



# The Tarzan Syndrome & "The Stiff Ancles' Society"

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# Agenda

- JA – Anecdotal Reports from Self & Friends
- PK – "The Obvious & The Hidden"
- PK – Litterature on the subject
  - *"The Tarzan-syndrome"*
- JA – Recognition of Self in Litterature?
- JA & PK – Perspectives



# Anecdotal Reports from Self & Friends

- "The Stiff Ancles' Society"



## "The Obvious" in Haemophilia

- PUPs
- Inhibitor-risk
- Adolescent Transition
- Pregnant partner
- End stage joint destructions
- Joint surgery & replacements
- HIV-control
- HCV-eradication
- Complex Co-morbidities in the elderly Haemophiliac, Cardiovascular Atherosclerosis
- Expansion of the aspects of Physiotherapy
- New principles of Medical Prophylaxis against bleeding



## "The Hidden" in Haemophilia

- Observations on men aged 30-50 with Haemophilia.
- "Every decade has its own presentation in Haemophilia".
- Misconceptions about the normal decay of joints
- Quotes from patients



## The eye-openers

- "I can't play football with my son!"
- "My Elbow bleeds when I do manual gear shifts!"
- "At 40 my body started smouldering"



# Recognition of own situation

- "Honey! I'm a Haemophiliac!
  - -Yes, Dear, You've been that your whole life"



- "At 47 I went "all in" on Prophy!" ...
  - "Why that late?"
  - "I wasn't a real Haemophiliac, the others were worse, I could handle it"
- But now I'm only an arthrosis patient



- Litterature on the subject
- "The Tarzan-syndrome"
- "Risk-taking" / "Risk Willingness" – the frontal lobe defect of males aged 18-25 years
- "I'll handle this myself! ...and preserve the right to be bitter about it"

## Three Wave Panel Study spanning 24 years DK 1988-2001-2012

- "Significant improvements in joint mobility and physical function have occurred over the last 24 years, but severe PWH older than 35 years still experience a decline in these areas with age."
- 2012 Proportions of constant prophy treatment (severe)
  - 0-15 years: 96% **Mum!**
  - 16-24 years: 81%
  - 35-44 years: 50%
  - **45-54 years: 30%**
  - 55-88 years: 37%



# The Tarzan Syndrome

- This refers to men whose behaviour is determined to a large extent by their maleness. For men affected by the Tarzan syndrome, the need for self-image and status will lead them to undertake behaviours which are not rational and sometimes even dangerous.



# The Tarzan Syndrome – In Haemophiliacs

- "They did not want Haemophilia to define them".
- Overcompensation by risky behavior
- "This is evident when they neglect their medicine, refuse painkillers, focus on sports , drink or have drowned out or ignored their disorder



# Identity

- An identity conflict arises between being a haemophiliac and being a man - trying to conform to hegemonic under standings of masculinity
- "the fear and experience of losing masculinity are the most dominant factors in explaining how the transition to chronic pain affects quality of life and masculine identity."



## Relationship to health care system

- "I've been the expert on my disease since i was 6 years old"
- Did patient-education match your life situation and growing understanding of physiology?
- Things you were taught too late? (microbleeds?)
- "My fellow haemophiliac understands me better than my doctor!"



# Is this really me?

- Recognition of Self in Litterature?



## Perspectives

- Want to be recognised, not pitied
- "brothers in arms" – "the doctor was never in the trenches"
- the doctor as observer and facilitator
- "re-setting" of mind, re-education on own disease
- Every Decade it's own history
  - Recognise & Learn
  - Recognise & Teach
- Advise from Danish Foundation of Haemophilia (Website bullet points)



BløderNyt

Nyheder

Aktiviteter

Blødersygdom

Hæmofili A og B

Von Willebrand

ITP

Meget sjældne

blødersygdomme

Pårørende

Hiv

Hepatitis C

Livet med blødersygdom

At stikke selv

Venekateter

Inhibitor

Udskiftning af led

Seniorliv

Jobsøgning

Rejse

Sport

Hjelm til børn

30-50 år

**30-50 år**

All in på bløderlivet

De stive anklers

klub

Unge

Behandling



# Advice / Bullits from DHS

- Temadage  
Specialet peger på, at temadage kan bruges til at samle blødere på tværs af alder. I undersøgelsen var der bl.a. interesse for træning og kost.
- Digital videns- og erfaringsdeling  
Specialet viser en interesse i at bruge digitale platforme til at dele og udbrede erfaringer mellem ligesindede og på tværs af generationer.
- Kaffekonsultationer/Fyraftensmøder  
Specialet udpeger et ønske om adgang til den nyeste viden om blødersygdom og flere redskaber til at håndtere sygdom og krop. I specialet forslås fx uformelle fyraftensmøder mellem blødere og hæmofililæger.
- Pjece til forældre og børn med blødersygdom  
Specialet peger på, at der kan laves en pjece til forældre for at styrke vidensdeling mellem generationer og personer i samme situation.
- Rollen som far  
Specialet viser, at relationen til mellem far og barn er noget af det, der fylder mest for mænd med blødersygdom i forhold til deres livskvalitet og maskuline selvforståelse. Det anbefales i specialet, at foreningen laver aktiviteter som styrker faderskab.