European Haemophilia Consortium
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Event Report: EHC Round Table of Stakeholders on 'Ageing and Haemophilia'

About the event

On Wednesday 20 April 2016, the European Haemophilia Consortium (EHC) held a Round Table of Stakeholders at the European Parliament in Brussels, Belgium, to discuss the topic of ageing and haemophilia. The event was part of a series of three events held to mark World Haemophilia Day, traditionally observed on 17 April, which also comprised an event on hepatitis C (HCV) and haemophilia and the screening of the documentary 'Haemophilia Stories' directed by Mr Goran Kapetanovic.

Some 65 participants attended the day's events, including patient representatives, healthcare professionals and industry representatives. A full list of speakers can be found here. The full agenda for the event can be found here. Presentations from the event can be consulted on the EHC website.

The event was supported by Members of the European Parliament (MEP) Mr Heinz Becker (Austria/ EPP) and Mrs Sirpa Pietikäinen (Finland/ EPP).

On ageing with haemophilia

Haemophilia is a rare and congenital bleeding disorder caused by a genetic defect resulting in a lack of or insufficient coagulation factors VIII or IX in the body. This causes, in affected individuals, an inability to clot blood, leading to bleeds in the joints, muscles and soft tissues. If left untreated, this can cause disability and sometimes death.

Until the 1960s there was no effective treatment to manage haemophilia, which meant that patients born with severe haemophilia until that time had a shorter life-expectancy (i.e. below 50 years of age) compared to their peers not affected by haemophilia. The advent of coagulation factor concentrates enhanced not only patients' life expectancy at birth but also their quality of life. As a result healthcare professionals are confronted today, for the first time in history, with an ageing patient population with severe haemophilia. This raises many medical questions on how to manage haemophilia with co-morbidities arising both from older age, such as for example cardiovascular or metabolic diseases and cancer; and haemophilia-related complications, such as arthropaty, inhibitors and viral infections due to the contamination with HCV and HIV[1]. The EHC decided to organise a Round Table of Stakeholders to look at treatment protocols in use and establish which healthcare services are needed for these patients.

Findings and discussions

People with haemophilia (PWH) are more at risk, compared to the general population, for certain co-morbidities arising from age, such as for example obesity, hypertension, osteoporosis and cardiovascular diseases (CVD). Additionally they also develop co-morbidities related to haemophilia such as arthropaties, liver- (caused by HCV infection) and renal- (caused by HIV treatment) diseases and vein damage. Also surgeries are more difficult to perform on an elderly PWH and healthcare professionals should screen for inhibitors, especially after surgery and particularly in patients with mild haemophilia. As such the toll of ageing on PWH is greater than in the general population, resulting in the need for special medical care. In fact, if left unaddressed, these co-morbidities can quickly deteriorate the mental and physical wellbeing of PWH.

[1] A majority of patients with haemophilia who were treated in the 1980s and early 1990s were contaminated with HIV and HCV viruses due to the contamination of their treatment.

One of the main challenges in their treatment and care is that there are no standardised screening and treatment protocols for the detection and management of age-related co-morbidities in PWH. Furthermore junior and non-specialist doctors treating these patients may not be aware of the full medical history of these patients, which further complicates diagnosis and treatment of co-morbidities.

Speakers at the event agreed that it was important to treat these patients with a multi-disciplinary approach that would involve various healthcare professionals such as physiotherapists, psychosocial workers, cardiologists, specialised dentists and urologists so that the patient can be treated more holistically. There were also discussions on whether geriatricians should be added to the team of haemophilia comprehensive care centres. Finally, haematologists should pay particular attention to whether the patient is able (both physically and mentally) to self-administer his treatment.

Psychosocial support is also very important. Firstly this is the first generation of people with haemophilia to enter old age. In fact, there is no reference point and no previous experience on how old age will be lived by PWH. Secondly, people who get older tend to develop what is called the 'fear factor,' i.e. the fear of losing control over one's mental and physical capabilities due to the deterioration of physical and mental health. Additionally, people with haemophilia tend to have had bad hospital experiences during childhood and they may find it difficult to let others take care of their treatment. Finally, pain is often present due to arthropaties and other co-morbidities, therefore it is crucial to offer ageing PWH pain management in the form of medicinal products together with adequate psychosocial support.

Speakers also noted the economic challenges that an ageing PWH poses to the health system. In fact, PWH will require more treatment (often prophylaxis), additional healthcare services and the number of PWH entering older age is going to increase in the future. Therefore it is important to develop standards of care to ensure adequate and cost-effective treatment and management. On the other hand PWH often need to retire earlier than their peers due to poor health conditions.

Conclusions

To address these issues, better information, education and coordination is needed for both healthcare professionals and patients. Healthcare professionals need to be made aware of the impact that haemophilia has on co-morbidities and haematologists should encourage the screening of non-haemophilia-related co-morbidities. On the other hand PWH need to communicate with all of their physicians about their disorder. National haemophilia organisations can provide assistance with this by developing information material as well as check-lists of things to discuss with healthcare professionals, social services and occupational therapists. The use of a diary to record health routines and changes can also be a useful tool to track medical progress.

A multidisciplinary approach is definitely recommended for these patients and the haemophilia centre and haemophilia nurse should play a central role in this. A series of healthcare professionals need to be involved in caring for these patients and transition to geriatric and palliative care should be planned when needed (often after 75 years of age). The development of standardised and evidence-based screening and treatment protocols to detect and manage age-related co-morbidities is also needed and for this purpose data collection is key.