EHC Round Table on Ageing and Haemophilia

Personal experience and NMO perspective

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Elderly hemophiliacs

- Their live expectancy is reaching almost that of general male population words like “senior citizen”, “old age”, “home for aged people”, “retirement” now starts to be real and concrete even for us

- Their age-related diseases are similar to those of the general population (cardiovascular diseases, cancer, osteoporosis)

- Surgery is more complicated and expensive, but doable (joint replacement and even transplantations)

- They ultimately die like any other people

So what is so special about them?
Hemophilia associated co-morbidities in the elderly patient

There are a number of medical problems directly related to haemophilia e.g.

- **Inhibitors**
  moving haemophiliacs back to sixties, causing serious disability; costly treatment

- **Chronic pain**
  substantially decreasing the quality of life

- **Liver diseases**
  due to Hepatitis C

- **Renal problems**
  due to earlier blood and plasma transfusions, by-effect of HIV drugs
Hemophilia associated co-morbidities in the elderly patient

- **Hemophilic arthropathy**
  - Elderly hemophilia patients have a high rate of joint instability and balance dysfunction, and high risk of falling (Haemophilia, Hill 2010)
  - High risk of fractures and serious injuries as a result of falling

- **Vein Health**
  - Difficulties maintaining access for self infusion

- **Bad oral health** due to
  - Fear of attending the dentist
  - Scared of bleeding following treatment
  - Dentists would not treat them once they knew they had hemophilia
Generation without experiences

- We used to live with hemophilia, our bleedings, our pain, our limitation; we know how to manage it
  - Many hemophiliac don’t consider themselves to be ill, or bleeding disorder to be an illness
  - To be hemophiliac is, as one my friends expressed it, rather a way of living. It is not a desirable way of living but one accepts the limitations and gets used to it.

- People in general have an image about what it is to be old, simply by referring to their grandparents, their neighbors, or some general media pictures

- The hemophiliacs don’t have such experiences, a clear picture on how it will be

- Even this fact may evoke some angst especially in the family

- We know how to manage the known. But like people in general, the unknown is frightening us
But ....we are worried
From surveys performed in Sweden and Denmark

- We often revile our fears about what will happen when we no longer are able to administrate the factor concentrate by ourselves due to shaking hands, weaken vision
- Are we psychologically prepared to manage other diseases or increased pain
- We will be weaker, and won’t get through everyday tasks
- About our economy, since being disabled means a poor pension and a lot of extra costs
- Liver cancer caused by Hepatitis C
- Or be unable to tell when we have a bleeding
What evokes angst and frighten us

An uncontrolled situation, questions like:

- Will I survive an accident? Will the paramedics look in my cell-phone for my (In Case of Emergency) ICR number?
- Will the staff in the emergency room treat me as hemophiliac?
- What happens if a police officer sees my arms and treat me as a drug addict rather than contact my doctor?
- What happens if I will be unable to tell when I have a bleeding

We could spend hours exchanging terrifying experiences from emergency rooms in local hospital
The Project

Seeing a lack of knowledge on how to handle ageing problems affecting also the elderly PWH:
- surprisingly even among the hemophiliacs themselves
- their relatives
- within the medical health care system
- at social authorities and institutions

A project was formed 2011 by the Swedish and Norwegian Hemophilia Societies with support from Bayer AB.
The Project

Aim of the project is to identify needs of elderly PWH in the Swedish and Norwegian hemophilia societies and to communicate these needs to members, the medical profession and social authorities.

The workshops discussions at the yearly “Feel-good” events for 50+ members and their partners are ground for the produced material.
The results

- A short information pamphlet “What is important to know about elderly PWH” to hand over in contacts with medical professionals (not for HCC) and social authorities.

- Checklists to be used in the regular meetings with doctors, social counselors and physiotherapists at the Hemophilia Care Centers.
  - Kind do not forget to talk/ask about
The results

Checklists to be used in contacts with the local health care, home service, social service, physiotherapist, occupational therapists and retirement homes.

- What I can manage when everything is OK
- What kind of support I need when I have a bleeding
  - Cleaning, shopping, cooking etc
  - Extra injection

Kind of checklists pointing issues to concern about:

- Pain management,
- Mental health
- Traveling
- Work after 50+
- Available assistive devices
Patient Self Record

To be used by PWH and their relatives in contact with the local and acute care

<table>
<thead>
<tr>
<th>Personal Health Record:</th>
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<tbody>
<tr>
<td>Name:</td>
</tr>
<tr>
<td>SS number:</td>
</tr>
<tr>
<td>Phone:</td>
</tr>
<tr>
<td>Mobile phone:</td>
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<td>Close relative</td>
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The self-record makes my contacts with the health care system easier:
In case of trauma, acute illness or any other medical management that concerns me, please contact:
Hemophilia care center: ____________________________ Phone: ____________________________
or the coagulation physician on call: ____________________________ Phone: ____________________________
Responsible physician at Hemophilia care center: ____________________________ Phone: ____________________________
Responsible registered nurse at Hemophilia care center: ____________________________ Phone: ____________________________

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<td>SS number:</td>
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<tr>
<td>Phone:</td>
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<tr>
<td>Mobile phone:</td>
</tr>
<tr>
<td>Surgeries and other procedures that I undergone:</td>
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<tr>
<td>Procedure</td>
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<td>------------</td>
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<table>
<thead>
<tr>
<th>My diagnosis: Factor</th>
<th>Severity</th>
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<table>
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<tr>
<th>Other diseases that I also have:</th>
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<tr>
<td>Allergies:</td>
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<table>
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<tr>
<th>Other important information: eg. home procedure, inappropriate medication due to my bleeding disorder:</th>
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Current medication

<table>
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<tr>
<th>Treatment – Bleeding disorder:</th>
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<tbody>
<tr>
<td>Number of ( )</td>
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In an acute situation: Always contact the coagulation specialist on call:

<table>
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<th>Other Medication:</th>
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<tr>
<td>Generic/Trade name</td>
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To consider when treating a patient with hemophilia:

- In acute injury do not delay treatment with factor concentrates
- Do not prescribe aspirin
- Do not give intramuscular injections
- Puncture of joints shall only be made in consultation with physicians specialized in hemophilia and performed by an experienced physician
Organizational challenges, how to cooperate with other specialists:

- Should HCC have regular meetings where different specialists, physicians are present to discuss a patient or group of patients?

- Should HCC be a coordinator; sending patients to different specialists, but still having the main responsibility for treatment, follow up?

- Should HCC refer a patient to a specialist and then expect that it is the specialist that contacts a hemophilia doctor to discuss whether the treatment may cause increased bleeding risks?
Adapted from Mauser-Brunshoten et al 2007

- Dentist
- Social worker
- Urologist
- Endocrine specialist
- Pharmacy (hospital & community)
- Cardiothoracic surgeon
- Cardiologist
- GP
- Nurse Haemophilia
- Orthopaedic surgeon
- Physiotherapist
- Pain specialist
- Rheumatologist
- Infectious diseases specialist HIV
- Infectious diseases specialist HCV
- Hemophiliac patient
Challenges for Hemophilia Care Centers

Economical challenges:

- The ageing population has a great impact on national public spending in health, how to preserve the treatment standards for PWH
- Increased cost of care for ageing PWH
- Needs for prophylaxis for adults and especially for elderly PWH
- The number of elderly PWH will continue to increase
Cooperating with HCC

A national advisory council where representatives from all HCC and NHS discuss global issues like:

- Patients expectations expressed via survey among our members
- Improvements of care and treatment, social support and rehabilitation of elderly PWH, with special consideration to pain, virus problems, problems related to growing old and also mental health.
- PSA-tests as one of the standard test to be performed
- Geriatricians as obvious consultants as orthopaedists are today
Cooperating with HCC

Local advisory councils (for each HCC) meets to discuss issues related to a specific HCC, e.g.

- Availability of counselling
- Role of welfare officers
- Physiotherapy with focus on elderly haemophiliacs
- Availability of specialists as consultants
Thank you
and
HAPPY AGEING!!