

The role of the physiatrist in the haemophilia comprehensive care team in different parts of the world

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Summary. The role of the physiatrist, as a member of the multidisciplinary haemophilia comprehensive care team, is to prevent and treat activity limitations and restriction of participation on the part of the patient. This role is threefold: (i) provide education to the patients, families and healthcare providers to detect disabling injuries and take adequate precautions; (ii) provide specialized treatment of musculoskeletal disabilities striving for the highest level of

functionality and (iii) Stimulate the patient's full participation in socio-economic activities of his country. Prominent physiatrists from different parts of the world describe the situation in Armenia, China, Egypt, France, Indonesia (and the Philippines), the Netherlands and South America.

Keywords: haemophilia, ICF, participation, physiatrist, rehabilitation

Introduction

Patients with haemophilia suffer from repeated bleeding episodes unless they are adequately treated with clotting factor. Repeated haemarthroses result in joint damage with pain and limited range of motion and muscle wasting. This results in impairments of the musculoskeletal system, which cause problems for patients in their activities of daily living, work, education and hobbies. The physiatrist has a role in the prevention and treatment of these problems. The World Health Organization (WHO) expert committee on disability prevention and rehabilitation defines rehabilitation as: all measures aimed at reducing the impact of disabling and handicapping conditions and at enabling the disabled and handicapped persons to achieve social integration. Rehabilitation aims not only at training dis-

abled and handicapped persons to adapt to their environment but also at intervening in their immediate environment and society as a whole in order to facilitate their social integration. The committee furthermore states that: the disabled and handicapped themselves, their families and the communities they live in, should be involved in the planning and implementation of services related to rehabilitation [1]. This indicates that the physiatrist will have to enable and stimulate the patients to take responsibility for themselves.

Definitions and context

In this context the committee defined the following terms:

Impairment: Any loss or abnormality of psychological, physiological or anatomical structure or function.

Disability: Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

Handicap: A disadvantage for a given individual, resulting from an impairment or a disability that limits or prevents the fulfilment of a role that is

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normal (depending on age, sex, and social and cultural factors) for that individual.

The physiatrist (specialist in physical medicine and rehabilitation) is the pre-eminently suitable medical specialist, who can assess the impact of disease on the functioning of the individual patient.

Disability prevention relates to all preventive measures aimed at:

- 1 reducing the occurrence of impairments (first level prevention),
- 2 limiting or reversing disability caused by impairment (second level prevention), and
- 3 preventing the transition of disability to handicap (third level prevention).

The physiatrist acts on the second and third levels of prevention.

Since 1981, extensive discussions have taken place, which have led to a change in approach from negative (with focus on which activities the patient is not able to perform and how much he is handicapped) to positive (with focus on what are his functional abilities and in what way is he able to participate in society).

In 2001, the WHO adopted the International Classification of Functioning, Disability and Health (ICF; <http://www.who.int/classifications/icf/site/icf-template.cfm>), which is a revision of the International Classification of Impairments Disabilities and Handicaps (ICIDH). In the ICF, functioning and disabilities are described on the level of body functions and structures, activities and participation. Body functions and structures relate to physiological functions and anatomical parts of the body. Activities relate to the execution of a task or action by an individual. Participation relates to the involvement of an individual in a life situation [2].

Functioning and health are not only associated with the underlying disease but also with, and influenced by, personal and environmental factors [3].

Environmental factors relate to the component, which describes the physical, social and attitudinal environment in which this individual lives and conducts his life. Personal factors are the particular background of an individual's life and living and are internal to this individual (including gender, race, age, etc.).

Application of the different levels of this context to haemophilia:

Health condition: the clotting defect.

Body structures: haemarthrosis and arthropathy.

Body functions: active range of motion (AROM), muscle strength, coordination.

Activities: personal hygienic care (home treatment with clotting factor), getting up from a chair, walking, cycling.

Participation: fulfilling one's social role like taking part in family life, attending school, employment.

Quality of life, in its multidimensional vision, effectively includes the aspects related to the family and the society in which this person is included and the social support available for him. The ICF Core set developed by the ICF Research Branch in Munich (<http://www.icf-research-branch.org/index.htm>) is the most complete version for the assessment of the haemophilic patient.

The role of the physiatrist

The physiatrist takes all the above-mentioned aspects into account when making the rehabilitation diagnosis and treatment plan. He analyses the impact of the disorder or disease on body functions and structures and assesses the functional abilities of the patient. He analyses the activities and participation of the individual in the context of this individual's life and living. With these components he makes a plan to prevent and treat activity limitations and restriction of participation. A multidisciplinary team is indispensable in this process.

The physiatrist takes the patient's history orally (measuring pain with a VAS scale) and performs a physical examination with emphasis on the musculoskeletal system (measuring AROM with a goniometer), and also he will observe the patient when undressing, dressing, rising from a chair, getting on and off the couch and walking (if needed this can be made more objective with the Timed Up and Go test and 50-m walking test). There have been several instruments described, which he can use to measure the health status of patients with haemophilia. The patients' perceptions on their functional abilities can be measured with the haemophilia activities list (HAL) [4].

The Functional Independence Score in Haemophilia (FISH) is a performance-based instrument to measure activities for patients with haemophilia. It incorporates seven activities in three categories (self-care, transfers and locomotion) [5].

The physiatrist has a role by creating awareness that physiotherapy and rehabilitation (next to availability of safe clotting factor) are very important for the treatment and rehabilitation of patients in the developing countries. Locally available medical and

social systems and materials should be used for both education and aids and adaptations. Trainers must be trained to develop local treatment protocols. Persons with haemophilia and their families need to be educated and trained to do exercises. Important treatment modalities are management of pain, active muscle-strengthening exercises, combined measures and exercises to regain range of motion, training, proprioception and coordination functional training and orthotics and shoe adaptations [6].

Historical aspects

Since ancient times, medicine in Egypt included physiotherapeutic measures. Physiotherapy was depicted in a relief tomb in Saqqara showing massaging of a shoulder and a knee. Heliotherapy (exposure to ultraviolet sunrays) was mentioned in Ebers Papyrus for pain relief '*To relieve any painful part the body is anointed and exposed to the sun*'.

The Kalup Papyrus describes treatment by mud and clay '*Thou shalt do for it: rub her feet and legs with a mat (mud and clay) until she is well*'.

Hydrotherapy (treatment by water) was also practiced. A sanatorium near Dendara temple has chambers equipped with basins. Water was poured over a statue, then flowed down a canal into the basins.

The therapeutic property of Egypt's climate has been mentioned since the Greek era. Socrates, the founder of climatic physiotherapy, referred to this fact in his famous papers entitled Egypt and Climatic Therapy. He advised people to go to Egypt and enjoy its warm weather and refreshing sea breeze.

Tourist sites offering curative services in Egypt include Helwan, Ein el Seera, Hurghada, Fayyoun, Oasis, Aswan, Sinai, Safaga on the Red Sea coast. Sanatoria were built in areas with physiotherapeutic features such as warm water and mineral and sulphur springs or those rich in curative warm sand and clay.

In Europe, the need for rehabilitation for war victims became an issue during the First World War. In France this resulted in 150 private institutes coordinated by the office National de Mutilité reformée de la guerre. In England, Queen Mary's hospital for the limbless was opened in 1915. After the First World War, there was less interest in rehabilitation. During the Second World War and shortly after there was a great need for rehabilitation. In 1944, Sir Ludwig Goodmann opened a special clinic for patients with paraplegia and tetraplegia in Stoke Mandeville. In the industrial rehabilitation centre in Egham and the government training centre in Hounslow in England and the military rehabilita-

tion centre Aardenburg in Doorn, the Netherlands, for instance, the main goal was to get soldiers back to work [7]. To date the official title of the speciality in Europe is 'physical and rehabilitation medicine' as defined under the European directive in the Journal of the European Union (EU). It goes under a variety of three names in different countries: Rehabilitation Medicine in UK and The Netherlands, physical and rehabilitation medicine (PRM) in France and Germany and physical medicine and rehabilitation in Spain and Turkey. The general structure of PRM services across Europe is fairly similar despite the differences between healthcare systems. PRM is recognized as a core service in each of the 28 member states of the Greater European region. Availability of PRM specialists has demographic variations; it is 0.27 per 100 000 pop. in UK, 1.65 in the Netherlands, 2.97 in France, 3.85 in Spain, to 6.80 in Croatia [8].

Physical and rehabilitation medicine and the role of the physiatrist in relation to haemophilia treatment

The first author (LH) has invited prominent physiatrists from different parts of the world to describe the situation in Armenia, Brazil, China, Egypt, France, Indonesia and the Netherlands.

The development of physical medicine and rehabilitation in Armenia

Rehabilitation medicine in Armenia was established by US NGO 'Project HOPE', following the devastating earthquake in 1988. In 1989, Project HOPE signed a 5-year agreement with the Ministry of Health of Armenia to establish the paediatric rehabilitation programme. Its goal was to train physical medicine and rehabilitation doctors, physical and occupational therapists, nurses and orthotists. This was the first step towards team work. Before the start of Project HOPE, only a physiotherapeutic approach (modalities) and some exercises (Soviet approach) were available for treatment of patients with disabilities.

Gradually the rehabilitation team was extended and speech therapists, psychologists and special educators were included too.

During these years, step-by-step, more and more children with different chronic conditions and disabilities were included, such as cerebral palsy, meningomyelocele (spina bifida), traumatic brain injury, spinal cord injury, and different other orthopaedic problems. Treatment of adults was also started.

Since 2005, patients with haemophilia began to get rehabilitation treatment.

In 2003 the World Federation of Hemophilia (WFH) came to Armenia and started to cooperate with our Association of Hemophilia and with the Institute of Hematology. In 2004, the haematologist was sent to Minneapolis, USA, for training. Since 2005, specialists from USA and Canada have come to Armenia twice a year, organizing lectures and workshops locally and seeing patients along with local specialists. In 2005, the WFH sponsored a physiatrist and physical therapist to get training at the Minneapolis Hemophilia Centre, which gave them a good practical start to work with people with haemophilia. In 2007, the author (LM) participated in the 10th WFH Musculoskeletal Congress in Stresa, Italy.

At the Institute of Hematology, the Haemophilia Centre was opened officially in February 2007. The centre has registered 206 children and adults with haemophilia.

The multidisciplinary team includes a haematologist, physiatrist, physical therapist and nurse. Combined clinics are organized once a month. Patients seen at the haemophilia centre are taught an appropriate home exercise programme and physical activities. In the Rehabilitation Centre, the treatment of children who need rehabilitation is organized. The team educates these people and their families.

The main problem in Armenia is the non-availability of the factor VIII (FVIII). The Armenian Association of Hemophilia provides patients with some amount of FVIII, but it is too little to prevent complications. The government also provides the Centre with FVIII: 60 000 IU a year, which is 6% of the amount of factor needed. Because of the above limitations, about 80% of people with hemophilia (PWH) have musculoskeletal problems, especially haemarthroses and other complications.

The second important problem is the shortage of orthopaedic surgeons trained for haemophilia treatment. The patients who need surgery cannot undergo an operation because of the lack FVIII and lack of qualified orthopaedic surgeons. With the help of WFH, training of orthopaedic surgeons to treat the patients with haemophilia will be planned.

Plans for the future are to organize outreach clinics in different regions of Armenia to consult the patients locally, to educate professionals and patients, to translate a booklet for patients and their families, and to organize comprehensive teams in Yerevan and in the different regions of Armenia.

Rehabilitation for haemophilia in China

China is estimated to have about 100 000 haemophilia patients, but only 4971 have been diagnosed and registered by 2007. Over 95% of PWH in China are receiving nil or minimal treatment. The development of haemophilia care in China began after a WFH Centre Twinning project began in China in 1997, particularly after WFH identified China as a priority country for development in 2000. An outcome of the twinning was the establishment of the Hemophilia Treatment Center Collaborative Network of China (HTCCNC) in 2004 when attention on comprehensive haemophilia care began. The six members of HTCCNC (Beijing, Tianjin, Jinan, Hefei, Shanghai, and Guangzhou) have complementary strength and collaborate to move haemophilia care forward in China.

In 2003, Dr Lixia Chen, a physiatrist in PUMCH visited Calgary, Canada, on a WFH physiotherapy fellowship. After the training, she established at PUMCH the first haemophilia physiotherapy and rehabilitation clinic in China. In order to promote and develop rehabilitation and physiotherapy care within the framework of comprehensive care, a Working Group consisting of physiatrists and physiotherapists from the six HTCCNC centres was formed in 2005. The goal of the Working Group is to promote rehabilitation and physiotherapy care for PWH in China. The initial aim was to promote awareness and training from a clean slate.

For the purpose of training the professionals, two conferences were held in 2005 and 2007 supported by the WFH and the Canadian Hemophilia Society (CHS). At the 2007 Conference, Kathy Mulder, Chairperson of WFH Musculoskeletal Committee, was invited to conduct workshops for professionals and patient groups. A third conference is planned in 2008. At present, in most of the six HTCCNC Centres, basic rehabilitation services including physiotherapy and occupational therapy can be provided to PWH, and in some centres, orthotics and psychotherapy are available. We also focus on education for patients and their families. In 2007, we published a booklet for patients covering bleeding management, pain management and function restoration after a bleed, including strengthening and stretching exercises to improve range of motion and recommendations for safe sports. A self-learning companion video CD providing practical and easy-to-follow demonstrations was also developed. Three thousand copies of each were distributed to patients for home use. We also provide physiotherapy and rehabilitation consultation to PWH and their families through the

website of Haemophilia Home of China. We collaborated with the CHS, WFH, Hospital for Sick Children (Canada) and Novo Nordisk Haemophilia Foundation on an education campaign and development of instruments appropriate for China for long-term outcome measurements for impairment, quality of life, training for professionals, etc.

But the challenges are still great. In most areas of China, professional experts on rehabilitation for haemophilia are extremely scarce, institution-based rehabilitation facilities and comprehensive haemophilia centres are not common, and community-based rehabilitation service for haemophilia is mostly unavailable. Recognition of the role of rehabilitation and physiotherapy for PWH is insufficient among both healthcare workers and patients even in major cities.

Thus, in 2008 and beyond, we plan to train experienced physiatrists and physiotherapists as trainers and teachers to conduct more workshops for other professionals in physical medicine and rehabilitation across China. Outreach programmes for professionals and patients and continuing education programmes for professionals will be developed. We also aim at developing practice standards and guides and to produce a practice manual on haemophilia physiotherapy appropriate for use in China.

Rehabilitation medicine in Egypt

According to the UN, Egypt is ranked 120 out of 177 on the Human Development Index scale. At the end of 2003, the Egyptian population was estimated to be 75 million. More than 1 million people would be living with a disability, 74% of them would suffer from mental disability, and 15% from mobility impairment [9].

Since 1987, Handicap International organizations work in Egypt to support local non-governmental organizations working in the field of disability (capacity building of local staff, management and financial support). In 1987, the first rehabilitation programme in support of mentally disabled children and their families was set up with Caritas. Between 1992 and 1994, this programme was run in partnership with the Caritas Seti Centre (centre for mentally disabled children and young adults). These actions have now been extended into other regions in Egypt. Nowadays, the largest rehabilitation centre is the Armed Forces Centre for physical rehabilitation in Cairo. Some government hospitals provide rehabilitation services free of charge, and national medical insurance or private medical insurance usually covers other costs, including the cost of assistive devices for

those people with insurance coverage. In the Sinai Desert, the Multinational Forces and Observers have outpatient clinics in both South and North Camp and a physiotherapy clinic in the South Camp was started. The facilities assisted more than 9000 patients and conducted 2700 physiotherapy sessions [10]. In November 2005, the Embassy of Japan upgraded a rehabilitation centre run by the Egyptian Red Crescent Society in Cairo. The centre assists about 500 people per month [11]. The Egyptian Federation for Handicapped Welfare Organizations comprise more than 300 organizations. Other organizations dealing with people with disabilities are CARE and the Hospital Day Association. Organizations dealing with socio-economic reintegration of vulnerable groups, including people with disabilities, are the Italian Cooperation in Egypt, the Social Fund for Development and Agriculture Cooperative Development International-Volunteers in Overseas Cooperative Assistance (Email from Ghassan Shahrouh, Coordinator, Syrian Campaign to Ban Landmines, Damascus, 16 April 2006).

According to Dr Magdy El Ekiaby, head of the haemophilia treatment centre in Cairo's Shabrawishi Hospital, haemophilia care has developed greatly in the world over the last two decades. In spite of this development, there is a huge gap in the standards of care between developed and developing countries. In its continuous efforts to improve the standards of care worldwide, the WFH is developing and promoting a 'National Hemophilia Care Program'. In 2003, the WFH launched a new comprehensive programme called Global Alliance for Progress (GAP). 'Since the start of GAP project in Egypt, dramatic improvements in haemophilia care have been noted,' says Dr El Ekiaby (9th WFH Musculoskeletal Congress 2005). Egypt's achievements include the diagnosis of 551 new patients with haemophilia and other bleeding disorders. The country has also established a new haemophilia treatment centre in Alexandria, improved laboratory capabilities, and increased the availability of treatment products by 53%.

A few centers have been established in Egypt that provide physiotherapy for haemophilic patients, including Shabrawishi Hospital, Cairo University, Ain Shams University and Alexandria University hospitals. However, our goal in Egypt is to properly enrol all haemophilic patients in the treatment centers to ensure proper diagnosis, prevention of complications and treatment including rehabilitation programmes together with proper education of the patients and their families. The First Regional Occupational Therapy (OT) Conference in the Middle East was held 27th to 29th April 2007 under the

supervision of Mrs Suzanne Mubarak, First Lady of Egypt. It was organized by members of The Committee for Developing Occupational Therapy in Egypt from Ain Shams University and October 6th University. The purpose of the conference was to (i) raise awareness of the role of occupational therapy, (ii) educate people as to the independence of occupational therapy as a health profession, (iii) help persons to upgrade their skills and reach their full potential and (iv) provide a forum for regional OTs to meet and discuss needs of the region. This may be of great help for haemophilic patients in the near future.

The rehabilitation situation as part of haemophilia treatment in France

Haemophilia affects approximately 6000 individuals in France and its treatment is coordinated by 26 regional haemophilia treatment centres (RHTC) with four missions: care, training, research and regional coordination of the treatment of haemophiliacs.

The RHTC in each region is managed by a coordinator specialized in haemophilia supported by specialized physicians, a coordinating nurse and a secretary. Approximately 80 physicians are active in these centres: haematologists, haemobiologists, paediatricians, rheumatologists and rehabilitation physicians.

Recently, a new structure has been progressively put in place. Haemophilia has been included in the national rare diseases plan and a reference centre designed to play an important role in the inter-regional structure and research activities has been approved. The RHTCs will become skills centres and will keep the same missions.

The role of rehabilitation for haemophiliacs is rather heterogenous throughout France. Until the 1980s, it was important for the treatment of children and adolescents with haemophilia.

There were several medical boarding schools that treated these patients. Therapeutic modifications have brought about the progressive closing of these non-polyvalent centres.

Rehabilitation treatment is currently provided at two levels as shown below.

Postsurgical rehabilitation and intensive rehabilitation for orthopaedic sequelae

There are no rehabilitation centres reserved for haemophiliacs, with the exception of the Osséja centre, which is a healthcare structure for chronic diseases equipped with a few specialized functional rehabilitation beds for haemophilic children and

adolescents. This centre also provides therapeutic education to patients. Adults can be treated in polyvalent rehabilitation centres or departments working in a network with the RHTCs.

Rehabilitation as part of day-to-day haemophilia treatment

Out of 21 RHTCs, which had responded to a query [12], 12 centres had a consulting rehabilitation physician and 11 had a part-time physiotherapist.

Muscle-joint and functional evaluations are performed regularly by the rehabilitation physician or the physiotherapist. The results are discussed by a multidisciplinary team in order to make necessary therapeutic adaptations such as the need for intensive rehabilitation, orthotics or surgical intervention.

The rehabilitation physician or coordinating physician of the RHTC also organizes external rehabilitation near the patient's home and calls the physiotherapist to provide him/her with the reports from the evaluation and the rehabilitation goals for the patient treated.

Rehabilitation treatment networks are being created in a few regions to provide training for professionals involved with haemophiliacs.

Last, the rehabilitation physician or physiotherapist participates in the therapeutic education for patients and their families: learning to diagnose bleeding events early, monitoring of their outcome, teaching self-rehabilitation.

In summary, the presence of a consulting rehabilitation physician or physiotherapist should remain a priority in each regional treatment centre. Each region should develop physiotherapist networks in coordination with the rehabilitation personnel in each treatment centre.

The role of the physiatrist in haemophilia care in Indonesia and the Philippines

Haemophilia care in Indonesia was started in 1965 when several laboratory tests for haemophilia were introduced by the late Dr Kho Lien Keng. Treatment using whole blood existed until 1975 when Dr Masri Rustam from the Indonesian Red Cross started making the cryoprecipitate. Data collection of haemophilia was started in 1995 and in 1997 the WFH programme was introduced by Professor P. Isarangkura from Thailand. In the same year, the National Integrated Hemophilia Care Team was established at Dr Cipto Mangunkusumo General Hospital in Jakarta together with the Indonesian Hemophilia Society.

Medical Rehabilitation care in Indonesia has been in existence since the late Professor Dr R Soeharso established in 1947 the Rehabilitation Center for physical disability, the blind, the deaf, and mental illness in Surakarta. Because of the increasing demand for rehabilitation care, the Ministry of Health extended and incorporated medical rehabilitation care into public hospitals in 1973, which later-on was extended to become the Medical Rehabilitation Unit. In an effort to support medical rehabilitation care, the Ministry of Health through the World Rehabilitation Fund started to send its physicians to have specialty training in physical medicine and rehabilitation with the purpose of developing medical rehabilitation care as well as education and training for the specialty. The PM&R Department at the Faculty of Medicine, University of Santo Tomas in Manila, the Philippines, was chosen as one among the training centres. There were 12 graduates from the centre. A residency training programme in PM&R was started in 1984 and at present there are around 320 physiatrists in the country. Not all of them are working in hospitals; some have private clinics.

Physiatrists are involved in every integrated haemophilia care team established in several hospitals throughout the country. There is continuing communication between the physiatrists, and in June 2006, a Workshop on Musculoskeletal Management in Haemophilia was organized. So far, haemophilia care is provided by a team, including a physiatrist, only in hospitals, and there is no special haemophilia clinic. The rehabilitation care provided consists of assessment by a physiatrist, physical therapy, occupational therapy and orthotic management.

In the Philippines seminars and workshops for physiotherapists and doctors have been organized twice. An exercise handbook for patients has been developed. The department of PMR at UST has played an active role in hosting the WFH-funded summer camp. This is a possible moving force to encourage exercise and physical activities among the haemophilia patients.

Rehabilitation medicine in the Netherlands

The military rehabilitation centre Aardenburg in Doorn was the first centre in the Netherlands followed by other rehabilitation centres in Enschede, Amsterdam, Leersum. In the 1950s, special rehabilitation centres for children also evolved from sanatoria for children. PRM is an official medical speciality in the Netherlands since 1955. The Dutch Haemophilia Clinic was founded by Professor Van

Crevelde in 1964 and was named the Van Crevelde-kliniek after his death in 1971. Here, the first haemophilia comprehensive care team took care of haemophilia patients and right from the start, professor Van Crevelde included a very well-known physiatrist, Dr A.C. van Swol, in the multidisciplinary team in pair with orthopaedic surgeons, Cesar therapists and a psychiatrist for children. Dr Van Swol was already a consultant in the rehabilitation centre for children in the same village. This tradition has been continued by the author (LH) who has been consultant physiatrist both in the Van Creveldekliniek and rehabilitation centre De Trappenberg for over 24 years. In the Netherlands, to date, there are 24 rehabilitation centres, which are all members of the branch organization RN (Rehabilitation the Netherlands). In 2006, 368 physiatrists were working as consultants in these 24 centres and PRM departments in hospitals and over 51 500 out-patients and 7650 in-patients were treated [13]. For many years, the Van Creveldekliniek was the only comprehensive care centre in Holland with a consultant physiatrist. There have been combined clinics since the start and nowadays the physiatrist has an outpatient clinic once a week together with the physiotherapist. Twice a month, this is combined with the orthopaedic surgeon and one of the haemophilia doctors. Inpatients are seen as needed.

In 1999, the Minister of Health wrote a policy document on haemophilia aiming at improving haemophilia care by concentrating knowledge and experience in a limited number of specialized hospitals. This stimulated the haematologists to seek cooperation with the departments of PRM in their hospital to fulfil one of the criteria (i.e. the presence of a consultant physiatrist). To date, there are 13 treatment centres recognized, however the intensity of cooperation with a PRM consultant differs.

The role of rehabilitation in South America

Brazilian haemophilic patients have received specialized haematological and clinical care in specialized healthcare clinics for more than 30 years – and, in the last 20 years, with the use of the anti-haemophilic factor.

Physiatrists systematically integrate haemophilic patient care in Brazil and in most South American countries, and prevention of disability has been a constant goal. However, adolescent patients usually neglect musculoskeletal care.

There has been a great difference in the way each South American country provides assistance to haemophilic patients.

Argentina offers care in specialized centres in its bigger cities. Uruguay also has reference centres with multidisciplinary teams. Both include physiatrist care.

Colombia, Brazil and Chile emphasize the relevance of the physiatrist and of rehabilitation care from the earlier stages onwards; however, they also offer treatment including postsurgical care for joint surgeries such as osteotomies, arthroplasties, etc.

Haemophilic care in Brazil has been provided preferentially in haemocentres (public organizations usually affiliated with universities, schools of medicine or university hospitals) for over 30 years. These haemocentres have the infrastructure for diagnosis and clinical follow-up, and for rehabilitative care in the acute stage aiming to prevent disability. For more complex processes such as joint pain, synovitis, muscle haemorrhages with sensorial changes, etc., for which a follow-up is necessary, patients are referred to reference centres in physical and rehabilitation medicine offering comprehensive care. The national healthcare system pays for all costs. A great challenge is the geographic distance between the patient's home and the healthcare service. This prompted a great effort towards emphasizing education and orientation of these patients for home-care including early usage of AHF, non-weight-bearing, ice and medical consultation within 48 h.

The reference centres in PMR are equipped for diagnostic assessment of joint instabilities, gait disorders, etc. The National Policy of Disease Prevention and Rehabilitation, established in 1999 corroborated by the National Rehabilitation Network provides health care for patients at risk of disability. However, there is low compliance to long-term programmes. In spite of all the counselling and use of currently available resources, many patients in Brazil and other countries show a high incidence of joint compromise in the second decade of life.

Every professional of the multidisciplinary team involved is trained in basic haemophilia care. The minimum knowledge to be transmitted to patients, their families and to all healthcare professionals includes understanding the importance of referral to specialized services:

- 1 Early care for haemophilic patient – education to prevent disabling injuries.
- 2 Physiatric care during the bleeding episodes – acknowledge of the need to refer the patient to specialized care.
- 3 Long-term rehabilitative treatment of musculoskeletal disorders.

The presence of HIV or hepatitis C must not restrict or hinder the patient from being included in a rehabilitation programme, but it is the responsibility of the physiatrist to adjust the therapy to the conditions of each patient.

One of the greatest concerns in the management of patients with haemophilia is the quality of life. A Healthcare Questionnaire of Quality of Life designed especially for the Latin American population is available at: '<http://www.iberohemofilia.net>'.

Conclusion

Rehabilitation Medicine is a relevant medical speciality when organizing comprehensive haemophilia care. Both in developing and developed countries around the world, there is active cooperation between physiatrists/PRM departments and haemophilia centres.

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References

- 1 Report of the WHO on Expert Committee on Disability Prevention and Rehabilitation. *Technical Report Series 668*, Geneva: WHO, 1981.
- 2 World Health Organization. *International Classification of Functioning, Disability and Health (ICF)*. Geneva: WHO, 2001.
- 3 Stucki G, Siegel T. Assessment of the impact of disease on the individual. *Best Pract Res Clin Rheumatol* 2003; 17: 451–73.
- 4 Genderen van FR, Westers P, Heijnen L *et al.* Measuring patients' perceptions on their functional abilities: validation of the haemophilia activities list (HAL). *Haemophilia* 2006; 12: 36–46.
- 5 Poonnoose PM, Manigandan C, Thomas R *et al.* Functional independence score in haemophilia: new performance based instrument to measure disability. *Haemophilia* 2005; 11: 598–602.
- 6 Heijnen L, Buzzard BB. The role of physical therapy and rehabilitation in the management of hemophilia in developing countries. *Semin Thromb Hemost* 2005; 31: 513–7.
- 7 Meij van der WKN. specialisme in beweging een eeuw revalidatie 5 decennia VRA Koninklijke Van Gorkum, Assen, 2005.
- 8 Ward AB, Gutenbrunner C. Physical and rehabilitation medicine in Europe. *J Rehabil Med* 2006; 38: 81–6.

- 9 El Deeb B. *National Report on Disability Statistics in Egypt 21–23 March 2005*. Central Agency for Public Motivation and Statistics (CAPMAS), Cairo, October 2005.
- 10 MFO. *Director General's Report to the 2005 Trilateral Meeting*. Rome: MFO, 2005: 20–35.
- 11 Embassy of Japan. Inauguration Ceremony of Egyptian Red Crescent Rehabilitation Centre. Press Release 37/2005, Cairo, 23 November 2005.
- 12 Livre Blanc de l'Hémophilie, July 2007.
- 13 Jaarbeeld 2006 Revalidatie Nederland, juni 2007.