the art of Aging
with comorbidities

A personal perspective

Dr. h.c. Cees Smit
Rotterdam, October 4, 2016
Messages

A long personal history behind each patient

Aging, comorbidities & the ‘fear factor’

The need for coordination
A long personal history behind each patient
‘Journey’, 1975

‘The disease we have fought is hemophilia. Every family with a handicapped or chronically ill child shares the same problems: lack of money, isolation from the community of the healthy, prejudice, misunderstanding in schools, loneliness, boredom, depression’

(ref. Robert & Suzanne Massie, Journey, 1975, p. XI)
Heden werden wij verblijd met de geboorte van ons zoontje en broertje

**CORNELIS**

M. SMIT-KROON
J. SMIT
en WILLY

Wij noemen hem KEES

Nieuwe Niedorp,
1 Januari 1951
Laagzijde B 249
Hemophilia: my own patient journey

Hemophilia, a rare disease
1 : 10,000 (the Netherlands ≈ 1,700 patients)

 Mostly males, females carriers
 X-linked recessive disorder

Hemophilia A, factor VIII
Hemophilia B, factor IX
Severe, moderate and mild

Characterized by mostly spontaneous internal bleeds in muscles and joints
Furthermore through trauma, accidents and operations

No treatment possibilities before 1965
D.E.S. The Bitter Pill

How Medical Indifference Turned a "Miracle" Drug Into a National Nightmare

Robert Meyers
Aging in severe hemophilia (n=338)

Mauser et al, Van Creveldclinic, Utrecht, 2010, personal communication
The success story of pediatric medicine:

Young children become older and older
HIV  
HCV
‘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)
Remarkable transitions

From unmet medical need $\rightarrow$ good treatment

Hemophilia (in the seventies)

HIV (in the nineties)

HCV (in the 2015’s)

Consequences: transition to care for older people
Aging in HIV/AIDS

Aging, comorbidities & the ‘fear factor’
Problems in elderly hemophiliacs

Bad joints and muscles

Stiffness, especially upon waking or after sitting for a long period of time

Limited walking, shopping

Tiredness because of viral infections

Limited ability to work / retirement

Comorbidity due to older age
Aging with haemophilia

Medical and psychosocial impact

E.P. MAUSER-BUNSCHOTEN
A. DE KNECHT-VAN EEKELEN
C. SMIT
Aging with HIV/AIDS in the Netherlands

A limited number of cool-sticks with the pdf of this publication is distributed from the AIDS Fonds and the EACS booths at the XVII International AIDS Conference - Vienna - July 18-23, 2010

Dutch Booth and EACS Booth in the Exhibition Hall

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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

- Hematologist
- Dentist
- Cardiologist
- Nephrologist
- Pharmacy (around the corner)
- Pharmacy (haemophilia centre)
- Infectious Diseases specialist (HCV)
- HCV Nurse
- Home Physician
- Orthopedic Surgeon
- Rehabilitation Specialist
- Physiotherapist (around the corner)
- Physiotherapist (national centre)
- Infectious Diseases specialist (HIV)
- HIV Nurse

ME & Self mgt
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?
The need for coordination
A Circle Full of Health Care Contacts

Hematologist

Dentist

Cardiologist

Orthopedic Surgeon

Rehabilitation Specialist

Physiotherapist (around the corner)

Physiotherapist (national centre)

Pharmacy (around the corner)

Pharmacy (haemophilia centre)

Infectious Diseases specialist (HCV)

Infectious Diseases specialist (HIV)

HCV Nurse

HIV Nurse

Home Physician

Nephrologist
HEALTH INSURANCE COMPANIES, SOCIAL AND MUNICIPAL SERVICES

THE PATIENT AND SELF-MANAGEMENT

(PARA)-MEDICAL PROFESSIONALS INCLUDING NURSES

RELATIVES, INFORMAL CAREGIVERS, FRIENDS AND NEIGHBOURS
Who should or could coordinate?

- Hemophilia centre / HIV centre
- Home physician
- Other medical specialists / nurses
- Nurse coordinator for the elderly
- Extension of my own network
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The need for coordination
Patient and public involvement in future care for senior citizens
The Wheel of Life
A Memoir of Living and Dying

“An inspiring account of exploration, conviction, and service. . . . This book chronicles a life lived passionately, compassionately, and well.”
—Richard Hoffman, New Age Journal

Elisabeth Kübler-Ross, M.D.
Author of On Death and Dying