



# **Health-Related Quality of Life for Ageing Patients with Haemophilia**

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John E. Maguire  
Elderly Man (1904)

# Dimensions of HRQOL Assessment



# Instrument Characteristics



- Generic vs. disease-specific
- Self- vs. other-rated
- Uni- vs. Multidimensional
- Adult vs. Children
- National vs. international

# Study Design

- **Study objectives:**
  - To describe health status, cognitive functioning and HRQoL of Italian elderly haemophilia patients
  - To evaluate the influence of co-morbidities on the health status and HRQoL in elderly haemophiliacs
  - To evaluate differences between haemophiliacs and controls
- **Study design:**
  - Multicentre case-control study
- **Population:**
  - Severe haemophilia A and B patients ( $\geq 65$  years) and age-matched controls without familiar haemorrhagic disease

# Health-Related Quality of Life Assessment



- Generic Instruments
  - WHOQOL-BREF (Skevington et al., 2004)
  - EQ-5D (Brooks, 1996)
- Instrument specific for Elderly population
  - WHOQOL-Old (Winkler et al., 2003)
- Haemophilia-specific Questionnaire adjusted for elderly
  - Haem-A-QoL<sub>elderly</sub> (v. Mackensen et al., 2004)

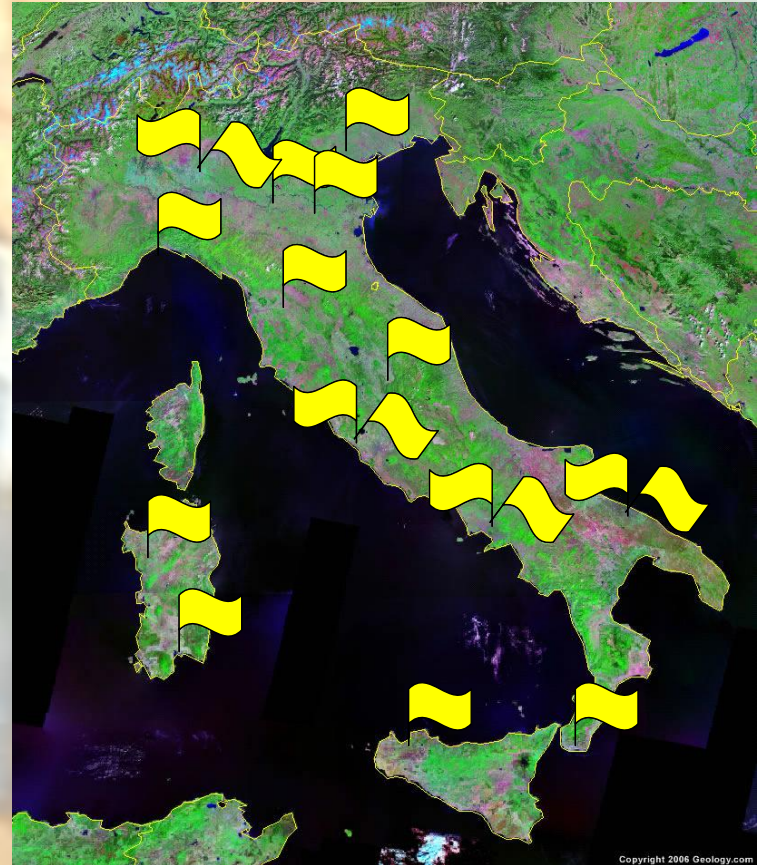
# Haem-A-QoL<sub>Elderly</sub>



- The Haem-A-QoL<sub>Elderly</sub> has been validated in the frame of this study and shows quite satisfactory psychometric characteristics (Cronbach's alpha for the total score  $\alpha = .967$ ).
- The Haem-A-QoL<sub>Elderly</sub> consists of 63 items pertaining to 11 dimensions:
  - Physical health
  - Emotions
  - View
  - Family
  - Others
  - Sport & leisure
  - Work
  - Dealing
  - Treatment
  - Future
  - Relationship

# Recruitment Status

- Out of 46 registered patients 39 participated (84.6%) and were matched with 43 non-affected controls.
- Clinical data of patients :
  - 85% had haemophilia A
  - 21% were on prophylaxis
  - 13% had inhibitors
  - 37% reported chronic pain
    - Median 90, range 0-100
  - 8.6 joint bleeds in past 12 months (Median 5, range 0-40)
    - 35% had no joint bleeds



# Socio-demographic Characteristics (n=83)

Socido-demographic data	Patients (n=39)	Controls (n=44)	p
Age: median range	68 years 65-78 years	68.5 years 65-79 years	n.s.
Marital Status:			<b>.004</b>
married	64 %	91 %	
single	23 %	-	
widowed	10 %	5 %	
divorced	2 %	5 %	
Living in the family	84 %	96 %	n.s.
School education:			n.s.
elementary	40 %	25 %	
medium	37 %	27 %	
high school	13 %	32 %	
university	11 %	16 %	
Previous profession:			n.s.
no	5 %	-	
blue collar	5 %	14 %	
white collar	23 %	18 %	
manager	8 %	14 %	
professional	15 %	9 %	
other	44 %	46 %	

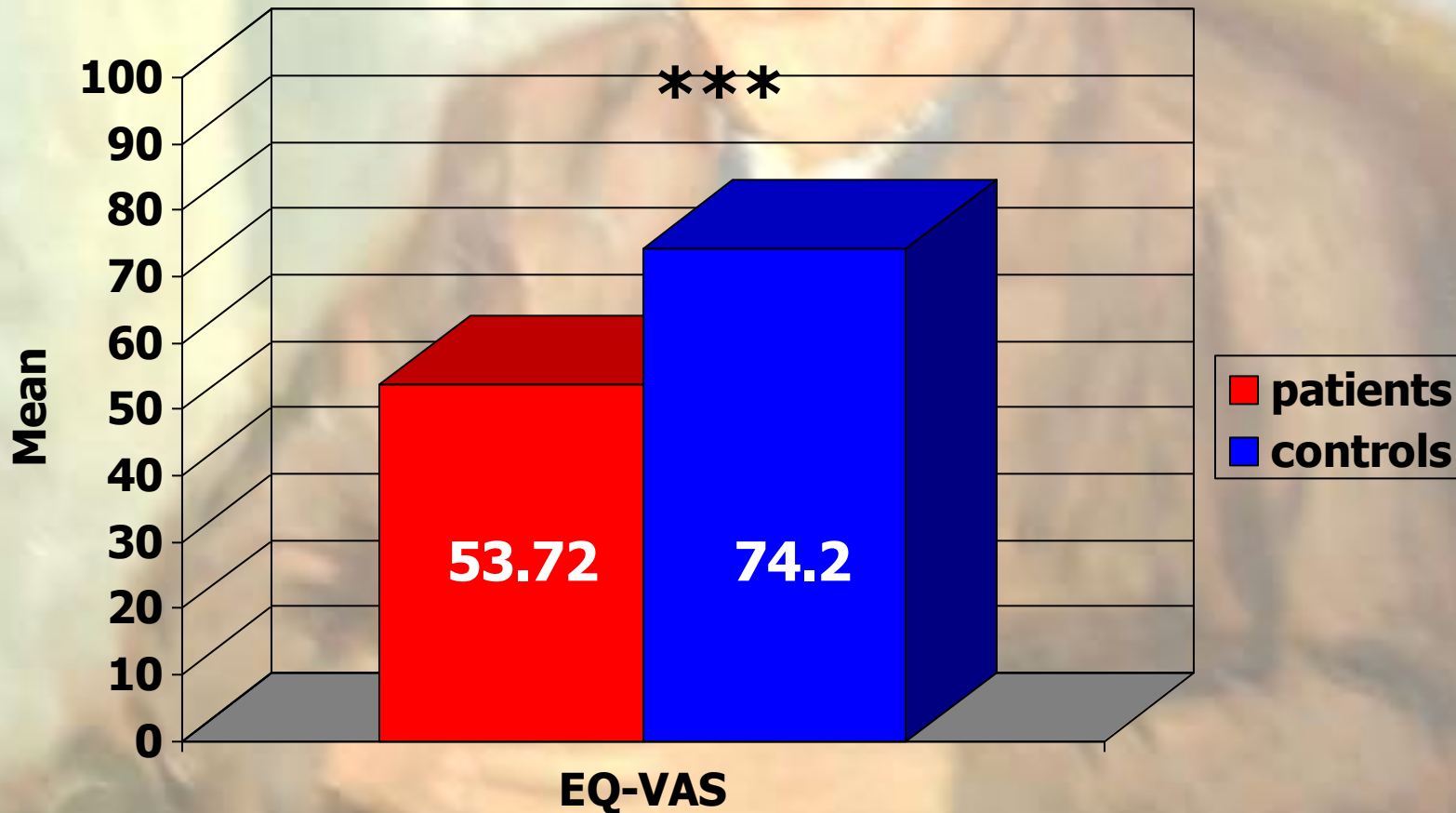




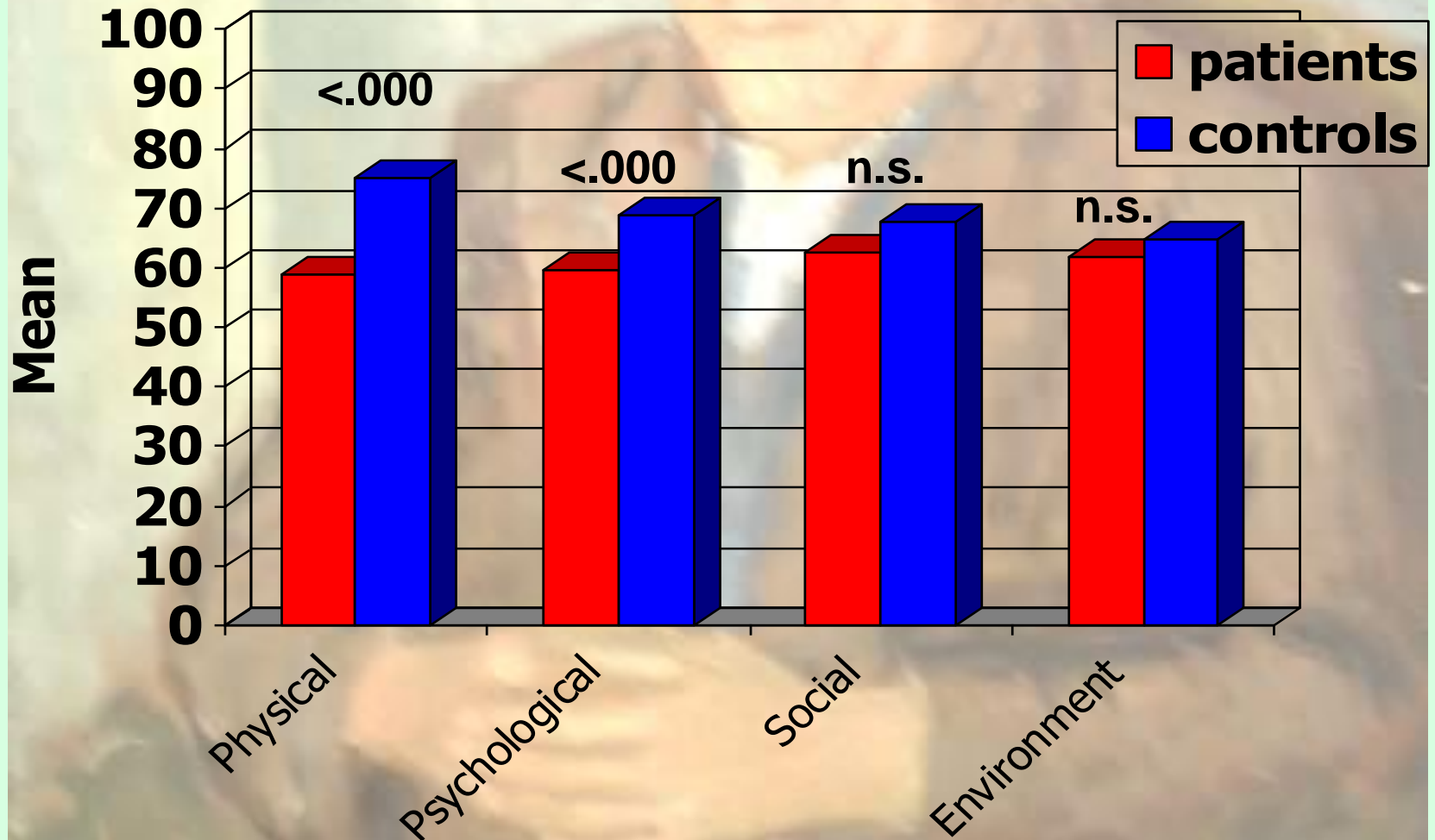
# Clinical Data (n=82)

Clinical Data	Patients (n=39)	Controls (n=43)	p
Infections: HBV	11 %	-	<b>.027</b>
HCV	87 %	5 %	
HIV	13 %	-	
Invalidity	76 %	9 %	<b>.000</b>
Hypercholesterolemia	3 %	39 %	<b>.000</b>
Orthopaedic Score			
Mean (SD)	19.8 (15.2)	1.36 (2.0)	<b>.000</b>
Median (range)	18 (0-67)	1 (0-10)	

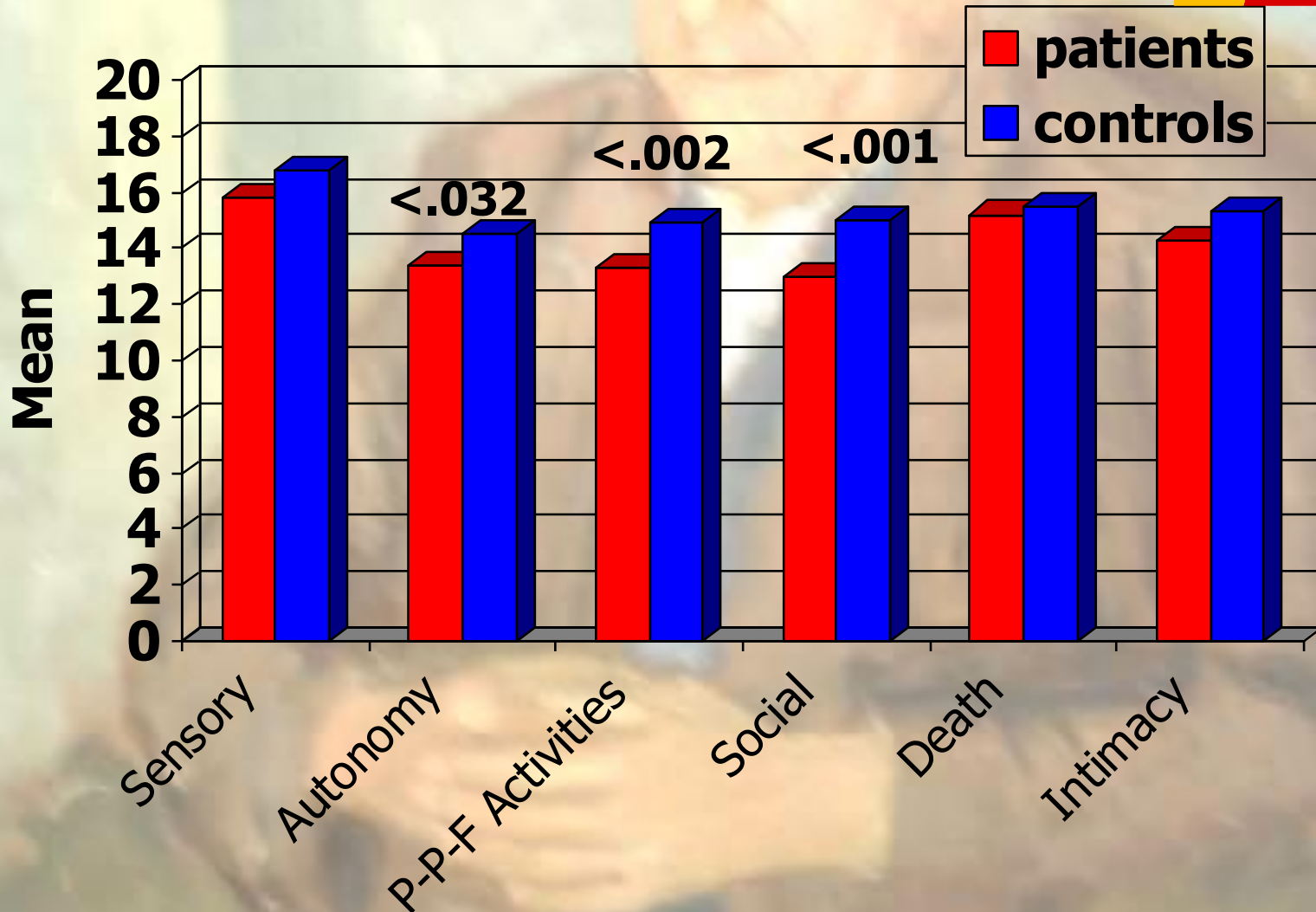
# Generic Quality of Life: EQ-Visual Analogue Scale



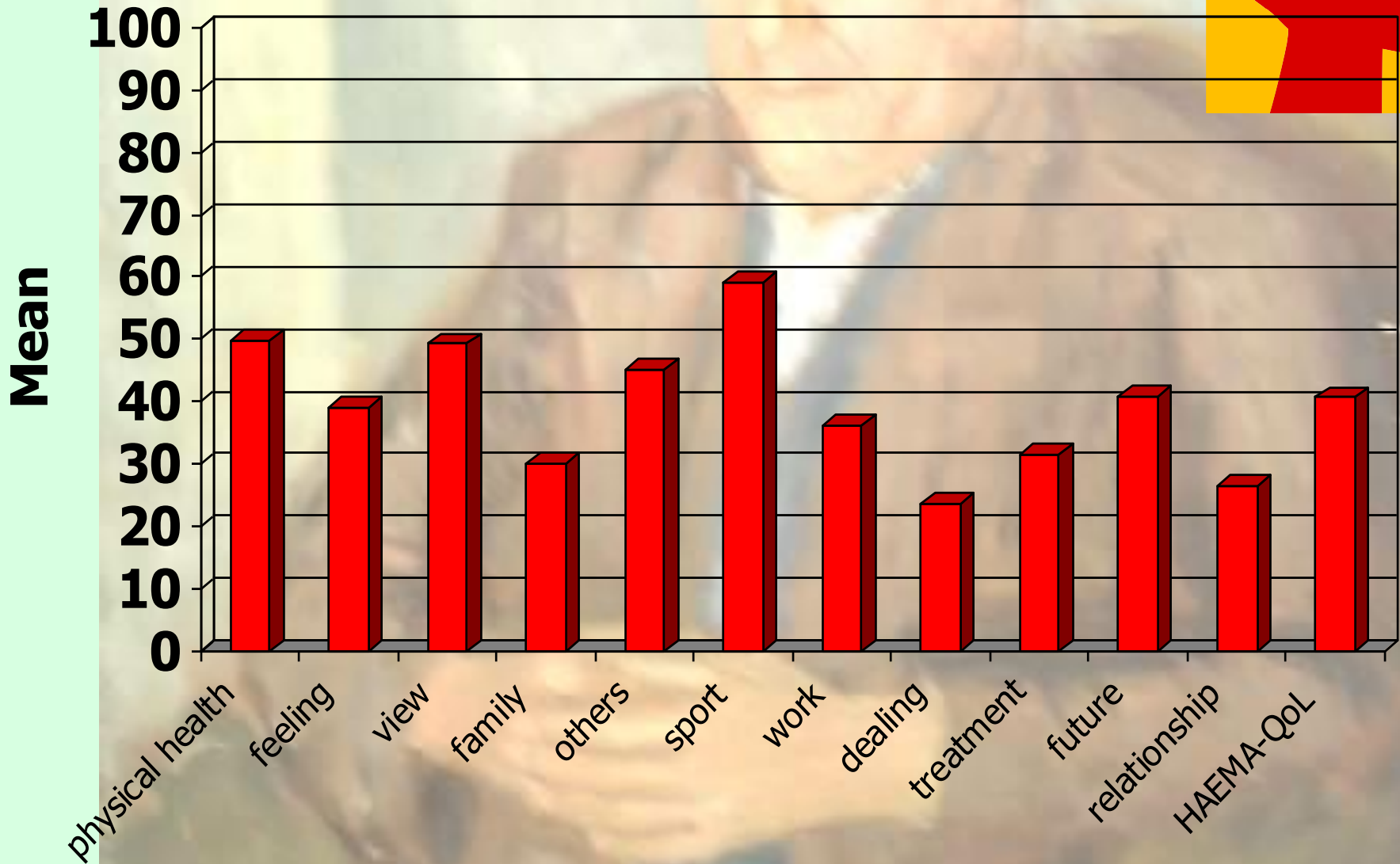
# Generic HRQoL: WHOQoL-BREF



# Geriatric HRQoL: WHOQoL-Old



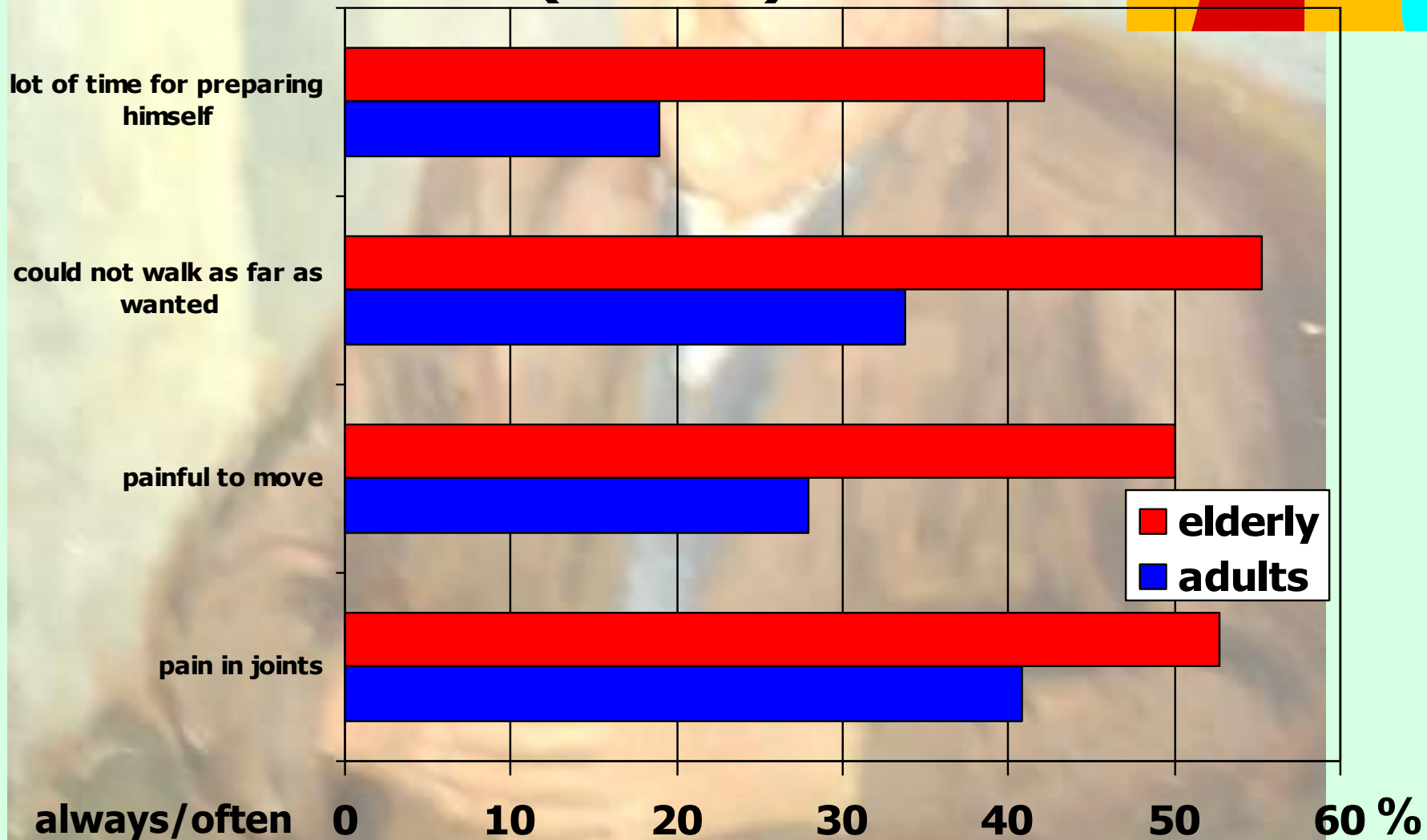
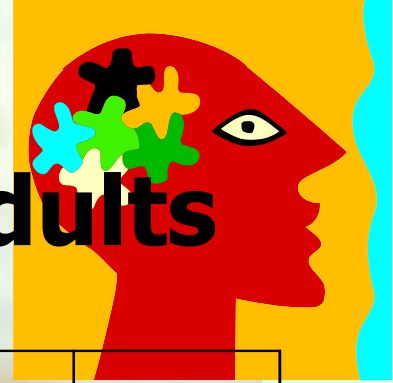
# Haemophilia-Specific HRQoL: Haem-A-QoL<sub>Elderly</sub>



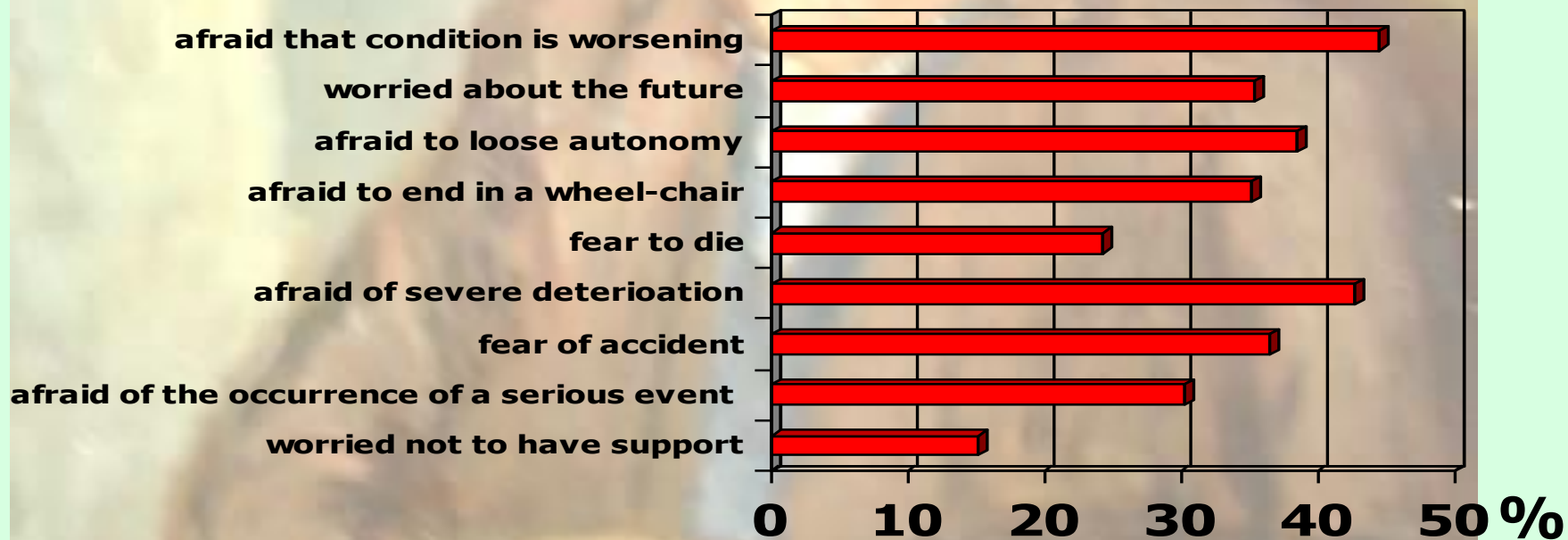
# Haem-A-QoL<sub>Elderly</sub> Physical Health



# Physical Health Comparison with younger adults (n=169)



# Haem-A-QoL<sub>Elderly</sub> Future





# Conclusions

- Haemophilia has a great impact on health-related quality of life of elderly patients
  - they are more impaired in their generic HRQoL (EQ-5D, WHOQOL-BREF) compared to controls
  - they show significant worse HRQoL in the dimensions 'autonomy', 'past-present-future activities' and 'social participation' in the geriatric WHOQOL-OLD
  - Haemophilia patients are mainly impaired in the dimensions 'sport', 'physical health' and 'view' in the haemophilia-specific Haem-A-QoL<sub>Elderly</sub>

# Outlook

- Since haemophilia patients are significantly less married compared to controls and their everyday life is impaired by their health condition, this can result in a worsen situation, because elderly patients need more assistance being less autonomous in daily life activities.
- Therefore special care and consideration should be dedicated to those patients.

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