Ageing with hemophilia: a personal reflection

Dr. Cees Smit, LUMC/HiN-6
Brussels, April 20, 2016
Aging
with
haemophilia

Medical
and
psychosocial
impact

E.P. MAUSER-BUNSCHTHEN
A. DE KNECHT-VAN EEKELEN
C. SMIT
Problems in older hemophiliacs

- Bad joints and muscles
- Stiffness, upon waking or after sitting
- Limited walking, shopping ability
- Limited ability to work / early retirement
- Inability to carry out at-home treatment
- Co-infections (hiv, hcv)
- Co-Morbidity, due to hemophilia or ageing
- Dependency on partner, social environment
Really Getting Older & The Issue of Co-Morbidity (1)

• Functional limitations
  *Physical deterioration, fatigue*

• Psychological complaints/symptoms
  *Fear and depression*
  *Feeling of losing control*
  *Less ability for self-care*
Really Getting Older & the Issue of Co-Morbidity (2)

• Social problems
  
  * Lack of understanding
  * Decrease of social contacts

• Societal problems

  * Less participation in labour and leisure time activities
  * An increase of disease costs
Really Getting Older & the Issue of Co-Morbidity (3)

• But the other side of the coin: coping skills!
• ‘With regard to ageing: ………. ‘

• ‘In jest, I tell people that I am holding my own while brothers and other relatives are going downhill as they hit their sixties. I am hoping to be completely caught up to them by age 70. And my coping skills are better than theirs!’
‘Ageing’
The patient perspective

• Three problems:

• Lack of coordination between physicians and other staff, which needs self-coordination

• The use of more medications (polypharmacy)

• The ‘fear factor’, who can take over coordination?
The ‘Fear Factor’

The ‘fear’ of losing control over one’s own situation:

• Loss of control of at-home treatment
• Inability to live independently
• Something may happen to the healthy partner
• May require visits with health-care providers with little or no knowledge of one’s hemophilia
• Loss of physical control, as in the case of unconsciousness (car accident, emergency care)
Where is the Coordination?

• Hemophilia CCC (training on ageing)
• Home physician
• Other medical specialists / nurses
• Case manager/nurse coordinator for older people with co-morbidity (e.g. hemophilia)

• Transition to geriatric care (when and how)
• Palliative care/end of life treatment
‘A song in the night’, 2012

• ‘My hemophilia, the one thing that I had thought would define my life from birth to death, had been utterly, totally and permanently cured’

(ref. ‘A song in the night, a memoir of resilience’, Robert IV Massie, 2012, p. 269)
The 2020 challenge

• Despite 50 years of modern hemophilia treatment, we still need:
  
  • A more final cure
  • Treatment for 70% of hemophiliacs
  • Lower priced products &
  • Care models for older hemophiliacs in especially nursing homes/end of life care
For correspondence

info@smitvisch.nl

www.smitvisch.nl