Physiotherapy Management of Haemophilia

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Forewords

Haemophilia is a lifelong inherited bleeding disorder characterized by severe, spontaneous bleeding resulting in chronic, painful joint deformities. Without treatment, individuals with haemophilia will die in childhood or early life. The development of safe and effective clotting factor concentrates has enabled newly diagnosed children with haemophilia to be treated safely with prophylaxis, or regular injections with clotting factor concentrate, to stop bleeds, particularly joint bleeds.

However, there is a generation of patients with haemophilia who had poor treatment in their childhood and now have major joint disability requiring physiotherapy support and often surgical intervention with joint replacements. In the developed world, high purity concentrates have enabled peri-operative delivery of concentrate factor by continuous infusion, which gives added safety, not only for the period of surgery, but also for the period of more intensive physiotherapy postoperatively.

In contrast, it has been suggested that 80% of those with haemophilia in the world do not have access to adequate medical care. Many of such individuals are undiagnosed, untreated and therefore suffer enormously. Although expertise of orthopaedic care cannot always be provided for such patients because of the constraint of lack of clotting factor provision for economic reasons, physiotherapy is a relatively less expensive option. Fortunately in the less resourced parts of the world, the provision of skilled personnel is sometimes better than in the so-called developed world because of the relatively lower salary paid. Consequently, as a generation of children grows up on prophylaxis, healthcare professionals will have much to learn from their more experienced counterparts in the less resourced countries.

The patient with haemophilia presents a particular challenge for those providing musculoskeletal care: quality of life can be

transformed by such care. We all hope that there is a generation of children with haemophilia growing up who will not have musculoskeletal problems — but until then, this comprehensive book *Physiotherapy Management of Haemophilia* will provide a useful reference for those providing physiotherapy care with the comprehensive care team.

Professor Christine Lee
Haemophilia Centre and Haemostasis Unit,
Royal Free Hospital, UK

Despite the extraordinary advances in the haematological prophylaxis and treatment of haemophilia, the musculoskeletal problems of this condition are still very common. Only 20–30% of the world population have access to adequate haematological management, mainly because of the high cost of replacement products. It has been demonstrated that with prophylaxis from 2 to 18 years, severe haemophilia can be transformed into mild haemophilia. Thus, in the developed countries, orthopaedic surgery is less often required in persons with haemophilia, although it is still necessary from time to time. Although I am the only orthopaedic surgeon operating on these patients in Spain, the musculoskeletal treatment of haemophilia only takes 5% of my professional time. On the contrary, in those countries without adequate economic resources, the orthopaedic complications of haemophilia still continue the same as they did 25 years ago.

The main complications of haemophilia from the musculoskeletal perspective include: haemarthroses, synovitis, articular flexion contractures, axial malalignment of the limbs, haematomas, pseudotumours and haemophilic arthropathy. All of these can lead to painful episodes and also to a progressive multiarticular disability, with tremendous psychological, family and professional implications. In my opinion, the ideal treatment of musculoskeletal problems in haemophilia should include:

1 an early and continuous haematological prophylaxis to try to avoid haemorrhages;
2 an aggressive haematological treatment of bleeding episodes when they occur;
3 the immediate aspiration of articular bleedings as soon as they are detected;

4 the early performance of procedures for synovial destruction (synoviorthesis, arthroscopic synovectomy, open surgical synovectomy) as soon as a synovitis is diagnosed;
5 an early and aggressive rehabilitation programme to avoid the development of fixed articular contractures.

Physiotherapy is particularly important in the prevention of fixed articular contractures which if left untreated will require further orthopaedic procedures. The importance of post-operative physiotherapy, after synovectomies, tendon lengthening or tendon releases, osteotomies, joint arthroplasties and surgical removal of pseudotumours must also be emphasized.

The close co-operation between physiotherapists, physicians specialized in rehabilitation and orthopaedic surgeons is paramount for the adequate treatment of musculoskeletal problems in haemophilia today. In my opinion, there has been, and there still is, a fruitful intellectual co-operation between myself, and Brenda Buzzard and Karen Beeton within the endeavour of the World Federation of Haemophilia. There is no doubt that such a long-lasting co-operation is the reason why the co-editors of this book have invited me to write this Foreword. I am sure that this excellent book, with well-known contributors from the UK and the rest of the world, will be of great value in the understanding of the most recent concepts in the physiotherapy management of haemophilia. The benefit will be not only for physiotherapists, but also for physicians specializing in rehabilitation, rheumatologists, orthopaedic surgeons and haematologists interested in the treatment of such a devastating condition. I am sure that its contents will give fruitful physiotherapy information for many years. The editors and contributors to this book are to be congratulated. We will gain immeasurably from this compilation of timely advances, enabling us to better serve our haemophilia patients.

E. Carlos Rodriguez-Merchan MD PhD
Haemophilia Centre, La Paz University Hospital, Spain

Preface

The management of haemophilia has changed enormously over the last 30 years. Prior to the widespread availability of factor replacement, patients suffered many bleeds in the musculoskeletal system and subsequently developed arthropathy affecting multiple joints. Today the outlook is more optimistic. Early and adequate treatment of bleeds and prophylactic programmes has ensured that recovery of bleeds is more complete and the devastating effects of arthropathy are minimized. Despite these developments many patients still present with bleeds, chronic synovitis and arthropathy due to inadequately treated bleeds in the past and therefore physiotherapy remains an important aspect of treatment.

Alongside these changes has been the development of the physiotherapy profession. Physiotherapists have increasing responsibility for the management of their patients and also have an increasing array of concepts and modalities with which to treat patients with haemophilia.

This book aims to provide a comprehensive overview of physiotherapy treatment concepts and management strategies currently available that can be incorporated into the management programmes for patients with haemophilia. It has been written by physiotherapists with a broad range of experience of haemophilia based on their clinical experience and supported by evidence from the literature when available.

We hope that this book will be useful in providing new ideas for physiotherapists who regularly treat patients with haemophilia as well as a source of reference for those who may only treat a few patients. We also hope that it will be a valuable source of information for other members of the comprehensive care team, the doctors, nurses, orthopaedic surgeons and counsellors who are also involved in managing these patients. Overall our

ultimate aim is that this book will highlight the vital role that physiotherapy can play in the care of these patients in improving musculoskeletal function.

Brenda Buzzard
Karen Beeton

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