


## ORIGINAL ARTICLE

## Musculoskeletal

# Barriers and facilitators of physical activity in adults with severe haemophilia: A qualitative study

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**Abstract**

**Background:** People with haemophilia (PWH) tend to be less physically active than the general population, but there is a lack of research on the specific barriers and facilitators affecting their participation in physical activities.

**Objectives:** This study aims to explore perceived barriers and facilitators to physical activity in severe PWH.

**Design:** An explorative qualitative study based on focus groups.

**Methods:** Four focus groups including 16 participants (severe haemophilia A patients) were conducted to examine the factors perceived as facilitators or barriers to haemophiliacs engaging in physical activity. One researcher conducted a thematic analysis of all data.

**Results:** Three themes were identified: body function, personal factors, and environmental factors. Key facilitators identified were access to prophylaxis treatment to reduce the risk of bleeding(s), the enjoyability of physical activity, fitness and health motives, social interaction, support, and low cost. PWH faced additional barriers to being physically active including hurtful joints, mobility issues, haemophilic arthropathy, dislike or disinterest, lack of motivation, fear of injury, tiredness, lack of time, lack of guidance, negative social influence, restriction, and lack of coordination of prophylaxis treatment.

**Conclusion:** This exploratory study demonstrated that participation in physical activity in PWH is influenced not only by their own abilities and attitudes, but also by external variables, including family, friends, healthcare professionals, structures, and communities. The results of this study may be used to assist caregivers and health professionals, inform programs, interventions, and policies to promote physical activity and health in severe PWH.

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**KEYWORDS**

body function, environmental factors, exercise, haemophilic arthropathy, motivation, personal factors

## 1 | INTRODUCTION

Worldwide, an estimated 1,125,000 people have the bleeding disorder haemophilia.<sup>1</sup> Haemophilia is a hereditary X-linked recessive bleeding disorder, which is characterized by a clotting factor VIII (haemophilia A) or factor IX (haemophilia B) deficiency due to clotting factor gene mutations. Haemophilia patients can be divided into three categories: severe, moderate, and mild. People suffering from severe haemophilia often bleed into their muscles or joints, and usually, this bleeding is spontaneous. People with moderate haemophilia bleed less often. However, after surgery, a major accident, or dental procedure, they may bleed for a long period. People with moderate haemophilia will seldom experience spontaneous bleeding. A person with mild haemophilia generally only bleeds as a result of surgery or major injury.<sup>2,3</sup> One of the most serious complications of haemophilia is haemophilic arthropathy, characterized by frequent intra-articular bleeding, accounting for 65% to 80% of all bleeding episodes, 80% of which occur in the elbow, ankles, and knees.<sup>4</sup> Haemophilic arthropathy often leads to chronic pain and disability prompting orthopaedic surgery and joint replacement.<sup>5</sup>

To minimize joint damage due to bleeding, patients receive regular prophylactic treatment with concentrates of factor (VIII or IX) via intravenous injection.<sup>6,7</sup> Prophylaxis is advised for people with haemophilia (PWH) before engaging in activities with a higher risk of injury. Accordingly, prophylaxis or preparatory on-demand replacement therapy is required before engaging in physical exercise or physical activity practice, depending on coagulation factor activity levels in a haemophilia treatment center.<sup>8</sup> Based on the risk of bleeding, preliminary replacement therapy and prophylaxis are occasionally administered simultaneously.

According to a systematic review, PWH had lower levels of exercise capacity than healthy individuals.<sup>9</sup> However, a more recent study done in the Netherlands showed that haemophilia patients have comparable levels of participation in sports as the general population.<sup>10</sup> Moreover, lower levels of physical activity due to a sedentary lifestyle may negatively influence exercise capacity of PWH.<sup>9</sup> These decreased levels of physical exercise may lead to physical dysfunction and obesity.<sup>11,12</sup> More recently, the World Federation of Haemophilia (WFH) has considered physical activity as a necessary component of good health.<sup>2</sup> Kahan et al.<sup>13</sup> revealed that PWH have a higher prevalence of obesity, which has significant consequences for joint function, physical impairment, and venous access to factor replacement product administration. By contrast, physical activity improves treatment efficacy and prevent bleeding in several studies.<sup>12,14,15</sup> Physical activity, physiotherapy, and sports can help improve health and quality of life. Increased strength and resistance can help avoid haemophilic atrophy and minimize the

incidence of musculoskeletal lesions.<sup>14,16</sup> The causes of lower levels of physical activity in PWH are complex and multifaceted.<sup>17-19</sup> The conceptual model of Physical Activity for People with a Disability<sup>20</sup> describes the link between physical activity behaviour, its determinants, and health, as well as the importance of contextual (personal and environmental) elements for people with disabilities. By recognizing that there are various drivers of physical activity, the model integrates barriers and facilitators of physical activity for persons with disabilities.

Researchers have mapped several barriers to physical activity, which includes fear of bleeding induced by trauma and lack of correct information available from physicians.<sup>21</sup> The complexity of haemophilia care has risen due to the rapid development of therapy possibilities.<sup>22</sup>

Despite the fact that PWH tend to be less physically active than the general population, there is a lack of research on barriers and facilitators affecting their participation in physical activity. To address this knowledge gap, a qualitative approach may help to better understand the perceived barriers and facilitators to physical activity among PWH. This information could then be used to develop preventive and interventional strategies to reduce sedentary lifestyles and promote physical activity among PWH. Therefore, the aim of this study is to explore the perceived barriers and facilitators to physical activity in adult PWH with severe haemophilia.

## 2 | METHODS

### 2.1 | Research design

This was an explorative qualitative study based on focus groups. The experience of physical activity in PWH was explored through four focus groups with patients who have severe haemophilia A. The objective was to elicit the specific experiences of what facilitated or hindered engaging in physical activity to inform practice and future research rather than to develop a new theory. Focus groups were chosen for data collection to generate a discussion around shared and unshared attitudes and experiences toward physical activity.

The study received approval from the Ethics Committee of Research in Humans of the University of Valencia (register code 2002705) and complied with the requirements in the 1975 Declaration of Helsinki and its amendment in 2008. Prior to participation, all participants gave written informed consent and were assured of their anonymity and confidentiality. The study is reported in accordance with Standards for Reporting Qualitative Research (SRQR) standards.<sup>23</sup>

**TABLE 1** Focus group topic list.

Theme	Topic
Introduction to the study of physical activity	<ul style="list-style-type: none"> <li>• Describing the view on what is physical activity and general perception on it</li> </ul>
Attitudes and perceptions on physical activity	<ul style="list-style-type: none"> <li>• Aspects of physical activity</li> <li>• Reason for physical activity</li> </ul>
Experience with physical activity	<ul style="list-style-type: none"> <li>• Recommendations in younger years for physical activity</li> <li>• The change in recommendation in physical activity now</li> <li>• Treatment and physical activity</li> <li>• Complaints during physical activity</li> </ul>
Relation with physical activity	<ul style="list-style-type: none"> <li>• Motivational factors</li> <li>• Social influences</li> <li>• Personal influences</li> <li>• Access to exercise</li> </ul>
Strategies to improve physical activity	<ul style="list-style-type: none"> <li>• Describing strategies to encourage haemophilia patients to exercise</li> </ul>
Review and wrap up	<ul style="list-style-type: none"> <li>• Any missed topics</li> <li>• Summary of focus group</li> </ul>

## 2.2 | Participants

A purposive sampling technique was used for this study, and participants were recruited through the “Asociación de Hemofilia de la Comunidad Valenciana” (ASHECOVA) and the network of the research group of the Physiotherapy Department of the University of Valencia. The investigator forwarded information about the study to potential participants who had previously participated in other studies and had shown an interest in participating in future research. Key inclusion criteria were: (1) diagnosis of severe haemophilia between 18 and 70 years old; and (2) informed consent signed. Key exclusion criteria were: (1) the patient did not understand the questionnaires, (2) withdrawal of informed consent, or (3) having an additional bleeding disorder.

## 2.3 | Focus groups

Four focus groups were held in the period of March through May 2022 in a suitable university room with the haemophilia patients at a time and date convenient for the participants and researchers. Before each focus group, the participants were asked to complete a questionnaire with basic demographics and clinical data regarding haemophilia. In addition, participants reported their perceived health status from excellent to poor with a 5-point Likert scale to give the researchers a subjective measure of their perceived health. This method demonstrated good validity and reliability for measuring general health.<sup>24</sup> A moderator (researcher JC) and an assistant moderator (observer) (researcher CC) conducted the focus group with the use of a topic list (see Table 1). The assistant moderator took notes during the discussions. Each focus group consisted of four participants and started with the introduction of the participants and the explanation of the purpose of the study by the researchers. The session lasted approximately 60 min. All focus groups were audio-recorded with the permission of the participants.

## 2.4 | Data analysis

The data were transcribed verbatim and content and thematic analysis was performed (by researcher CC). Inductive content and deductive content analysis were performed on the transcripts. The transcripts were read multiple times and coded line by line to identify emerging concepts by one researcher. The concepts were recognized as they arose, and there was no limit on the number of concepts.<sup>25</sup> The concepts were then matched with the themes present in the Physical Activity for People with a Disability model.<sup>20</sup> ATLAS.ti (ATLAS.ti scientific software version 22..2, Berlin, Germany) software was used to code the data. Each focus group was analyzed independently to ensure that all particular viewpoints from each focus group were taken into consideration. During analysis, the researcher considered whether a theme represented the views of all participants and rich descriptions were used to exemplify sources.

## 3 | RESULTS

In this study, 16 participants took part in four focus groups (see Table 2). All the participants were male and lived in the Community of Valencia (Spain). The age of the participants ranged from 18 to 59 years old with a mean age of 39.5 years. Each focus group lasted between 45 and 60 min. Figure 1 illustrates a schematic model of the physical activity for people with a disability model applied to haemophilia patients, Figure 2 shows the current health status of patients with haemophilia and Figure 3 shows the frequency of participation in physical activity/sports on a weekly basis. Three main themes emerged from the focus groups: (1) body-function, (2) personal factors, and (3) environmental factors (Figure 1).

**TABLE 2** Demographic information focus groups participants.

Characteristic	
Sex	Male (n = 16)
Age (years)	18–59 (mean: 39.5)
Inhibitor	No (n = 14) Yes (n = 1) No answer (n = 1)
Bleeding episodes (muscular or joint) in the past 12 months	0–5 (mean: 1.3)
Joints with arthropathy or damaged due to haemophilia	Ankles (n = 12) Knees (n = 7) Elbows (n = 9) Hip (n = 2) Shoulders (n = 3)
Smoker	Yes (n = 6) No (n = 10)

### 3.1 | Body function

All participants identified a number of barriers and facilitators regarding body function. Body function was defined as having properly functioning body parts. Participants felt confident in participating in physical activity if they had access to *prophylaxis treatment* beforehand. Having access to *prophylaxis treatment* reduces the risk of joint bleeding.

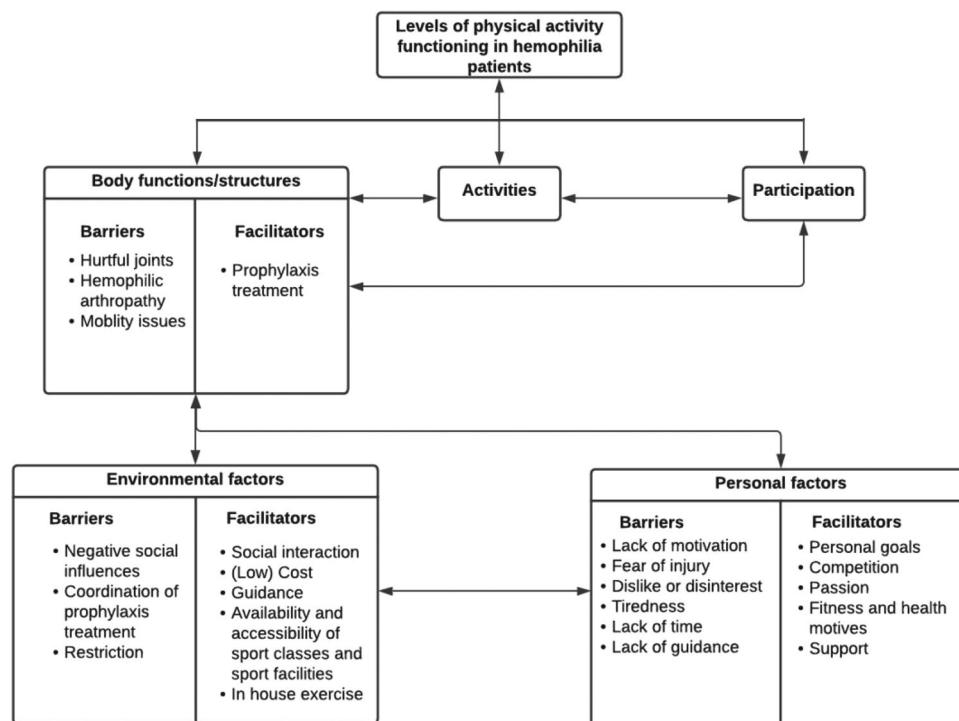
“I wanted to play baseball at a professional level, but they wouldn’t let me. Then later they told me you can play it carefully with prophylaxis and all that” P4, FGD 4

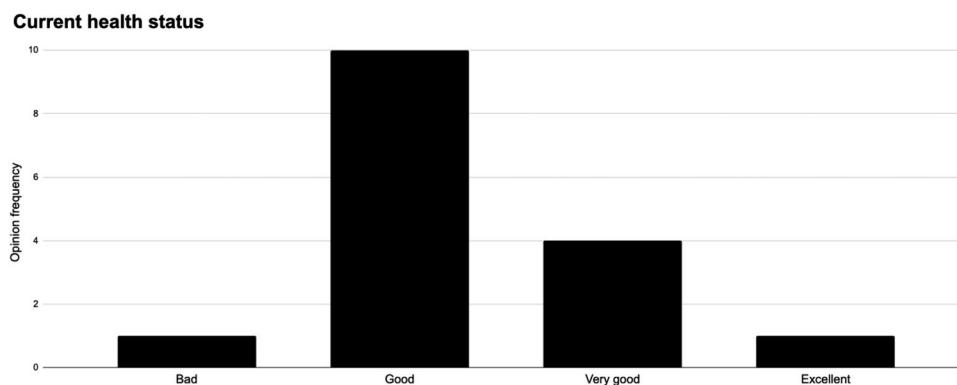
Frequent bleeding into the *joints* were mentioned frequently in the elderly participants. These participants described that their *joints* are of poor quality and hinder them from being active. The most frequently mentioned joints that led to *mobility issues* are the ankles. Most of the participants have problems with their ankles and therefore developed *mobility issues*. Another barrier to being physically active is the development of *haemophilic arthropathy*. Older participants, as they were not treated from a young age with prophylaxis for bleeding into the joints they described their *joints* are of poor quality and hinder them from being active. However, some of their younger counterparts experienced haemophilic arthropathy as well.

### 3.2 | Personal factors

The facilitators reported by all the participants were both related to their own impact on the social influence of others. The facilitators expressed focus on their own attitudes, intentions, and self-efficacy. One of the most prominent facilitators was the subtheme of *fitness and health motives*. This sub-theme refers to the physical and psychological reasons for engaging in physical activity. The most common motive for physical activity was goal oriented.

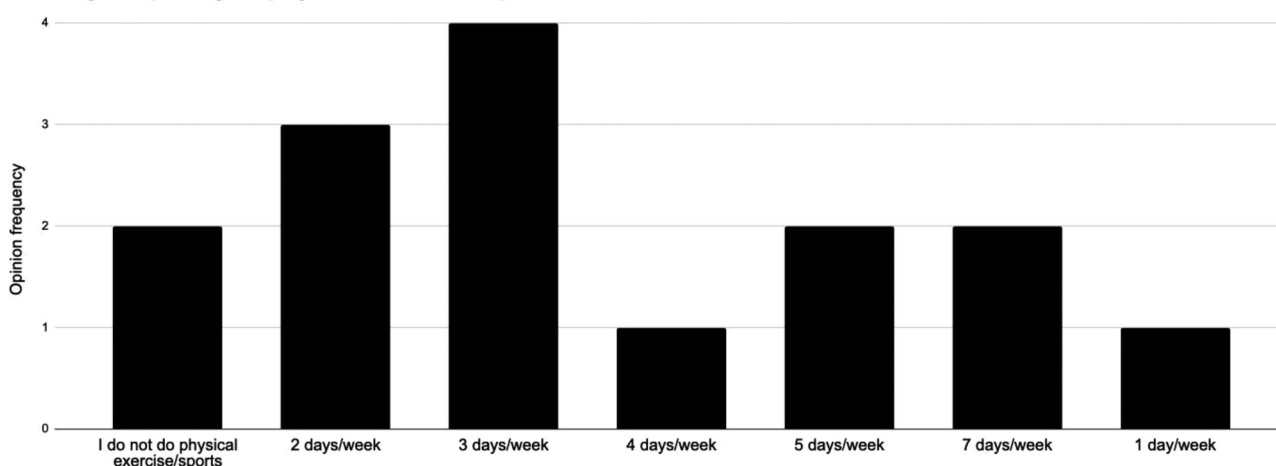
“Well, it gave me much more self-confidence because I look good in the mirror. I saw that my body is getting stronger. Achieve much more mental health by feeling comfortable with my body. After all, that also motivates you to keep doing it.” P1, FDG 4

**FIGURE 1** Schematic model of the physical activity for people with a disability model applied to haemophilia patients.



**FIGURE 2** Histogram of current health status of patients with haemophilia.

### Weekly frequency of physical exercise/sports



**FIGURE 3** Histogram of current physical activity levels of patients with haemophilia.

Some of the participants mentioned preventive reasons to participate in physical exercise. Such as building resistance and increasing mobility to prevent future bleeding into the joints. Other participants described *passion* as a reason to be active. Being passionate about a sport would motivate the participants in continuing sports activities. Participants also reported being able to exercise with others that have similar limitations, such as other haemophiliacs, would motivate them and make them feel *supported* while engaging in physical activity. Moreover, *support* and positive influences from family, friends, and healthcare professionals also played a facilitating role.

Many personal factors influenced participants not to be active. *Dislike or disinterest* was usually created in childhood and resulted in negative feelings towards physical activity. Many of the participants had *negative social influences* which made them lose interest in being active. Often during childhood, the participants would have not been allowed to participate in particular sports such as football making it more difficult for them to create a positive relationship with exercise. Most participants admitted that they continued to play soccer

secretly as children because it helped them build relationships with other children.

“Because they (the parents) didn’t let me play sports. If you wanted to integrate with the children, you had to play and when they play sports, they played football. While I was doing it, I was harming and injuring myself. And well, being injured resulted in not having a good relationship with doing sports.” P2, FDG 4

The lack of a relationship with being active resulted in some participants in *lack of motivation*. *Lack of motivation* is also a result of today’s general sedentary lifestyle, which does not invite being more active. Moreover, having regular injuries also decreased motivation.

Another barrier that was identified by the participants was the *fear of injury*. This fear was a result of the lack of *coordination for prophylaxis treatment* since participants feared the risk of bleeding by exercising without factor coverage before (when they were children, they did not have factor coverage and now that they have, it is now always received

before exercise). Other barriers that were identified by the participants were *lack of time* and *tiredness*. These two factors influenced the desire of the participants to engage in physical activity. Another important barrier to physical activity is a *lack of guidance*. The participants described how not knowing what exercises to do, would decrease the probability of exercising. One participant argued that he had been to several physical therapists, but they were unwilling to work with him because he was a haemophilia patient.

"I wanted a physio, and I've always said I have haemophilia and they say, no, I can't help you." P2, FGD 2

### 3.3 | Environmental factors

Environmental factors also played a role in the physical activity behaviour of all participants. The most important identified facilitator was *guidance*, all participants agreed that having a specialized professional guide you through the exercise is highly motivating for engaging in physical activity. Moreover, participants described how not only going for exercise but also having *social interaction* before and/or after the workout has a positive effect on their perception of exercise. As part of the *social interaction*, participants preferred exercising in a group with other haemophiliacs as they share more or less similar experiences. *Low cost* was also identified as a facilitator for physical activity.

"I join groups that are similar. You will train better because you are on a par with others, you are on the same, the same wave." P1, FGD 3

"For example, those who continue going to the association should know that the exercise at the association is free" P1, FGD 1

Participants also reported environmental factors that constituted barriers to physical activity. The common one was a *negative social influence*. This *negative social influence* was present in multiple aspects of the participants' lives. In general, it started with the *restriction* of exercise by the physician. All participants were told that contact sports are forbidden. The more elderly participants were also told by physicians to not waste any Factor VIII by exercising. Furthermore, the participants' parents discouraged them from being active in general due to their fear of bleeding occurring. Also, the *coordination of prophylaxis* was described as a barrier. Often prophylaxis was administered on days when there were no sporting activities, so participants felt less confident exercising and refrained from doing so.

"I'll give you an example, now an activity is done on Mondays and Wednesdays, but the prophylaxis is given to all those who do it on Tuesdays and Thursdays. It doesn't make sense." P2, FGD 3

## 4 | DISCUSSION

This qualitative study contributes to the existing literature by delving into the perceived barriers and facilitators of physical activity in adult people with severe haemophilia. The key results of the focus groups reported include the influence of accessibility to prophylaxis treatment, fitness and health motives, the enjoyability of the physical activity, the influence of the social environment of PWH, and guidance during performing physical activity. Thus, while PWH experience some of the same barriers and facilitators as healthy people, there are also specific factors related to their disease. The variety of themes uncovered in the data demonstrates the complexity of the topic and is consistent with the conceptual model of Physical Activity for People with a Disability.<sup>20</sup>

Access to prophylaxis treatment was found to be a key facilitator for participating in physical activity. However, the non-coincidence of the days of prophylaxis with the scheduled days of exercise, resulting in less safe circumstances for the participants to engage in physical activity was experienced as a barrier. As suggested by Forsyth et al.,<sup>26</sup> prophylaxis treatment and exercise should be scheduled on the same day to allow for safety during exercise. This may also be a way to ensure to physical activity is maintained in the long run.

Another facilitator of physical activity was fitness and health motives. These findings are consistent with the current literature. According to Rasinaho et al.<sup>27</sup> older adults with moderate to severe mobility limitations utilized disease management as a motivation for staying active. These results are consistent with Giacobbi et al.,<sup>28</sup> which found that positive physical activity experiences result in increased self-perceptions, ranging from global self-esteem to more defined and individual competence and self-efficacy judgments in individuals with physical disabilities. Encouraging self-efficacy in PWH is important for building confidence and integrating physical activity into their daily life.<sup>17</sup> In addition to fitness and health motives, low cost was also identified as a facilitator of physical activity. Further studies have shown the safety and effectiveness of low-cost resistance band exercises in PWH.<sup>9,29</sup>

The enjoyment of physical activity was also found to be facilitating participation in physical activity. PWH are more likely to engage in physical activity when it is perceived as fun.<sup>30</sup> The choice of sport, according to De la Corte-Rodriguez et al.<sup>17</sup> should be determined on an individual basis. To put it another way, PWH should not be compelled to participate in sports that they dislike. PWH should participate in a sport that they enjoy in order to get the most benefit from their physical exercise.<sup>12</sup> Moreover, reasons such as lack of time, tiredness, fear of injury, and general disinterest in physical activity formed a barrier for PWH. These reasons do not only apply to PWH but were also reported by the general population as barriers to physical activity.<sup>31,32</sup>

Factors related to physical health including painful joints, arthritis in knees, elbows, ankles, and osteoporosis were frequently reported as a barrier to physical activity. This suggests that physical health plays an important role and has a significant impact on people's lives and experiences.<sup>33</sup> It's worth noting that physical health was identified as a barrier for both active and inactive people. A possible explanation for



this might be that intrapersonal and social factors also play a role in physical activity behaviour. It is known that PWH have a higher risk of developing cardiovascular diseases and chronic conditions when obese and inactive.<sup>18,19,34,35</sup> As a result, physical activity should be promoted because it benefits not only cardiovascular, metabolic, immunological, and psychological health but also musculoskeletal health in PWH. The significance of physical activity in these adults must be emphasized, but this need is not yet being met.<sup>17,36</sup>

The social environment is crucial to whether PWH are physically active. Participation in sports activities has been shown in PWH to create a sense of belonging and increase the number of friends. Furthermore, being able to participate in sports provides the feeling of being like others, and leads to improved self-perception, which makes the person in turn more self-confident.<sup>12</sup> The results suggest that recommendations from specialists and overprotective parents contribute to lower levels of physical activity. This study supports evidence from previous observations from Biasoli et al.<sup>37</sup> which indicated that insufficient physical activity was caused by a lack of education by haematologists and other related professionals and parental (over) concern. Furthermore, insufficient physical activity throughout childhood in PWH increases the risk of not attaining a sufficient peak in bone mass, which promotes the development of osteoporosis.<sup>38,39</sup> Additionally, parents face a challenge in balancing their child's desire for a typical active lifestyle with the necessity to safeguard them from injury.<sup>40</sup> Therefore, a guide with suggestions for physical activity for parents of haemophiliacs should be developed.

Another frequently mentioned barrier to physical activity was a lack of guidance during physical activity. A comparison of the findings with those of another study confirmed that if resources were provided and support from a personal trainer was received, it helped PWH to enhance and maintain their physical activity.<sup>41</sup> Since haemophilia is a rare disease, it can be challenging to create patient-specific programs for physical therapists and personal trainers who are unfamiliar with the condition.

The findings of the present study indicate that several factors should be taken into account in order to impact physical activity behaviour in PWH. Individual advice on how to improve physical activity behaviour should primarily be made in regard to the fact that each haemophilic has different needs when it comes to physical exercise. The findings of this study concur with those of a recent study that emphasizes that physical activity behaviour in PWH is multifactorial and is influenced by access to adequate medical treatment.<sup>42</sup>

This study had several strengths. The qualitative nature of this study helped to understand the perceived barriers and facilitators to physical activity in PWH by interviewing participants who have haemophilia. This was meaningful since it allowed individuals to express their perspectives and experiences with physical activity. The focus groups were a strength of this study, as they provided the opportunity to seek clarification when needed.<sup>43</sup> A limitation of the study was that only a small set of focus groups were held with haemophilia patients. However, similar themes, sub-themes, and sample sizes<sup>44</sup> arose among the focus

groups, and it should be considered that haemophilia is a rare disease. Also, a larger sample size would probably not have led to different conclusions. Moreover, it should be considered that all participants have access to prophylaxis treatment, while approximately 75% of PWH in low- and lower-middle-income countries have limited or no access to the treatment.<sup>45</sup> Caution should be taken when extrapolating the present data to other severe PWH with a greater disability or without factor coverage.

The data obtained from this study on the barriers and facilitators to physical activity for severe adults with haemophilia can be used to improve the physical activity of this population through better-informed interventions, caregiving, programs, and policies. Physical activity behaviours may be enhanced by addressing pain, fear, and support for treatment(s), as well as creating a strong therapeutic partnership and a regular physical activity plan. Based on the data, possible recommendations for increasing physical activity behaviour in PWH are presented. The findings have contributed to the understanding of some already known barriers and facilitators, as well as added new information to the literature.

Future research should focus on developing programs with all relevant stakeholders to increase physical activity in PWH and apply these results in the real world to improve the fitness and health of this population.

## 5 | CONCLUSION

Despite improvements in medical care for haemophiliacs to lower the risk of haemophilia-related bleeding, this has not affected their exercise habits. PWH still encounter barriers while trying to engage in physical exercise. The availability of treatment is one of several factors that affect physical activity. PWH face additional barriers while attempting to engage in physical exercise compared to their healthy counterparts. Therefore, it's critical that physicians provide tailored recommendations for engaging in physical activity and be up to date on the barriers and facilitators faced by PWH.

Our recommendations for improved physical activity behaviour in PWH are the following:

- Awareness campaigns for parents of children with haemophilia with helpful fitness recommendations.
- Motivate children by creating a positive relationship with physical activity from a young age.
- Create more specialized guidelines on physical activity in PWH aimed at physical education teachers and trainers in gyms/sports facilities.
- Coordinate the administration of prophylaxis treatment with the scheduled physical exercise sessions.
- Remove the fear of injury by individualizing exercise (programs).

## CONFLICT OF INTEREST STATEMENT

The authors have no competing interests.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

## ETHICS STATEMENT

The study was approved by the Ethics Committee of Research in Humans of the University of Valencia and informed consent was obtained from all participants.

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