



ORIGINAL ARTICLE

Musculoskeletal

European principles of care for physiotherapy provision for persons with inherited bleeding disorders: Perspectives of physiotherapists and patients

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Abstract

Introduction: In their Chronic Care Model, the World Health Organisation states that people with chronic disorders and their families should be informed about the expected course, potential complications, and effective strategies to prevent complications and manage symptoms. Physiotherapists are a key professional group involved in the triage, assessment and management of musculoskeletal conditions of persons with a bleeding disorder (PWBD). Nevertheless, recent reports describe access to physiotherapy for those with these conditions is only sometimes available.

Aim: Access to high quality individualised physiotherapy should be ensured for all PWBD, including those with mild and moderate severities, male and female, people with von Willebrand Disease (vWD) and other rare bleeding disorders. Physiotherapy should be viewed as a basic requisite in their multidisciplinary care.

Methods/ results: Following a series of meetings with physiotherapists representing the European Association for Haemophilia and Allied Disorders (EAHAD) and PWBD representing the European Haemophilia Consortium (EHC) and a review of

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publications in the field, eight core principles of physiotherapy care for persons with a bleeding disorder have been co-produced by EAHAD and EHC.

Conclusion: These eight principles outline optimum standards of practice in order to advocate personalised patient-centred care for physical health in which both prevention and interventions include shared decision making, and supported self-management.

KEYWORDS

bleeding disorders, co-production, physiotherapy, prevention, shared decision making, supported self-management

1 | INTRODUCTION AND BACKGROUND

Bleeding disorders can cause abnormal bleeding. Severe haemophilia is perhaps the most well-known inherited bleeding disorder and the most common consequence is repeated bleeding into joints and muscles. However, there are mild and moderate haemophilia patients, male and female, persons with von Willebrand Disease (vWD) and other rare bleeding disorders that also deal with the consequences at a musculoskeletal level; all typified by a degenerative process of irreversible changes to joint articular cartilage and other muscular structures.¹⁻³

Due to the complexity of this condition, the World Federation of Haemophilia (WFH) guidelines on the care of persons with any bleeding disorder (PWBD) recommend ready access to a range of services provided by a multidisciplinary team of specialists.² They state that physiotherapy is important and should be provided to patients throughout their lifespan. In Europe, both the European Association for Haemophilia and Allied Disorders (EAHAD) and the European Haemophilia Consortium (EHC) share the objective of physiotherapy for all, as one of many mutual goals.³

The primary goal of physiotherapy is to develop, maintain and restore people's maximum movement and functional potential. Physiotherapists help people maximise their quality of life, looking at physical, psychological, emotional and social wellbeing encompassing the health spheres of promotion, prevention, treatment/intervention, and rehabilitation. Clinical practice guidelines for physiotherapists working with PWBD have recently been developed by a Canadian working group following standardised methodology including literature review, and appraising and grading of evidence, that can be used to increase the uniformity and quality of physiotherapy care provided to PWBD.⁴

Despite inclusion within international guidelines, a survey of thirty-seven European countries by the EHC (2015)⁵ and a scope of physiotherapy practice survey of eighty physiotherapists from twenty-four European countries by the EAHAD (2019)⁶ reported access to physiotherapy for persons with bleeding disorders was only sometimes available. And where available, there was considerable heterogeneity in access and clinical practice of physiotherapy care for persons with haemophilia across Europe. This was more recently highlighted in a peer review of United Kingdom haemophilia centres, which noted that

up to 60% of centres had insufficient or minimal physiotherapy services for PWBD.⁷

Easy access to high quality individualised physiotherapy should be ensured for all persons with bleeding disorders. This should be optimised by viewing physiotherapy as a basic requisite in a multi-disciplinary care approach. Close collaboration with other healthcare specialists then helps ensure a high standard clinical practice in physiotherapy, as well as relevant education and competency of physiotherapists. Interventions focused on Shared decision-making and supported self-management of physical health, as well as prevention of the musculoskeletal consequences associated with bleeding disorders, underpins these principles. The aim of this report is to develop principles that outline and clarify the optimum standard of physiotherapy services and practices for all European PWBD.

2 | METHODS

This report is the result of an initiative of healthcare professionals and persons representing the EAHAD and the EHC. The team involved in the development of this document included: two physiotherapists representing the EAHAD physiotherapy committee, one EAHAD physiotherapy coordinator and two physiotherapists representing the EHC (one as physiotherapist and person with a bleeding disorder, one as a member of the EHC Medical Advisory Board) and three further persons with a bleeding disorder. Eight European countries were represented in the team. A series of four meetings with the team helped develop the aims and objectives of this document, leading to the development and agreement of eight principles through round table discussion and debate. The document was then shared with four additional EAHAD physiotherapy committee and 18 network co-ordinators and EHC leadership; further refinements were made to the document based on their feedback.

3 | RESULTS AND DISCUSSION

Following a series of multidisciplinary meetings with European physiotherapists in bleeding disorders care, persons with a bleeding disorder

TABLE 1 European principles of care for physiotherapy provision in bleeding disorders

<i>Access and service provision</i>	
1	Physiotherapists should practise in partnership with other health professionals to manage and provide services to persons with bleeding disorders.
2	Access to physiotherapy should be provided to all individuals with a bleeding disorder.
3	Persons with a bleeding disorders should be able to self-refer to a physiotherapist.
<i>Assessment and treatment</i>	
4	Persons with a bleeding disorder should be offered assessment and treatment of their musculoskeletal condition and personal needs built on a shared decision-making approach.
5	Persons presenting with a bleeding disorder should be offered supported self-management as part of the management plan to recognise and develop their capability to manage their own health and take responsibilities for their wellbeing.
6	Physiotherapy assessment and care should be clearly and accurately recorded and shared between relevant members of Haemophilia Treatment Centre care teams and the person with the bleeding disorder.
7	All aspects of the physiotherapy process can be delivered in a diverse range of settings.
<i>Education and continuing professional development</i>	
8	Physiotherapists should maintain continuous up-to-date learning and professional development relevant to bleeding disorders.

and a review of publications in the field, eight core principles of physiotherapy care for persons with a bleeding disorder, listed in Table 1, were co-produced across three themes: access and service provision, assessment and treatment, and education and continuing professional development. They are presented and discussed per statement.

3.1 | Physiotherapists should practise in partnership with other health professionals to manage and provide multidisciplinary services to persons with bleeding disorders

The Chronic Care Model of the World Health Organisation (WHO) states that all persons with chronic disorders and their families should be informed about the expected course, potential complications, and effective strategies to prevent complications and manage symptoms.⁸ Thus, PWBD need to be equipped with sufficient knowledge and skills to self-manage their physical health and well-being. Bleeding disorders are disorders that have a significant degree of musculoskeletal manifestations and, as such, physiotherapists are well placed to work in partnership with PWBD and the wider multidisciplinary team (MDT) to enhance overall health and well-being of persons under their care. Comprehensive care by a multidisciplinary team of healthcare professionals including availability of a physiotherapy service is the preferred

model of care provision.⁹ Physiotherapists providing care under the umbrella of the haemophilia treatment centre is preferred.

As of yet, there remains no fully defined term of what is deemed an acceptable level of physiotherapy provision for PWBD; views range from physiotherapy being most appropriate in acute phase interventions only to physiotherapy being a profession that develops extended clinical roles and leads research.¹⁰ Recent advances in bleeding disorder treatment options and telehealth mean people are more likely to seek physiotherapy outside their Haemophilia Treatment Centre (HTC), namely, locally in the primary care setting, and may require the establishment of a 'hub and spoke' model to link back into the HTC. Timmer and colleagues¹¹ describe this as vertical integration consisting of pathways that connect community-based generalists with hospital-sited specialists. However, both primary care physiotherapists and PWBD have identified knowledge of primary care physiotherapists about bleeding disorders as a challenge to this approach.¹¹ Recommendations to support this model include: a 'named' specialised physiotherapist within the HTC; informing primary care physiotherapists about bleeding disorders by developing formal practice guidelines; improving collaboration between primary care and HTCs through establishing mechanisms for two-way and open communication, and; building a network of those with care experience in PWBD.¹¹

Physiotherapists also play a key role in peri-surgical planning and care for those undergoing orthopaedic surgery and are an important member in teams delivering interventions for complex pain management. With regards to practice guidelines, a Canadian working group of physiotherapists recently published clinical practice guidelines that can be used to educate and provide guidance to physiotherapists new to a HTC and to those in primary care outside a HTC.⁴

3.2 | Access to physiotherapy should be provided to all individuals with a bleeding disorder

The World Physical Therapy organisation describes the 'profession' of physiotherapy as the interaction between the physiotherapist (individual), patients/clients, other health professionals, families, care givers and communities in a process where movement potential is assessed and goals are agreed upon using knowledge and skills unique to physiotherapists.¹² As such physiotherapists are a key professional group involved in the triage, assessment and management of musculoskeletal conditions of PWBD. The 'profession' of physiotherapy views an individual not as their disease or related symptoms, but as a person living with a disease/ symptom of a disease,¹² that may or may not be impeding their preferred way of life in the present or the future. Physiotherapists can offer expert assessment, advice, rehabilitation, and help optimize physical activity levels, health and well-being. They are key in helping PWBD and the multidisciplinary team prevent, understand and manage the acute and persistent musculoskeletal complications across a person's life span.

The medical treatment for haemophilia has seen enormous advances within the past 20–30 years. The greater availability of efficient and safe clotting factor replacement and non-substitutive

therapies has revolutionized the physical symptoms and perception of persons with severe haemophilia.¹³ Nevertheless, significant physical impairment secondary to haemophilic arthropathy in those who did not benefit from prophylaxis during childhood, along with a fear of bleeding and exacerbating already painful joints will still require rehabilitation. Furthermore, it is now becoming clear that persons with moderate and mild haemophilia, as well as female haemophilia carriers and persons with vWD and other bleeding disorders, can develop long term joint damage and experience social and physical limitations.¹³⁻¹⁶ Van Galen and colleagues¹⁷⁻¹⁸ recently reported that a quarter of persons with von Willebrand factor activity $\leq 30U$. dl⁻¹ experience joint bleeding with most bleeding starting during childhood and associated with higher scores on the Haemophilia Joint Health Score (HJHS) and lower quality of health-related quality of life.

The cost benefit of physiotherapy provision in a bleeding disorder service model has yet to be fully evaluated. In their analysis of haemophilia physiotherapy care in the Netherlands, de Kleijn and colleagues calculated that it would cost < 1% of the country's national total budget for haemophilia to provide the most optimal physiotherapy service in HTC.¹⁹ More recently Timmer and colleagues¹¹ attempted to quantify the number of physiotherapy sessions needed to manage acute joint bleeds and muscle haematomas in their cohort, thereby providing a potential baseline for centres to use to appropriately cost and provide adequate physiotherapy services. A median of eight physiotherapy treatments following joint bleeding, six following muscle bleeding, nine for treating an episode or flare up of synovitis and fifteen for haemophilic arthropathy were reported.

3.3 | Persons with a bleeding disorder should be able to self-refer to a physiotherapist

We advocate that implementing and adopting easy and direct access to physiotherapy and where possible self-referral would enable PWBD to have maximal control over their own life in order to meet their musculoskeletal health goals, in the broadest possible way. However, barriers to accessing such care provision such as socioeconomic deprivation, education levels and insurance coverage need to be acknowledged and actively improved upon where possible.²⁰

Terms such as 'direct access' and 'self-referral' refer to ideal circumstances where physiotherapy services are available to PWBD without the requirement of a referral other than registration with a HTC. In many HTCs this approach is available to PWBD, and our view is that this should be an aspiration of all HTCs, so that PWBD can see the right healthcare professional (of choice) at the right time. In many national health service delivery systems throughout the world, the users of physiotherapy services do not require such a referral.²² In these instances, direct access to physiotherapy services is supported by national/ provincial/ regional/ state legislative frameworks and by the standards of professional practice of physiotherapists. In general practice there is a growing body of research evidence supporting the clinical and cost effectiveness of such services and their acceptability among service users.²¹⁻²² This approach to proactive, person-led access to

care is strengthened when HTCs promote and enable adequate self-management for persons living with long term, chronic conditions.¹⁰

3.4 | Persons with a bleeding disorder should be offered assessment and treatment of their musculoskeletal condition and personal needs built on a shared decision-making approach

We advocate physiotherapists and PWBD adopt a shared decision-making (SDM) approach in the clinical environment. SDM is a stepwise collaborative process that relies on reciprocal information sharing between the practitioner and patient around options available, evidence and potential benefits and harms.²³⁻²⁴ It supports the decision by people to make a single informed decision about their health or healthcare in that moment of their lives.^{23,25} PWBD need personalised knowledge and skills individual to oneself them to manage one's their life-long physical health. SDM is emerging as the preferred approach as recent studies have shown that active personalised patient engagement in designing and evaluating prophylaxis with support from the multidisciplinary treatment team has been effective in reducing bleeding and improving overall quality of life and physical activity.²³

Much of the information regarding physiotherapy available for PWBD refers to the perceived 'technical application' of physiotherapy, namely, doing prescribed exercises and manual therapy.²⁶ Early proponents of physiotherapy for PWH highlighted that the musculoskeletal complexities and limited availability of treatment for bleeding influenced intervention so that each physiotherapy rehabilitation plan was individualised with goal based, functional improvement at its core.²⁷ A systematic review by Strike and colleagues²⁸ evaluating the safety and effectiveness of exercise for PWH found interventions including at least one resistance exercise, isometric exercise, bicycle ergometry, treadmill walking and hydrotherapy produced improvement in pain, range of movement (ROM), strength and walking tolerance. Subsequent randomized controlled studies have shown exercise to improve ROM, strength, walking tolerance, gait, balance, and quality of life, in addition to decreasing pain and anxiety.²⁹⁻³¹ In a more recent review of advances in musculoskeletal physiotherapy for haemophilia, Stephensen and colleagues concluded that exercise via its effect on pain, joint ROM, strength and mobility, can have a positive impact on maximizing mobility, function as well as improving quality of life, and that programmes incorporating hydrotherapy and functional exercise appear of most benefit.²⁶ Physiotherapists have a key role in helping PWBD and the multidisciplinary team prevent, understand and manage the acute and persistent musculoskeletal complications of haemophilia.¹² They are skilled in communication approaches with those in pain or fearful of their physical state and build therapeutic relationships that are distinct from, but complimentary to, medical and nursing colleagues. Utilising a personalised shared-decision making approach with an individual, physiotherapists can offer expert assessment, advice, rehabilitation, and help optimize physical activity levels, health and well-being. Whilst regular monitoring of musculoskeletal health with a standardised tool such as the HJHS is important for

all persons with a bleeding disorder, assessment should encompass more than just a joint score and the type and timing of monitoring be personalised to the individual.

3.5 | Persons presenting with a bleeding disorder should be offered supported self-management as part of the management plan to recognise and develop their capability to manage their own health and take responsibilities for their wellbeing

Supported self-management (SSM) is when healthcare professionals, teams and services work in ways that ensure that persons with long-term conditions have the knowledge, skills, confidence and support they need to manage their condition(s) effectively in the context of their everyday life.^{32–33} Every day, PWBD, their family members and carers will make decisions, take actions and manage a broad range of factors that contribute to their physical health. SSM acknowledges this; supporting PWBD to develop knowledge, confidence and skills about their musculoskeletal health and functioning in society to make the optimal decisions and actions. We advocate for patient organisations and physiotherapists to collaborate and co-produce patient education and awareness of the importance of physiotherapy, and SSM in taking responsibility for their wellbeing.

WFH guidelines recommend a multidisciplinary review for PWBD with a potential for musculoskeletal bleeding at least annually for adults and every 6 months for children.² However, physiotherapy for PWBD should be more than just measuring the joints once per year. Delivering supported self-management involves offering coordinated and personalised care, support or treatment and supporting people to recognise and develop their own strengths and abilities to enable them to live an independent and fulfilling life. As medical treatments advance in haemophilia and other bleeding disorders, so too should support for physical health and activity for individuals to help them live the best life they want to.¹⁰ SSM is fundamental to this approach, such that PWBD are active partners in determining outcomes that are important to them and how to achieve them. There is no single approach to deciding what support to provide and how; however, what it should be is 'personalised'. Approaches may involve information provision, self-efficacy and behavioural change training that can be delivered one-to-one, in a group or utilising different technologies such as online consultations and self-monitoring.

3.6 | Physiotherapy assessment and care should be clearly and accurately recorded and shared between relevant members of Haemophilia Treatment Centre care teams and the person with the bleeding disorder

Communication with other core HTC team members is essential to confirm clinical diagnosis, shared decisions and coordinated care. This is particularly important where PWBD self-refer to physiotherapy and where care is supported in partnership with other health professionals,

locally, in hub and spoke approaches. Physiotherapy staff in all settings are required to maintain records in whatever system or format their employer specifies. A record can be on paper or in electronic format, or a mixture of both, and should include all the information relating to the health status and management of the individual. Clinic letters or digital records are acceptable, provided all elements of the assessment, intervention, judgment and treatment are recorded. A good record will enable an independent reader to understand what conversations took place, what information was exchanged, the extent of any examination performed, what treatment was provided and on what clinical reasoning decisions were made, and to monitor changes from previous visits over a longer period of time, especially as more documentation becomes digitised.³⁴

Awareness of accurate record keeping specific to PWBD such as the outcome of assessments such as the HJHS, bleed related data together with ROM, pain, function, activities and participation, is also important as it permits a 'shared language' between clinicians and PWBD. This is especially important in a rare disease setting as it enables clinical discussion with others internationally and is a good way of enabling professional development and clinical support.

3.7 | All aspects of the physiotherapy process can be delivered in a diverse range of settings

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 aims to prevent musculoskeletal impairment throughout life. In some countries we are now witnessing children with haemophilia having minimal or no joint damage participating in normal sport activities similar to their peers,³⁵ while others in less affluent countries are only beginning to see the benefits of basic physiotherapy interventions on joint health.³⁶ These contrasts can also be seen in the ageing population of persons with haemophilia, who are living longer with significant multi-morbidity and significant physical impairment secondary to haemophilic arthropathy. In addition, the success of new treatments and prophylaxis for severe haemophilia have to date not been widely applied to those with non-severe-haemophilia, vWD and other bleeding disorders in whom the potential for bleeding and subsequent chronic joint disease remains.^{14,16,37} As physiotherapy continues to assess and rehabilitate acute musculoskeletal bleeding and injuries with a view to preventing chronic changes, it is important that the other 'lifespan' issues associated with bleeding disorders, such as ageing, living with chronic arthropathy and surgery requirements are not forgotten.³⁸ Post-surgery physiotherapy is crucial in enabling a good functional outcome. Rehabilitation approaches need to be developed and tailored to help people manage these co-morbidities and achieve their activity and participation goals, and it is likely that this will involve provision in a diverse range of settings. This can include HTC, primary care, school and leisure facilities as well as delivery by technological advances, for example, telehealth, online platforms, apps and other digital delivery options. E-health and in

particular remote monitoring is emerging as a future direction of healthcare. In the context of self-management and improvement of health, telemedicine and tele-rehabilitation is an attractive option for PWBD to improve health status monitoring and treatment satisfaction and has been shown to be acceptable to both patients and healthcare professionals, particularly for those who live far away from their HTC.^{39–40} Additionally, physiotherapists should work with and provide advice and education to other practitioners such as Pilates and yoga teachers, coaches and sports trainers to promote physical activities and well-being in PWBD. Close working and optimal understanding with patient organisations are also important to ensure widespread engagement in physical health promotion.

3.8 | Physiotherapists should maintain continuous up-to-date learning and professional development relevant to bleeding disorders

A recent survey of the practice of physiotherapists managing PWBD in Europe highlighted the ongoing need to establish a pan-European network of physiotherapists to support collaboration and education for physiotherapists working in the bleeding disorders community.⁶ Currently, education about bleeding disorders is not included in undergraduate training. Supporting opportunities for physiotherapists' attendance at national and international meetings and workshops enabling formal education as well as networking is essential to facilitate continued learning and skills development. Bleeding disorders are rare diseases; therefore, we advocate that physiotherapists are given equitable access to learning and development opportunities including further education attendance at congresses on par with medical and nursing colleagues. Only by integrating physiotherapy fully into care provision can comprehensive care be truly provided to PWBD.

4 | CONCLUSION

Bleeding disorder care is witnessing a significant shift towards a new era of potentially life changing medical treatments which offer a future of minimal or no bleeding, thus changing the role of the multidisciplinary team. Physiotherapists have skills in health promotion, injury prevention, treatment/intervention, and rehabilitation to maximize movement, function and well-being. It is essential that physiotherapists work with PWBD in the co-design of future musculoskeletal services. When given the opportunity to discuss what matters to them, PWBD are able to identify pragmatic life, clinical and research goals that they want to be active participants in: physical function and well-being, limiting disease progression and having active life choices rate highly.

These principles of care for physiotherapy provision co-produced by EAHAD and EHC outline optimum standards of practice in order to achieve personalised patient-centred care for physical health in which prevention, SDM, and supported self-management are advocated.

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CONFLICT OF INTEREST

All authors have no conflict of interest in respect of this work.

DATA AVAILABILITY STATEMENT

This is a consensus review and data sharing is not applicable to this article as no datasets were generated or analysed during the current study.

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