The role of the physiotherapist in the management of people with haemophilia: defining the new normal

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Abstract

Physiotherapists aim to maximise quality of life and movement potential within the spheres of promotion, prevention, treatment/intervention and rehabilitation. Haemophilia care is witnessing a significant shift towards a new era of potentially life-changing treatments which offer a future of minimal or no bleeds for people with haemophilia. As such, physiotherapy intervention should be more proactive rather than reactive to treat and rehabilitate recurrent bleeding episodes. The role of the physiotherapist within the multidisciplinary team includes the differential diagnosis of musculoskeletal bleeding, supporting and encouraging higher levels of physical activity, rehabilitation to maximise physical potential and capabilities, assessment and treatment of non-bleed-related musculoskeletal issues, managing comorbidities and falls risk, and improving the longitudinal surveillance of musculoskeletal health. Encouraging and supporting people with haemophilia to become more active will improve wellbeing and improve health and health outcomes, and physical activity is becoming one of the most important outcomes for people with haemophilia. Recommendations on the best way to accurately capture these data are vital to ensure the full health benefits of new treatments for people with haemophilia are clear.

Key words: Activity; Arthropathy; Haemophilia; Musculoskeletal; Physical therapy; Physiotherapy

Submitted: 10 January 2020; accepted after double-blind peer review: 4 March 2020

Introduction

Haemophilia is an inherited X-linked recessive bleeding disorder affecting over 1 million men worldwide (Iorio et al, 2019). It is characterised by recurrent bleeding into muscles and joints, causing synovial hypertrophy, destruction of the articular cartilage and ultimately haemophilic arthropathy (Jansen et al, 2007). The early use of prophylactic factor concentrates can prevent joint bleeding, but once joint arthropathy is established, use of factor concentrates may not prevent further joint deterioration (Hanley et al, 2017). The subsequent loss of range of movement and the effects on muscle strength and biomechanics can lead on to a loss of functional ability and a reduction in physical activity (Beeton, 2002; van Genderen et al, 2004).

Historically, physiotherapy has been reactive as people with haemophilia would have numerous recurrent haemarthroses, developing chronic synovitis and target joints. There are a myriad of new technologies in haemophilia care, many of which have reached the clinic, giving people with haemophilia the possibility of a bleed-free life (Butterfield et al, 2019). The future challenges for physiotherapists in delivering optimal musculoskeletal health alongside advances in medical treatment include how to rehabilitate subtle and existing musculoskeletal problems, patients with milder bleeding phenotypes, and older patients with progressive arthropathy and increasing frailty (Stephensen et al, 2018). In the changing treatment landscape, physiotherapists need to be more proactive and this article discusses the impact on the role of the physiotherapist in managing people with haemophilia.

How to cite this article:
Wells AJ, Stephensen D. The role of the physiotherapist in the management of people with haemophilia: defining the new normal. Br J Hosp Med. 2020 https://doi.org/10.12968/hmed.2020.0016

Job code M-GB-00000383. Date of preparation: June 2020

Role of physiotherapy

The ability to move is an essential element of health and wellbeing and central to what it means to be healthy. Physiotherapy is directed towards the movement needs and potential of individuals, providing rehabilitation and services to develop, maintain and restore maximum movement and functional ability and prevent musculoskeletal impairment throughout the lifespan (World Confederation for Physical Therapy, 2015). Physiotherapists aim to identify and maximise quality of life and movement potential within the spheres of promotion, prevention, treatment and intervention, and rehabilitation. As such the provision of physiotherapy is recognised as an essential service in the NHS Service Specification for Haemophilia (NHS England, 2013) with agreed standards of care for both children and adults defined by the Haemophilia Chartered Physiotherapists Association (2017a,b). Despite these recommendations, a national peer review has highlighted the need for more specialist physiotherapists within haemophilia services across the UK (UK Haemophilia Centres Doctors' Organisation, 2019).

The last decade has witnessed advances in haemophilia treatment options, such as the availability of coagulation factors with a longer plasma half-life that allow for wider intervals between treatment, therapeutic products based on mechanisms other than the replacement of the deficient factor, and gene therapy (Mannucci, 2020). It is likely that bleeding episodes and arthropathy will be less prominent for people with haemophilia in the future.

The changing role of physiotherapy for both children and adults with haemophilia has been well documented (De Kleijn and Mauser-Bunschoten, 2017; Stephensen et al, 2018). Physiotherapy intervention should be much more proactive in terms of optimising biomechanics to prevent musculoskeletal bleeding. As part of the multidisciplinary team, physiotherapists are likely to focus on:

- Differential diagnosis of musculoskeletal bleeding
- Supporting and encouraging higher levels of physical activity
- Rehabilitation to maximise physical potential and capabilities with increased expectations of what is achievable
- Assessment and treatment of non-bleed-related musculoskeletal issues
- Managing comorbidities and falls risk
- Improving the longitudinal surveillance of musculoskeletal health.

Recognition of bleeding

Differentiating a joint or muscle bleed from musculoskeletal pain is challenging for both patients and clinicians. There is currently no way of doing this other than by using clinical reasoning skills, and the specialist skills of a physiotherapist are essential (Stephensen et al, 2018). We are already moving towards a future of minimal bleeds for people with haemophilia but this will pose new challenges for patients and clinicians alike. Older people with haemophilia have been advised for many years to recognise symptoms of pain, swelling and reduced range of movement as some of the early to moderate signs of bleeding (Hanley et al, 2017). Bleeding triggers an inflammatory response, so it is understandable that differentiating between bleeding and inflammation is problematic. People with haemophilia who are taking factor prophylaxis would in the first instance be advised to treat a joint or muscle bleed with an extra dose of factor. If factor is no longer indicated when a painful episode is experienced, being unable to treat in the same way may increase anxiety in some people with haemophilia, which could further complicate the pain response.

Younger people with haemophilia may have never experienced a bleed so helping them to understand what their body is telling them when they pick up injuries is vital. There is a difficult balance between ensuring that children and their care givers are aware of what to look out for in terms of potential bleeds, and trying not to raise anxieties which can affect day to day life by avoiding activities perceived as risky.

The introduction and effects of some treatments mean that many people with severe haemophilia may now experience a bleeding pattern more aligned to someone with mild haemophilia, and the presentation of a bleeding episode may be very different for them.

Clinicians will be seeing a variety of people who may be misinterpreting symptoms in joints as bleeds as well as people who might be ignoring or not recognising small signs of problems.

Supporting and encouraging higher levels of physical activity and function

National guidelines suggest that children should aim to be active for 60 minutes per day and adults for 75–150 minutes per week (UK Chief Medical Officers, 2019). There is a greater emphasis now that being active does not necessarily mean doing sport and exercise, but reducing sedentary time. The mental and physical health benefits of activity are vast, and these can be achieved through either being active in a single bout or accumulating activity from shorter bouts throughout the day (Murphy et al, 2019). For people with haemophilia, being active has been challenging because of the recurrent bleeding episodes and the subsequent effects on joint pain, reduced range of movement, and reduced strength and proprioception. Many people with haemophilia should be well informed about the particular benefits to their joints of building strength and being active, having been educated on anatomy, effects of bleeding and how to look after their musculoskeletal system from a young age. With new treatments for haemophilia meaning that an individual with haemophilia could potentially have no bleeding episodes, the majority of people with haemophilia may now be able to strive for the same levels of activity as suggested for the general population.

There is increasing interest in optimising prophylaxis treatment based on an individualised patient pharmacokinetic profile (Dargaud et al, 2018), and it will be important that physiotherapists work closely with the multidisciplinary team in order to coordinate changes in physical activity that align with changes in their treatment. Incorporating clinical joint examinations, degree of arthropathy and physical capabilities into the delivery of individualised prophylaxis to optimise outcomes for each patient and develop their individual physical activity programme will be an essential role for physiotherapists in the future.

Many older people with haemophilia who had no access to prophylaxis as children were advised not to exercise because of the risk of bleeding; these people may benefit from personalised prehabilitation to increase muscle strength and cardiovascular endurance together with advice on pacing strategies to manage levels of pain. Pacing involves maintaining an even level of activity throughout the day, rather than, for example, trying to do everything in the morning and then having to rest all afternoon. Pacing is not all about stopping activities but organising activities to time and not to pain.

Encouraging and supporting people with haemophilia to become more active is already a large part of the physiotherapist’s role. There are many barriers to becoming more active, with bleeding episodes being just one. As with the general population, trying to change behaviour for well-known and understood positive health benefits is not as easy as it may seem. A deep understanding of what motivates and what hinders people is crucial. Linking together with psychology colleagues when discussing activities, hobbies and interests and how to encourage people to become more active, will increase the likelihood of achieving improved wellbeing and improved health and health outcomes for people with haemophilia. It is important that physiotherapists ‘make every contact count’, by discussing activity at every patient appointment. With the introduction of social prescribing, it will become much easier to link people with activity schemes and prospective hobbies in the community to help improve and sustain both physical and mental wellbeing.

Measuring physical activity

Physical activity is becoming one of the most important outcomes for people with haemophilia and yet there are no guidelines or consensus of opinion on how these data should be collected. Self-reported measures are known to be inaccurate, so the use of physical activity monitors may offer a more objective and accurate assessment which has already been successfully used in large population based studies (Matthews et al, 2012). Self-reported data tend to be overestimated, and contain little information on intensity and type of activity. Increasingly, wearable activity monitors and mobile health technology provide a promising method of monitoring musculoskeletal health and the impact on activity participation. Monitoring physical and sedentary behaviours, by tracking real-time body movement with accelerometer and global positioning systems, enables the time, type and intensity of activity to be evaluated. Recommendations on the best way to accurately capture data on physical activity are of paramount importance if we are to ensure the correct representation of new treatment benefits for people with haemophilia.

Sport and careers

Clinicians will give advice on sport and careers for people with haemophilia from a young age. Sports with a risk of head trauma, for example rugby or boxing, are not advised, and even with new treatments this advice is likely to remain unchanged. The importance of peak factor levels in sport are unknown, and the catastrophic repercussions of an intracranial haemorrhage are not worth the risk. Careers in the military, police force and fire brigade are not currently options for people with bleeding disorders. It may be that restrictions start to lift in these areas as newer technologies for haemophilia treatment become more commonplace.

Comorbidities for people with haemophilia

Increasingly, age-related comorbidities including cardiovascular disease, hypertension, diabetes, cancer, renal disease and obesity have been described in people with haemophilia (Konkle et al, 2009; Miesbach et al, 2009; Siboni et al, 2009; Khleif et al, 2011). However, joint arthropathy remains the main comorbidity, leading to deconditioning, balance problems, increased falls risk and frailty in older people with haemophilia. Haemophilia physiotherapists will need to provide tailored rehabilitation programmes to address these problems if all people with haemophilia (regardless of age) are to benefit fully from improved medical treatments.

For a large proportion of adult people with haemophilia with minimal or no bleeds, the biggest issue will be their existing musculoskeletal problems. About a third of painful joint episodes in people with haemophilia with arthropathy are not associated with bleeds but are in fact an exacerbation of arthropathy (Chaplin, 2019). Pain in haemophilia has often been attributed to haemarthrosis, arthropathy and synovitis, but this area has not been widely researched and the prevalence and understanding of chronic pain and inflammation is unknown. Pain is highly complex and remains poorly understood in people with haemophilia. Musculoskeletal pain can be categorised into nociceptive, peripheral neuropathic and central mechanisms, with nociceptive pain including inflammatory, ischaemic and mechanical processes (Smart et al, 2010). Many people with haemophilia have chronic centralised pain, with both inflammatory and mechanical episodes as well as bleeding. The influence of behavioural and psychological factors in people with haemophilia is similar to that in people with other long-term pain conditions, and as such a multidisciplinary approach to pain management is key (Elander, 2014).

With recurrent bleeding episodes becoming a thing of the past, many people with haemophilia may feel increasingly confident to geographically move further away from their haemophilia care team. Attendance for routine clinical reviews will continue, but some of these may be possible via teleconference and digital platforms. People with haemophilia may increasingly seek advice from local services who may have little knowledge of their underlying condition. Where this is the case, it is important that physiotherapists working outside of bleeding disorders services liaise with the haemophilia comprehensive care centre to ensure appropriate care pathways are implemented. In a physiotherapy outpatient setting, most standard interventions are possible and restrictions are minimal. However, as there is a lack of evidence as to the potential benefits and detrimental effects of standard physiotherapy interventions for people with haemophilia, it is important that when designing the physical therapy or rehabilitation programme that the physiotherapist considers global joint involvement and a risk vs benefit analysis of all chosen assessment and intervention techniques to avoid triggering bleeding episodes (Forsyth et al, 2020). It is important to remember that when people with haemophilia injure themselves, there is an additional bleeding component on top of the acute injury that may impact recovery or cause a worsening of symptoms with repeated bleeding. Table 1 summarises the key factors for a physiotherapist to consider when seeing a patient with a bleeding disorder.

Table 1. Key factors for a physiotherapist to consider when seeing a patient with a bleeding disorder

Type of bleeding disorder	Haemophilia A (factor VIII deficiency) Haemophilia B (factor IX deficiency) Von Willebrand's disease Other factor deficiency or platelet disorder
Severity	Mild, moderate or severe Current inhibitor Y/N
Treatment	Factor (intravenous): standard half-life or extended half-life Desmopressin or DDAVP (nasal spray) Tranexamic acid (tablets) Other: for example, non-factor replacement therapy, gene therapy (currently under clinical trial in haemophilia A and haemophilia B)
Frequency of treatment	For example, alternate days/every 4 days/every 2 weeks/on demand
Pharmacokinetic profiles	Factor levels and timing of physical activities and rehabilitation
Any associated problems	Arthropathy Orthopaedic surgery
Which specialist haemophilia centre is the patient registered with?	Link in and liaise with specialist physiotherapist

Surveillance of musculoskeletal health and outcome measures

The past few years has seen a big focus on longitudinal joint assessment and outcome measures. The haemophilia joint health score is the most widely used musculoskeletal outcome measure used for people with haemophilia in the UK and worldwide (Hilliard et al, 2006). It uses a standardised assessment of the three most frequently affected joints: the knees, elbows and ankles, and is recognised by commissioners on the NHS England (2019) Quality Dashboard for Haemophilia. With increased global use, it appears there is considerable variability among those using the tool, and it might not be sensitive for extremes of good and poor joint health (Bladen et al, 2013; Stephensen et al, 2014; Nijdam et al, 2016). The International Classification of Functioning, Health and Disability Framework, published by the World Health Organization in 2001, is a universally applicable framework which can be used to advance the development of policies and services to meet the needs of people with any health condition. It considers structural and functional changes, activities and participation, in a context of both personal and environmental factors, and may be an appropriate model to develop long-term surveillance tools for future care of people with haemophilia (Fischer et al, 2017). The International Classification of Functioning, Health and Disability Framework encourages a more holistic approach to patient care and it is recognised that a battery of tests evaluating biomechanical function, point-of-care imaging, performance and participation in activities as well as clinical examinations of joint structure is needed (Stephensen et al, 2018). There is more recognition that physical and mental health interlinks and working closely with psychology colleagues in the bleeding disorders multidisciplinary team is encouraged. It might be of benefit for physiotherapists to use a goal attainment approach to personalise the monitoring of treatment and support enhancement of function and physical activity.

Conclusions

Haemophilia care is witnessing a significant shift towards a new era of potentially life changing treatments which offer a future of minimal or no bleeds, thus changing the role of the multidisciplinary team. Physiotherapists need to be increasingly flexible in their

Key points

- Physiotherapists are experts in health promotion, injury prevention, treatment/intervention, and rehabilitation.
- It is essential that physiotherapists work with people with haemophilia in the co-design of future musculoskeletal services.
- New technologies in haemophilia will require proactive physiotherapy intervention to optimise physical activity and prevent musculoskeletal bleeding.
- Pain is highly complex and remains poorly understood in people with haemophilia.
- Differentiating between bleeding and inflammation is difficult for both patients and clinicians.
- Encouraging and supporting people with haemophilia to become more active will improve wellbeing and improve health and health outcomes.
- Recommendations on how to accurately capture data on levels of physical activity and participation while using newer products are required.
- Haemophilia associated joint arthropathy as a comorbidity remains an issue in spite of new products, and tailored rehabilitation programmes are needed if all people with haemophilia (regardless of age) are to benefit fully from improved medical treatments.
- Longitudinal surveillance of musculoskeletal health should be patient relevant and be in the context of the International Classification of Functioning, Health and Disability Framework.

approach, incorporating complex clinical reasoning of musculoskeletal problems, chronic pain, psychosocial aspects and emerging haemostasis management. Physiotherapists will be more proactive in promoting and encouraging higher levels of physical activity and a broader range of patient goals and expectations in terms of activities, hobbies and social connections with a reduced treatment burden. People with haemophilia are well informed about their bleeding disorder and it is essential that physiotherapists work with patients to co-design future musculoskeletal services that promote person-centred care.

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Conflicts of interest

The authors received an honorarium from the *British Journal of Hospital Medicine* for writing this article – this has been donated to Hampshire Hospitals NHS Foundation Trust.

Disclosure

This non-promotional article will form part of a supplement within the *British Journal of Hospital Medicine* which has been funded by Roche Products Limited and Chugai Pharma UK Limited. Roche and Chugai suggested the healthcare professionals who have written this article. Roche and Chugai have carried out full review to ensure compliance with UK regulations. The views and opinions of the authors are not necessarily those of the *British Journal of Hospital Medicine*, its publisher, advisers, or advertisers. No part of this publication may be reproduced in any form without the permission of the publisher.

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