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LETTER TO THE EDITOR

Comprehensive care on paper only? The challenge for physiotherapy provision in day to day haemophilia practice

Dear Editor

Comprehensive care for people with haemophilia (PWH) is endorsed by the World Federation of Haemophilia (WFH), and it is now the preferred model of care provision for people with inherited bleeding disorders. This overarching approach to care provision is both a rapid acute service as well as a preventive medicine approach and has proven successful in terms of outcomes related to morbidity and mortality, quality of life and general health, even with the associated higher costs for the expertise required.[1] Centres should have specialist haematologists/paediatricians, specialist nurse and physiotherapists, 24-hour laboratory and clinical support, as well as access to specialist orthopaedics, dental and HIV/hepatology services.

The WFH describes physiotherapy for PWH as being a lifelong requirement, whereby assessment, education and treatment are provided for acute bleeds and chronic musculoskeletal (MSK) complications with a range of physical medicine techniques. This description serves only to describe physiotherapy as an intervention. The World Confederation of Physical Therapy 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.[2] It would appear that the full set of competencies of the physiotherapist are not being recognized or utilized in haemophilia treatment centres.

Haemophilia is a disease that has witnessed enormous advances in medical treatment 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 of haemophilia. Such advances also require that clinicians understand the mechanism of action of newer medications on haemostasis and MSK health.

However, these advances in haemophilia treatment have brought in to focus potential inadequacies of a 'cradle to grave' approach that tends towards a biomedical model of care focussing on medical treatment (factor concentrates or non-substitutive therapies). With global inequity of access to such care, we are now witnessing children with haemophilia having minimal or no joint damage participating in normal sporting activities similar to their peers,[3] with others in developing countries only beginning to see the benefits of basic physiotherapy interventions on joint health and well-being.[4] The latter example with a younger population with limited access to treatment contrasts further against the emerging clinical issue of an ageing population of men with haemophilia, who are living longer with significant multi-morbidity and significant physical impairment secondary to haemophilic arthropathy.

Those adults on regular treatment are eager and willing to participate in higher levels of physical activity (even with their joint damage), but remain fearful of bleeding and exacerbating already painful joints.[5] It is acknowledged that PWH find it difficult to distinguish between acute haemarthrosis joint pain and pain associated with haemophilic arthropathy. Acute pain significantly impacts quality of life and is greater when present on a backdrop of ongoing persistent pain.[6] An increase in age is also associated with a decrease in quality of life predominantly related to haemophilia-specific MSK complications, that is, joint disease. Management of acute and ongoing pain as well as improved differentiation between acute and chronic joint damage symptoms was identified by PWH among the most important research objectives that mattered to them.[7] Physiotherapists can help with the aforementioned issues, as long as they are adequately represented in the haemophilia team with respect to dedicated time, training and resources.

Haemophilia is a disease that has a significant degree of MSK manifestations and as such, physiotherapists are well placed to work in partnership with PWH and the wider multidisciplinary team (MDT) to enhance overall health and well-being of people under their care. As of yet, there remains no fully defined term of what is deemed an acceptable level of physiotherapy provision for people with haemophilia. The perception of the role of physiotherapy in haemophilia remains unclear, ranging from a view of it being most appropriate only in an acute phase intervention [8] to a profession that develops extended clinical roles and leads research.[9] These extended roles are underpinned by competency requirements and can include performing MSK ultrasound, prescribing orthoses, working with physical education teachers in schools and radiological requesting.

Much of the information available for PWH refers to the perceived 'technical application' of physiotherapy, that is, doing prescribed exercises. Whereas the 'profession' of physiotherapy views an individual not as their disease and symptoms of it, but as a person living with a disease/symptoms of a disease, 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 skilled in communication approaches with those in pain or

On behalf of the EAHAD Physiotherapy Committee

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fearful of their physical state. They build and maintain therapeutic relationships that are distinct from, but complimentary to, medical and nursing colleagues. They are key in helping PWH and the multidisciplinary team prevent, understand and manage the acute and persistent MSK complications of haemophilia.

Although the comprehensive care model of haemophilia care is endorsed by most, and for physiotherapy services in particular, the level of service provision varies greatly. Whilst a widely quoted tenet of clinical services, it remains that almost 30% of centres in Europe have 'sporadically available' physiotherapy, although the quality and amount of 'consistently available' physiotherapy in the remaining 70% are unknown.[10] Of greater concern is that following a national peer review of clinical services, 60% of comprehensive care and haemophilia centres in the UK have 'insufficient' physiotherapy provision for PWH.[11] This is despite the national service specification stating physiotherapy as a key function of a comprehensive care centre.

The cost benefit of physiotherapy provision in a haemophilia service model has yet to be fully evaluated, although some have made attempts to quantify just how little that extra cost may be to provide good services. The Canadian Hemophilia Society highlighted that a primary focus on clotting factor concentrate (CFC) cost savings saw a lack of funding for human resource that included physiotherapists. This meant that centres had limited ability to be able to fully evaluate health outcomes associated with expensive coagulation therapies, a situation seen as critical given the evolution of clinical practices with newer treatments. They estimated an investment of 2%-3% of the savings made on CFC prices being sufficient to provide countrywide staffing needs including physiotherapy.[12] Similarly in their analysis of haemophilia physiotherapy care in the Netherlands, De Kleijn and colleagues[13] calculated that it would cost <1% of the country's total budget for haemophilia to provide the most optimal physiotherapy service for PWH.

Call to action: We call upon funders, medical professionals, centre directors and patient organizations to come together to enable the development and provision of physiotherapy services fit for the present and the future for all those with inherited bleeding disorders. The EAHAD physiotherapy committee encourage services to instigate a comprehensive root and branch review of physiotherapy services, taking into account the possible barriers and facilitators to their current service models (Figure 1). In other MSK care settings, physiotherapists who are enabled and supported to work in enhanced clinical roles in complex situations can support patients to make decisions that lead to successful clinical outcomes and high levels of satisfaction. We encourage therapists to critically examine their own practice, as well as asking centre directors and therapy managers to see the value of a well-defined physiotherapy service within haemophilia. We call on clinicians to look at ways of working

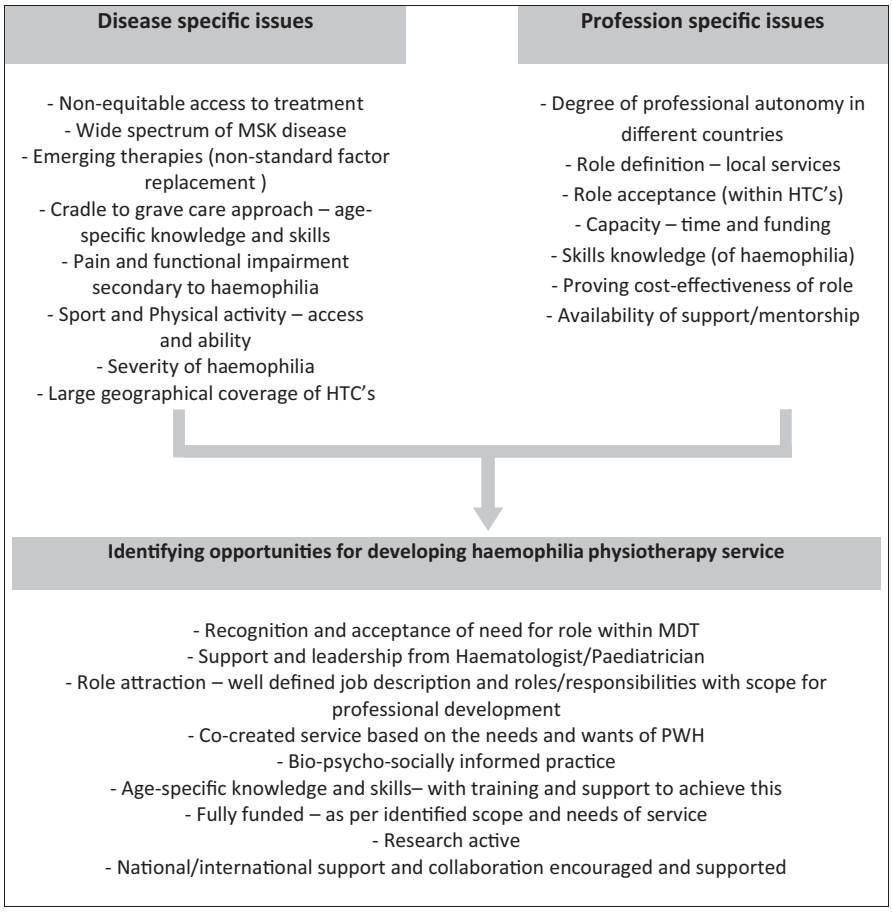


FIGURE 1 Recommendation for reviewing provision of a local haemophilia physiotherapy service

together, learning from each other and understanding how medical and physiotherapy roles can complement and enhance patient care. We advise that services are co-designed with PWH to ensure that a true vision of what matters to them is produced. As a rare disease and specialist service, we ask that physiotherapists are given equitable access to learning and development opportunities including further education attendance at congresses on a par with medical and nursing colleagues. Only by integrating physiotherapy fully into care provision can you say that you are providing comprehensive care to PWH.

It remains unclear if new treatments (EHL's, non-substitutive therapies) will considerably reduce the frequency of bleeding in patients treated. Indeed, even if bleed reduction/eradication is achieved in the short term, the medium- and long-term issues associated with pre-existing joint damage (and function and quality of life issues) may remain. In this context, the role of the physiotherapist must and will evolve towards MSK health surveillance alongside a preventive as well as a curative role.

When given the opportunity to discuss what matter to them, PWH are able to identify pragmatic life, clinical and research goals that they want to be active participants in. Looking at those themes identified by such work, it is clear that physical function and well-being, limiting disease progression and having active life choices rate highly—are what physiotherapists are best able achieve when being part of a comprehensive haemophilia care team.

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