



## The Good Life: Quality of Life among Danish PWBD

### Method

- Anonymous study conducted in collaboration with the haemophilia centers.
- The data has been collected through questionnaires.
- Longitude: 30 years (1988, 2001 and 2012).
- Focus: Danish people with bleeding disorders (PWBD) quality of life
- Respondents: Moderate to severe haemophiliacs type A and B and von Willebrand disease type 3.
- 250 respondents: 54 children and 196 adults.
- The data is stored in a dataset.

### Main findings among adult PWBD

- The age dispersal of Danish PWBD is starting to look more like that of Danish males.
- Because PWBD are getting older, more and more are affected by lifestyle and age related illnesses. There is currently very little knowledge about this new development.
- A positive tendency towards less sickness absence caused by bleedings can be detected among adult PWBD.
- On average PWBD feel less limited in terms of mobility.

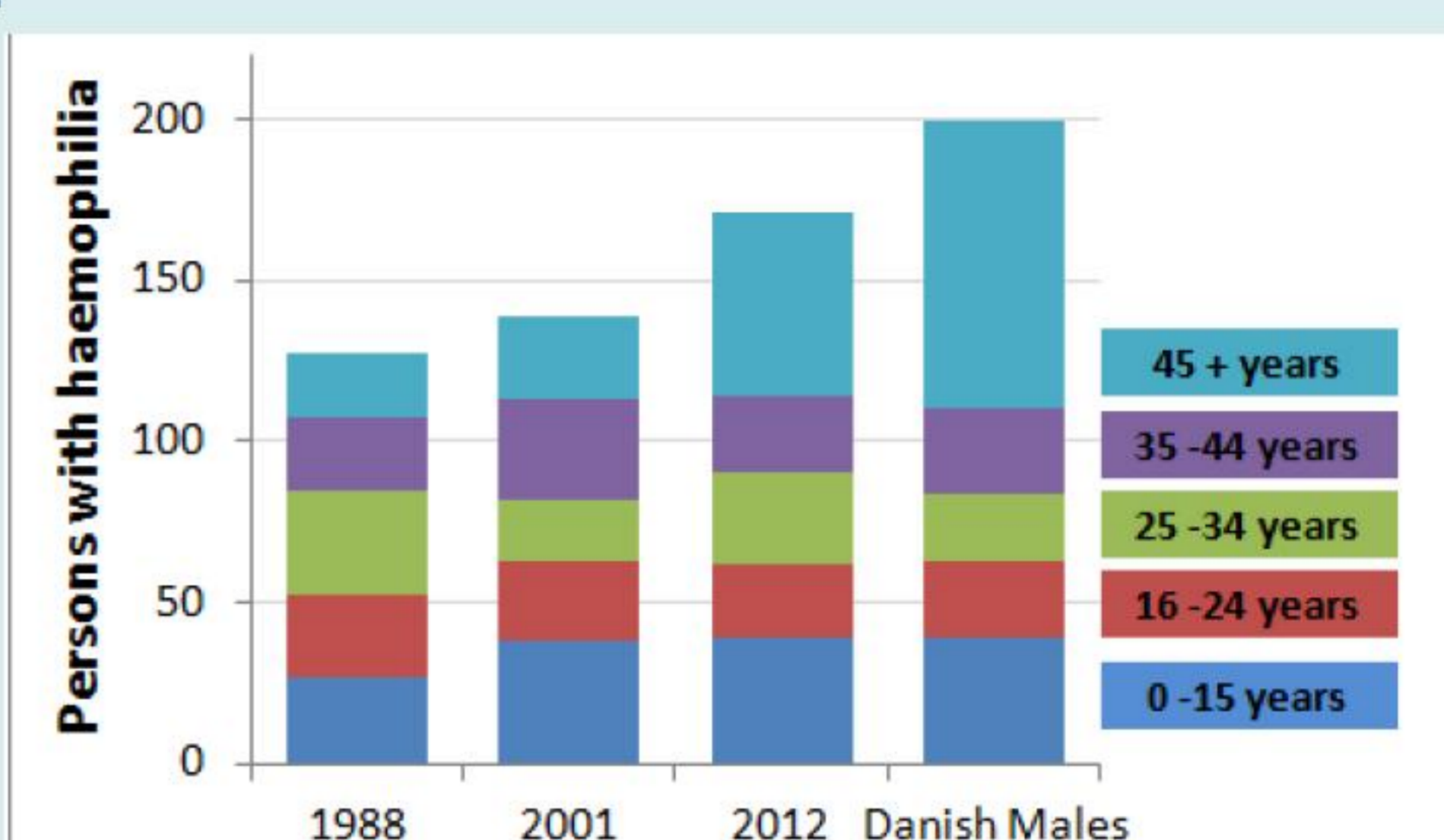


Figure 10.1 (QOL, 2012, p. 53)  
Age dispersal of Danish PWBD 1988, 2001 and 2012 compared to Danish males

### Main findings among young PWBD

- Generally, PWBD rarely think of life threatening bleedings and 79 % of the children evaluate their health as excellent or very good.
- For the children there seem to be a very positive development regarding bleedings. Over the years the number of bleedings among children seem to have dropped.
- As the table indicates the PWBD under prophylactic treatment will generally experience mobility limitations over time.
- The bleeding disorders seem to have less impact on choice of education and job options than previously. The bleeding disorders are, however, still seen as a barrier in regards of pursuing the dream education, especially among the 25-44 year old.
- The employment rate among PWBD between 16 and 34 is higher than among Danish males. However, later in life (between 35 and 64) the employment rate drops below that of Danish males.

	0 - 15 year	16 - 24 year	25 - 34 year	35 - 44 year	45 +	All
<b>1988</b>						
Ankle joint	19%	50%	67%	80%	75%	56%
Knee joint	12%	38%	73%	86%	95%	59%
Elbow Joint	4%	52%	79%	90%	70%	59%
Hip joint	0%	5%	9%	45%	44%	18%
Schoulder joint	4%	5%	21%	33%	37%	19%
Total (N)	27	24	33	22	20	125
<b>2001</b>						
Ankle joint	6%	20%	76%	71%	91%	48%
Knee joint	3%	8%	32%	82%	100%	44%
Elbow Joint	0%	13%	24%	79%	92%	41%
Hip joint	3%	0%	6%	23%	50%	16%
Schoulder joint	0%	4%	6%	22%	55%	16%
Total (N)	34	25	19	28	26	131
<b>2012</b>						
Ankle joint	-	22%	61%	92%	75%	66%
Knee joint	-	4%	29%	42%	77%	48%
Elbow Joint	-	4%	21%	50%	70%	45%
Hip joint	-	0%	4%	17%	37%	20%
Schoulder joint	-	4%	11%	29%	42%	27%
Total (N)	-	23	28	24	57	132

Table 10.1 (QOL, 2012, p. 58)  
Motion restriction in joints in times without bleedings, distributed according to age, 1988, 2001 and 2012

### Conclusion

#### Improved health, function, and participation:

- Higher life expectancy.
- Fewer bleedings that require factor treatment.
- Fewer PWBD with hepatitis C.
- Improved mobility.
- More PWBD are studying or working.
- Less sickness absenteeism caused by bleedings.

#### But challenges remain:

- Young PWBD still experience mobility limitations.
- Multimorbidity is a new challenge for older PWBD and the national health care system.

