

Sports participation recommendations for patients with bleeding disorders

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Abstract: There are several sets of guidelines recommending sports participation for patients with bleeding disorders. Though there is a perceived risk of injury and the associated bleeding complications, several studies have been done in this patient population and have found no increased risk. In addition, there are many other benefits to participation including improvement in physical fitness status, better health outcomes, improvement in quality of life, and the development of increased flexibility, gait coordination, and muscular strength, which may actually reduce the risk of subsequent injury. With adequate pre-participation preparation and surveillance, patients with hemophilia have few restrictions in their choice of activity. In the United States, the National Hemophilia Foundation (NHF) proposes stratification of activities into safe, safe-to-moderate, moderate, moderate-to-dangerous, and dangerous risk groups. The safe through moderate categories can be routinely recommended with the proper preparation. Though hematologists often use these recommendations when counseling their patients, these guidelines may not be as accessible for primary care and sports medicine providers. This article is to serve as a review of the related literature, specifically on the benefits of physical activity without an increased risk of injury in hemophilia patients, and will summarize a set of recommendations regarding safe athletic participation for individuals with bleeding disorders from both individual studies and from health regulatory bodies like the NHF.

Keywords: Hemophilia; sports recommendations; swimming; quality of life; bleeding events

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Introduction

There are several sets of recommendations regarding athletic participation for patients with bleeding disorders including hemophilia A and B. These recommendations have been set by various regulatory bodies including the United States Centers for Disease Control and Prevention (CDC), the National Hemophilia Foundation (NHF), the Canadian Hemophilia Society (CHS), and the World Federation of Hemophilia. Individual and institutional research bodies have also commented on the topic with

their recommendations. Though these guidelines are widely utilized by hematologists, a review of the literature regarding risk of injury and the current recommendations for participation is required for primary care physicians who may see these patients as well as sports medicine physicians that may see these athletes in the field or following an injury. This article is a review of the related literature and will summarize a set of recommendations regarding safe athletic participation for individuals with bleeding disorders. Although the emphasis of this paper will be on patients with hemophilia A and B, similar principles are

applicable to patients with other bleeding diatheses such as von Willebrand disease. As a general recommendation, all patients with a bleeding disorder should be evaluated by their primary care physician and hematologist prior to beginning athletic activities to ensure proper management.

Status of physical fitness in the population

We begin our review with a discussion on the many benefits of athletic activity in all individuals, including those with a bleeding disorder. Participation in athletic activities is extremely important in maintaining a healthy lifestyle and preventing numerous adverse health outcomes. In the United States, the CDC reported a 36.5% prevalence of obesity in adults and 17% in children and adolescents during the period from 2011 to 2014 (1,2). The prevalence of obesity appears largely unchanged from rates reporting data from 2003–2004 (3).

The burden of obesity on health is significant. An increased body mass index (BMI) is known to increase the risk of adverse health outcomes including heart disease, stroke, type II diabetes mellitus, and certain types of cancer (1). These risks can be reduced with regular physical activity and athletic pursuits. Other benefits associated with regular exercise and athletic activity include cultivating the ability to work in teams, improving self-esteem and self-confidence, and reducing stress. These benefits extend to patients with hemophilia and other bleeding disorders.

Children and adolescents with hemophilia tend to be less fit, have a lower aerobic exercise tolerance, and are more overweight than other children. As such, they are at risk for poorer health outcomes as an adult and may have an increased risk of injury in the context of the patient's bleeding diathesis (4). In a 2009 study, 29.5% of hemophilia patients were found to be overweight (5). Another 2009 study examining 37 children with hemophilia noted 16% of participants were overweight and 3% were obese (4). These rates of increased BMI exceed the expected rates for the general population as noted by the CDC (4). Though these examples lack specificity in their delineations of overweight versus obese, it is still of note that hemophilia patients are at increased risk for obesity and associated complications. It is expected that there are similar findings for the adult hemophiliac population.

Given the gravity of the health concerns associated with physical inactivity and the increased prevalence of increased BMI among hemophilia patients, guidelines concerning the

sports participation of patients with bleeding disorders are needed.

Sport participation and risk of injury in patients with hemophilia

Given the poor outcomes associated with obesity and the potential benefits associated with exercise, it is important for patients with a bleeding diathesis who are receiving prophylaxis to be encouraged to participate in regular physical activity. The studies on hemophilia patients discussed in this review apply to patients receiving regular prophylaxis at concentrations ranging from >1% to >15%. Recommendations for factor prophylaxis in the reviewed literature vary from routinely scheduled prophylaxis to immediate pre-participation prophylaxis. All patients participating in athletic activity should receive prophylaxis with routine surveillance under the guidance of a hematologist; specific regimens should be tailored per individual need. It is our recommendation that any questions regarding prophylaxis from general practitioners or sports medicine physicians be directed to the patient's hematologist.

One of the largest studies supporting the participation of hemophilia patients in athletic activity followed 217 severe hemophilia A or B patients (6). Seventy-one percent of subjects reported participating in sports; most commonly these activities were swimming, cycling, tennis, fitness exercises and ice skating (6). Even in patients who could reportedly only run sometimes, 70% of the 64 individuals followed in the study participated in some sporting activity (6). Compared with population data from the Netherlands, patients with severe hemophilia A or B were as active as the general population and more active in terms of the percentage of individuals who swim or cycle (6).

A follow-up study built upon this work showed that at least 30–60 min of physical activity per day for hemophilia patients is required to maintain adequate muscle strength and reduce the rate of injury (7). The key findings of this study are similar to other studies. It is of note however, that though the duration of this study was impressive at 10–20 years, the number of patients followed in these studies was extremely limited ($n=3$) (7). Tikitsky *et al.* [2009] suggest that participation in a resistance training program may reduce the frequency of bleeding from 3 to 2 times per week or may even eliminate spontaneous bleeding events (5). Köiter *et al.* [2009] in their study noted similar results, specifically that there was no association between athletic participation and an increased risk of

injury, even in those children with increased frequency or duration of participation (8). Their work evaluated 99 pediatric hemophilia patients who participated in sports on an average of 5 times per week; the five most common sports activities in this group were soccer, swimming, tennis, gymnastics, and a cardio/fitness program (8). In the course of the study, no children developed a joint motion limitation (8).

Seuser, *et al.* [2014] specifically looked at the orthopedic challenges faced by hemophilia patients and their relationship with physical activity. They found a significant difference in gait control and coordination between children with hemophilia and healthy children; “rhythmicity” was the most apparent deficit in children with hemophilia (9). The authors suggest that athletic participation helps cultivate various skills that promote adequate gait coordination including improving muscle strength, endurance, and flexibility. Moreover, they noted that regular physical activity reduces the risk of hemarthrosis and improves fitness, muscle strength, balance, and coordination (9). Their study also found that regular physical activity was associated with a better quality of life (9). Relevant to these recommendations, research suggests that parents of children with hemophilia are less likely to encourage their child’s participation in athletics; though this finding was not statistically significant (9). Seuser *et al.* [2014] recommend that after a thorough physical examination and counseling regarding safe athletic practices, all patients should exercise for 30–120 min 2 to 4 times per week (9). Additionally, regular exercise should be initiated at a young age (9).

Appropriate physical activities for patients with hemophilia

Although, there is not a consensus on which sports should be encouraged for patients with a bleeding disorder, there is a significant body of literature discussing the appropriate selection of a physical activity or sport.

In a review of more than 5 million reported sports related injuries in 44 different athletic activities in well individuals, the activities least associated with risk of injury included water polo, walking, cross country skiing, golf and swimming (10). The highest risk of injury was reported for basketball, squash, luge/tobogganing, water-skiing, bodybuilding, wrestling, and basketball (10). Activities with a lower risk of injury may be more suitable for a patient with hemophilia. The most frequently recommended

sport for patients with a lower level of personal fitness is swimming due to the low risk of injury and bleeding events as well as the substantial benefits associated with an increase in activity level (9,10).

Of note, to assess for an activity that might be a good fit for a patient with a bleeding disorder given the above considerations, Seuser *et al.* [2007] developed a checklist that assesses a patient’s overall fitness score, as some sports may require a more advanced state of fitness to avoid injury (10). The checklist assesses balance and coordination, torso strength, aerobic endurance, flexibility, and body fat content (10). This checklist may specifically be of utility for sports medicine practitioners working closely with patients with hemophilia.

Ross and Goldenberg [2009] evaluated the risk of bleeding and other complications in hemophilia patients relating to injuries occurring in different high- and low-impact activities (4). High-impact sports studied included football, basketball, baseball, bowling, gymnastics, hockey, running, skiing, snowboarding, soccer, softball, tennis, and track and field (4). Low-impact activities included weight training, cycling, Frisbee, golf, swimming, tee-ball, and walking/hiking (4). Their analysis noted no difference in the rates of injury or in frequency of bleeding complications in the high-impact versus low-impact groups (4). This study suggests that with the proper supervision, equipment, and precautions, a great variety of athletic activities can be enjoyed by patients with a bleeding disorder including traditionally high-impact activities that have been avoided. Regular exercise by patients with hemophilia has been shown to improve strength, increase joint range of motion, reduce pain, and reduce the frequency of bleeding events (4).

Tiktinsky *et al.* [2009] evaluated the association between risk of injury and the level of activity, specifically if strenuous activity was associated with an increased risk of bleeding (5). They found that 25 of 44 severe hemophilia A or B patients between the age of 12 and 25 participated in strenuous physical activity at least once per week including ball games, walking, and running (5). No significant difference in the average number of bleeding events per month was noted between groups with a different activity level. In those who did have a bleed, the etiology of injury was more likely to be traumatic in the strenuous group (5). These findings suggest that patients who participate in strenuous physical activities are no more likely to have a bleeding event compared to those who participate in less strenuous activities (5).

Maffett *et al.* [2016], in their case study of a Division I

Table 1 Summary of recommendations for athletic participation by patients with a bleeding disorder

Establish care and regular follow-up with a hematologist and a primary-care physician
Receive factor prophylaxis per current recommendations with appropriate supervision
For children over the age of 6, we recommend a minimum of 60 min of exercise per day
Children should, in general, not be excluded from organized physical activities
For adults, recommend a minimum of 150 min of moderate-intensity aerobic exercise in addition to muscle-strengthening exercise
Ensure a pre-participation visit with the patient's hematologist regarding potential activities and review of the proper precautions
Assess the patient's fitness status and ability to participate safely in athletic activities. May utilize the "think once, think twice" method to assess interest in and competency for participating in a chosen activity
Recommend activities reviewed as "safe" or "moderate" by the NHF and activities mentioned by the Canadian Hemophilia Society and World Federation of Hemophilia

NHF, National Hemophilia Foundation.

NCAA basketball player with hemophilia, described the benefits and risks of athletic participation for hemophilia patients (11). This player was able to safely participate in basketball with proper prophylaxis and supervision and ultimately went on to have a successful collegiate career followed by involvement with a professional team (11). During the course of his collegiate participation, this player developed only one bleeding injury which healed well (11). This case study showed that hemophilia patients can and should participate in sports, including more traditionally high risk contact or collision sports if there is interest, given adequate treatment and surveillance. Participation should be coordinated and should include an evaluation by a hematologist. Adequate precautions by coaches and professional staff, adequate administration of prophylaxis, and treatment of any injuries with factor should be pre-arranged (11). With these precautions, patients can enjoy a wide range of activities (*Table 1*).

Recommendations by health organizations

Several health organizations have provided their recommendations regarding activity selection for hemophilia patients. The NHF in collaboration with the CDC published its guidelines for participation in sports in their manual *Playing It Safe* (12). This publication strongly encourages patients with bleeding disorders to participate in a wide variety of sports and regular athletic activity. The guidelines cite many benefits associated with regular activity in patients with hemophilia, including promoting a healthy weight, self-esteem, and self-confidence and decreasing the risk of hypertension, heart disease, stroke, and cancer; as

well as the more specific benefits including decreasing the risk of a spontaneous bleeding event (12). NHF guidelines recommend adequate training, preparation, and supervision in the case of children participating in athletics, and endorse a wide variety of physical and sport activities. The sports and activities listed as safe include: archery, aquatics, cardiovascular training equipment use (elliptical, stationary bike), fishing, frisbee, golf, hiking, tai chi, snorkeling, swimming, and walking (12). The sports listed as dangerous for those with bleeding disorders includes BMX racing, boxing, diving, football, hockey, lacrosse, motorcycles, motor-cross racing, power-lifting, outdoor rock climbing, rodeo, rugby, motorized scooters, snowmobiling, trampoline, and wrestling (12). The dangerous activities are not recommended by the NHF for patients with a bleeding diathesis (12). Despite these cautions, the NHF advocates regular physical activity, highlighting the point that inactive children with a bleeding disorder have more spontaneous bleeding than those who are active (12).

Another resource for recommendations regarding athletic participation is available from the CHS in their publication *Destination Fitness* (13). The CHS guidelines recommend regular activity and athletic participation for patients with hemophilia citing the many benefits associated with exercise. Specifically, for hemophilia patients, benefits of regular physical activity include improving flexibility, maintaining joint health, improving proprioception, improving general mobility and improving general functioning allowing for greater individual autonomy (13). Several aspects of athletic activities that may pose greater risk for individuals with hemophilia include activities involving contact or collisions, activities

with repetitive movements and extreme movements, activities with great speeds or heights, and activities that may involve a great force of impact (13). Despite these cautions, athletic participation is still recommended after careful consideration of different activities with proper prophylaxis, precautions, and surveillance by caregivers and physicians. The CHS guidelines promote the “think once, think twice, and think again” method of activity selection. Specifically, patients may “think once” about generally safer, often recommended activities for patients with a bleeding diathesis including swimming, golf, yoga, hiking, sailing, canoeing, kayaking, bicycling, and tai chi (13). “Think twice” activities may be associated with a greater risk of injury but may still be appropriate for this patient population; these activities include badminton, basketball, baseball, bowling, tennis, skating, volleyball, cross country skiing, running, soccer, and hacky-sack (13). The “think again,” category includes several activities that pose a significant risk of injury in patients with or without a bleeding diathesis. These activities include football, hockey, downhill skiing, rollerblading, skateboarding, karate, snowboarding, wrestling, boxing, taekwondo, dirt-bike racing, racquetball, and snowmobiling (13). It is recommended that hemophilia patients avoid these activities.

Another document from the CHS, *All About Hemophilia: A Guide for Families*, includes similar recommendations (14). These guidelines concur with the recommendations that athletic activity should be encouraged in this patient group. The guidelines note that though there are specific risks associated with particular activities, choosing a sport is a highly individualized decision (14). The specific benefits and risks must be weighed for an individual patient and the chosen activity. Generally, recommended activities for hemophilia patients include swimming, cycling, walking, tai chi, and other, unspecified exercise programs (14). However, other activities are not to be summarily excluded. Close monitoring by a healthcare professional is recommended prior to and for the duration of all types of participation.

Guidelines for the Management of Hemophilia, published by the World Federation of Hemophilia (WFH), emphasized the importance of regular physical activity and the message that even contact sports or other activities classically viewed as more dangerous may be enjoyed by hemophilia patients on proper prophylaxis (15). The sports more typically recommended by the WFH include walking, golf, badminton, archery, cycling, rowing, sailing, and table tennis; however, high contact and collision sports such as

soccer, boxing, wrestling, and hockey may be considered on an individual basis (15).

Discussion

Current research and recommendations support regular physical activity and athletics in patients with hemophilia and other bleeding disorders. The most important recommendation is that patients wishing to participate in sports and athletic activities must have proper guidance and support from their hematologist and primary care physician. This includes appropriate surveillance and counseling regarding potential athletic participation as well as ensuring adequate factor prophylaxis.

Different prophylactic regimens have been used in patients with hemophilia. The literature reviewed notes different cutoff levels for factor prophylaxis, including >1% and >5%. Some studies recommend higher level of prophylaxis; however, given the reported findings noting no increase in the risk of injury with participation with prophylaxis levels >1% and >5%, higher prophylaxis concentrations are likely unnecessary.

For children with hemophilia older than 6 years of age, the American Academy of Pediatrics (AAP) recommends 60 min of exercise or physical activity per day (16). Children under the age of 6 including those with hemophilia should be encouraged to develop a healthy lifestyle with activity as tolerated. Adults are recommended by the CDC to participate in 150 min of moderate-intensity aerobic exercise as well as additional muscle-strengthening activities every week (17).

A wide range of sports and athletic activities may be enjoyed by hemophilia patients without an increased risk of injury. The most commonly recommended activity in the reviewed literature was swimming. Walking and running were next most frequently recommended. Other recommended activities included are listed in *Table 2*. Research suggests that more intense or strenuous participation as well as higher-impact activities are not associated with an increased risk of injury. This information should be considered when counseling a patient on participation.

It is our recommendation that patients with hemophilia be assessed by their hematologist prior to beginning athletic activity and the different options and necessary precautions reviewed. A review of the patient's fitness status is also recommended prior to the initiation of activity to ensure the patient may participate safely. There are

Table 2 Recommendations by the National Hemophilia Foundation for athletic participation

Safe sports
Archery
Aquatics
Elliptical machine
Stationary bike
Fishing
Frisbee
Golf
Hiking
Martial arts/tai chi
Snorkeling
Swimming
Walking
Moderately risky sports
Bicycling
Rowing machine
Ski machine
Treadmill
Circuit training
Body sculpting (exercise class)
Physio ball (exercise class)
Frisbee golf
Pilates
Weight lifting/resistance training

several tools available to help hematologists determine an appropriate activity. One method includes using the “five-item fitness checklist” created by Seuser *et al.* [2007] (10). This checklist assesses a patient’s balance and coordination, torso strength, aerobic endurance, flexibility, and body fat content. However, the time and equipment required to do this evaluation may be longer than available in a typical appointment. In this case, it is reasonable to inquire about which activities the patient is interested and then spend time counseling regarding safe participation in this sport. This includes discussion of safety precautions, adequate preparation, and appropriate surveillance relating to the chosen activity. Children will likely require more

surveillance by caregivers knowledgeable of the patient’s medical status. The “think once, think twice” method may also be utilized to explore patient interest and facilitate a discussion of a proposed activity. If receiving adequate prophylaxis and adequately prepared, it is our belief that a wide range of athletic activities can be enjoyed, including those sports more typically thought of as associated with injury. It is important that individuals be able to participate in an activity that they are interested in and appeals to their peer group, especially in children.

However, there are still some activities which are considered to be too dangerous. The NHF’s recommendations include restricting some of the most dangerous activities, including BMX racing, motor-cross cycling, rodeo participation, wrestling and boxing. In children and perhaps more novice athletes, the activities noted by the NHF to be safe or of moderate risk are recommended. Moderate-to-dangerous activities may also be acceptable depending on the individual in question, and ensuring proper prophylaxis, adequate surveillance, and immediate access to care. This is to be determined by the patient, the patient’s parents in case of children and adolescents, and the supervising hematologist. A list of the activities recommended by the NHF is listed in *Table 2*. The sports most recommended by these guidelines include swimming, golf, yoga, hiking, sailing, rowing, canoeing, kayaking, bicycling, tai chi, archery, and table tennis. It is possible for hemophilia patients to participate in a wide range of athletic activities providing them with the innumerate benefits of a healthy lifestyle and social involvement.

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Footnote

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