tensions in my joints as I do these exercises, and I worry that I'm going to cause bleeds as opposed to getting exercise.

5.12.2 | Barriers to physical therapy

The most common barriers to participating in physical therapy (PT) related to the nature of therapy and the physical therapist him/herself. For example, many of those interviewed expressed a need to understand the evidence behind PT (whether it will work and how), and have a clear sense of the purpose/objective of the prescribed exercise program and/or recommendations. Credibility of the physical therapist and the information he/she shares with the patient was seen as important. Another barrier, though less commonly reported, included time management and competing priorities, one that was also cited as a barrier to exercise in general.

I believe I'm a better judge of what my abilities are than someone else.

If there was evidence that showed it,... but I know there's things that you can do and I know PT helps a lot and so, yeah, I would try.

I think if the objective is too vague it's going to drop in my priority queue.

Yeah, their knowledge and their flexibility, because of course most people don't know about hemophilia patients and don't work with them a lot... the people I've worked with have been open to learning, and they've had a very solid foundation in their domain, so that they have other knowledge they could bring to it.

5.13 | Topic: Perceived facilitators to exercise and/or physical therapy participation

5.13.1 | Facilitators to exercise

The most common motivator for exercise, among those who regularly exercise, was having someone to exercise with. Among all participants, the most commonly cited motivator was keeping physically or mentally fit. As mentioned above in barriers to PT, some participants (non-regular exercisers) reported that they are motivated by a clear goal or purpose for exercise.

... My wife and I do this together... and we have a number of friends that we all go to classes together.

I try not to lose too much ground [physical condition]... Try to keep my reflexes working. It's the best thing you can do for yourself as you age, to get some kind of movement in your life.

5.13.2 | Facilitators to physical therapy

The primary motivating factor for PT that was reported was a past or current positive experience with PT. Participants mentioned learning useful exercises to help with range of motion, experiencing a benefit in pain relief, and that PT was helpful in improving function and pain after a surgery. Two participants also mentioned the importance of a clear concrete goal as something necessary for them to be motivated to participate PT.

Long story short: she taught me all these cool exercises!

6 | DISCUSSION

Most subjects described difficulty with balance, often ascribed to joint problems. They believed that staying active and strong could positively influence balance, but many did not exercise regularly. This concurs with previous research showing that beliefs do not necessarily lead to changes in exercise behavior,¹² and that both exercisers and non-exercisers with arthritis are aware of the benefits of exercise.¹³

Many expressed fear and worry related to falling, which has been noted as both a barrier²¹ and a facilitator³¹ of exercise in other

populations. Those who exercised regularly did not view exercise as hazardous, while those who did not dependably exercise articulated worry that dangers of exercise may offset the benefits. Differences between exercisers and non-exercisers have also been noted in people with arthritis, with both groups noting similar barriers and benefits to exercise, but regular exercisers more likely to modify exercise and feel that benefits outweighed risks.^{13,32,33}

The most common obstacle to exercise was pain and enablers included having someone to exercise with and maintaining mobility. Barriers to partaking in physical therapy included weak proof of its success and distrust in the therapist. Positive experiences in physical therapy in the past and the connection with the therapist were facilitators. These findings are consistent with previous research demonstrating interactions between expectations, previous experiences and adherence.³⁴

Many of our findings parallel those reported in people with arthritis,^{13,17} where symptoms of joint disease were barriers to exercise, yet improvements in symptoms were also seen as possible benefits of and motivators for exercise.^{13,33} Our subjects were less consistently positive about exercise than has previously been found in qualitative research in people with hemophilia,¹⁰ which may be partially due to differences in sample size, hemophilia severity and questioning regarding falls. Although qualitative research cannot be used to draw conclusions at the population level, it is interesting to note that pain, falls, and concerns about both falling and exercise were noted across subjects interviewed of all ages and severities.

Strengths of this study include the use of double coding,³⁵ and the range of age, exercise behavior, fall history, and severity of hemophilia across subjects.²⁵ Although qualitative research allows for a flexible examination of individual experiences,^{16,36} results cannot be generalized.²⁵ Participants were volunteers and the interview guide was designed by the researchers, which could both influence findings.³⁷ Fall recall may have been improved with use of a standardized fall history questionnaire. Subjects were not asked to describe their factor treatment schedule, which may have provided additional information when considering barriers and facilitators to exercise. Subjects who reported a history of joint replacements and/or fusions had severe or moderate disease, which may skew the data related to joint health in this study.

7 | CONCLUSION

While these results cannot be generalized, this study suggests that views and past incidents in people with hemophilia impact exercise behavior. A more individualized approach that considers patient beliefs may enhance long-term exercise in these patients.^{17,22} Attending to pain, fear, and support for interventions, while encouraging a robust therapeutic alliance and a plan for routine exercise may aid fall prevention behaviors. Similar recommendations for improving adherence to exercise have been made in other populations.^{16,17,25} Directions for future research include development of quantitative survey instruments to assess exercise beliefs in people with hemophilia, and designing interventions informed by patient beliefs in an effort to make exercise more meaningful and enhance adherence.

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RELATIONSHIP DISCLOSURE

None of the authors have any disclosures relevant to this paper.

AUTHOR CONTRIBUTION

L.M. Flaherty and J. Schoeppe designed the research study, conducted the research, analyzed the data, and wrote the paper. R. Kruse Jarres and B. A. Konkle aided in designing the study and writing the paper.

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