Ageing and haemophilia

A personal perspective and more

Dr. h.c. Cees Smit
Strasbourg, April 18, 2017
Haemophilia: my own patient journey
D.E.S. The Bitter Pill
How Medical Indifference Turned a "Miracle" Drug Into a National Nightmare

ROBERT MEYERS
Ageing in severe haemophilia (n=338)

Mauser et al, Van Creveld clinic, Utrecht, 2010, personal communication
Ageing in HIV/AIDS

Remarkable transitions

From unmet medical need → good treatment

Haemophilia (in the seventies)

HIV (in the nineties)

HCV (in the 2015’s)

Consequences: transition to care for older people
Agehiv.nl  Cobra study results
Really Getting Older & The Issue of Comorbidity (1)

Functional limitations

*Physical deterioration, fatigue*
*Less ability for self-care*

Psychological complaints/symptoms

*Fear and depression*
*Feeling of losing control*
Really Getting Older & the Issue of Comorbidity (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 Comorbidity (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!’
A Circle Full of Health Care Contacts

- Haematologist
- Dentist
- Cardiologist
- Nephrologist
- Pharmacy (around the corner)
- Pharmacy (haemophilia centre)
- Infectious Diseases specialist (HCV)
- HCV Nurse
- Home Physician
- Haemophilia Nurse
- Orthopedic Surgeon
- Rehabilitation Specialist
- Physiotherapist (around the corner)
- Physiotherapist (national centre)
- Infectious Diseases specialist (HIV)
- HIV Nurse
HEALTH INSURANCE COMPANIES, SOCIAL AND MUNICIPAL SERVICES

THE PATIENT AND SELF-MANAGEMENT

(PARA)-MEDICAL PROFESSIONALS INCLUDING NURSES

RELATIVES, INFORMAL CAREGIVERS, FRIENDS AND NEIGHBOURS
The patient at the center? That's so 2015!

In this way the health care provider places the patient in the vicinity of the health care provider. I as a patient now say: “Control it, you as a health care provider, that you fit in my area.”
The ‘fear factor’

Three problems:

Comorbidity & the use of multiple medication (polypharmacy)

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

Who can and lead coordination when self-care is no longer possible?
Who should or could coordinate?

- Haemophilia centre / HIV centre
- Home physician
- Other medical specialists / nurses
- Nurse coordinator for the elderly, nursing homes
- Extension of my own network
Life style ‘society’ problems
Life style ‘patient’ solutions
Messages

A long personal history behind each patient

The importance of medical research/transitions

Aging, comorbidities & the ‘fear factor’

The need for coordination

Life style changes
For more information

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