UK Standards of Care

Service Provision of Physiotherapy For Children with Haemophilia & other Inherited Bleeding Disorders

Service Provision of Physiotherapy for Children with Haemophilia
Authors: Nicola Hubert & Stephen Classey
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Background

The Physiotherapy Standards for Haemophilia care were originally written by the Haemophilia Chartered Physiotherapists Association (HCPA) to assist physiotherapists with the management of patients with haemophilia & related bleeding disorders in 1996 (1). These were reviewed and updated in 2002 (2) and again in 2012 (3). Regular review of the standards of care has since has been carried out. The current Standards were endorsed by the UK Haemophilia Doctors Association (UKHCDO) in 2017. There is no uniform model for the provision of physiotherapy for children with haemophilia and levels of provision currently vary between haemophilia centres.

The NHS Service Specification for Haemophilia suggests a model of care where patients have access to, and regular review by, experienced specialist physiotherapists trained in line with the HCPA (4). This perspective is endorsed by both the UKHCDO musculoskeletal guideline (6) and the WFH guideline for the management of Haemophilia (7). More recently a set of quality standards have been established for the care of people with inherited and acquired haemophilia and other bleeding disorders by the UKHCDO Peer Review working party in partnership with the West Midlands Quality Review Service. These standards recognise physiotherapy as a core component of the haemophilia comprehensive care team (5). The main tenants of practice are too:

- Undertake assessments and initiate interventions to prevent or minimise the risk of musculoskeletal injury/recurrence of a previous injury
- Ensure ongoing monitoring of joint health
- Facilitate good physical function and participation in activities
- Provide rehabilitation of acute, subacute and chronic manifestations of musculoskeletal disease
- Provide activity and health education and to promote participation amongst patients with haemophilia.

This document aims to provide a ‘framework’ for the establishment of standards for provision of physiotherapy to children with haemophilia, and to compliment the Service Provision of Physiotherapy for Adults with Haemophilia & Inherited Bleeding Disorders - UK Standards of Care (8).

STANDARD 1- Physiotherapy provision

- *Children should have access to a physiotherapist with specialist knowledge of haemophilia, paediatric musculoskeletal conditions, normal paediatric variants and child development (4).*

- *The physiotherapist should be a member of the Haemophilia Chartered physiotherapists Association (HCPA) and be able to attend / undertake training to ensure the continuation of best practice and provision of quality care (4).*

- *The specialist physiotherapist should have dedicated/protected hours and flexibility within this to manage their haemophilia caseload/service.*

- *The specialist physiotherapist should be supported in continuing education activities that will ensure awareness of current best practice, and current research and developments within haemophilia. Including knowledge and skills of physiotherapy practice unique to this area (i.e. up to date assessment techniques and relevant outcomes) and medical advances (i.e. emerging new medical treatments) (9)*

STANDARD 2- Referral and triage

Children referred for physiotherapy should be seen within the appropriate time frame according to the clinical status and have access to physiotherapy telephone triage and advice.

- ***Acute condition referral****- a patient should be reviewed as soon as clinically possible, normally within 24 hours (10,11,12). This could be a telephone triage or face to face review as an outpatient or inpatient.*

It is acknowledged that when a referral occurs prior to a bank holiday / weekend, review should be the next available and clinically appropriate appointment.

- ***Chronic condition referral****- a patient should be offered an appointment which will be within 2 weeks.*

Physiotherapy management may take place within the local paediatric physiotherapy setting as deemed clinically appropriate. The overall responsibility of physiotherapy management should remain with the specialist physiotherapist with effective communication between professionals.

STANDARD 3- Physiotherapy clinical management

Physiotherapists working with children with haemophilia should provide the highest standards of clinical care.

Clinical care should be consistent with the Quality Assurance Standards for Physiotherapy Service Delivery documented by the Chartered Society of Physiotherapy (13), and in line with the standards of conduct, performance and ethics, set out by the Health Care Professions Council (14).

Patient care and clinical management where possible should be evidence based and informed by clinically suitable guidelines. A suggested resource is Physiotherapy Management in Haemophilia (15).

Each physiotherapy episode of care should:

- *Include a thorough neuro-musculoskeletal assessment to monitor joint health & function and participation.*

- *Show evidence of appropriate outcome measures throughout the assessment, management and review process (9,10,11,12).*

- *Incorporate medical specific haemophilia questioning - diagnosis and factor level, presence of inhibitor, treatment method, bleeding history, compliance.*

- *Undertake onwards referral to other specialties such as radiology, rheumatology or orthopaedics when clinically appropriate.*

STANDARD 4- Regular multidisciplinary review

As stated within the National Service Specification and Quality Standards, all children with haemophilia should be offered regular clinical multidisciplinary review (4, 5). The physiotherapy review should form part of a seamless multidisciplinary review of the patient, with relevant information being shared amongst team members.

- *At minimum, patients with severe/ moderate haemophilia should be reviewed by a physiotherapist 6 monthly & those with mild haemophilia annually where clinically required (5).*

- *Children with frequent bleeding episodes, coagulation factor inhibitors, or complications of bleeding episodes such as symptomatic arthropathies may require more frequent review (10,11, 12).*

- *Patient review will include the use of standardised & validated clinical examination scores and assessment tools, e.g the Haemophilia Joint Health Score (HJHS) (16), which should be incorporated into the prospective assessment of patients receiving prophylaxis (16,17,18).*

- *The use of validated functional and psychosocial outcome measures for children with haemophilia is endorsed as part of the regular review process when relevant (18), and should consider the domains of impairment, activity and participation and function acknowledged in the World Health Organisation (WHO) ICF framework (19).*

- *A record of bleeding events, time off school and activity participation should be noted (18).*

- *Those with a known history of intracranial haemorrhage should be monitored using appropriate standardised assessments to identify any sequale, if problems are identified, these will be discussed within the multidisciplinary team to facilitate management or onward referral as appropriate (22).*

- *The review should involve identification and action (where necessary) on age appropriate health related issues e.g development, obesity, bone health.*

- *Copies of the assessments, scores and physiotherapy recommendations should be shared within the multidisciplinary team, local therapy team and appropriate multiagency teams involved with the child and entered on required databases.*

STANDARD 5- Education

Clear information should be provided related to how to manage all aspects of bleed risk, musculoskeletal health and well being of the child.

Information to the patient/carer and other relevant agencies should be provided based on the clinical assessment of the patient and most up to date evidence (6,15).

Education may include*:*

- *The role of physiotherapy within the comprehensive care team in the management of haemophilia.*
- *Identification and management of acute intracranial and musculoskeletal bleeding episodes.*
- *Long term implications of the impact of haemophilia on the musculoskeletal system.*
- *The contribution of muscle power and proprioception in providing joint protection.*
- *Recognition of normal musculoskeletal variants and child development.*
- *Promoting the impact and role of physical activity, exercise and sport on a child's health and offer support in choosing activities (20).*

STANDARD 6- Transition

The physiotherapist should assist in the seamless transfer of haemophilia care to the adult setting, with adult services taking joint responsibility with children's services for transition and be guided by national policy and paperwork (21).

This may include:

- *Planned attendance at joint clinic review with the adult team prior to transition to provide a complete and comprehensive handover of care.*

- *Providing relevant documentation with any standardised assessments, previous history and management.*

- *Promotion of independent management of the individual's condition, within school, further education and career.*

- *Ensuring contact details are given to the adult physiotherapy team.*

References

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