

Validation of the HEP-Test-Q for the Assessment of Subjective Physical Performance in English-Speaking Haemophilia Patients

Poster 168-P-W

Sylvia von Mackensen¹, Dörte Czepa², Kate Khair³, Leonard Valentino⁴ & Thomas Hilberg²

¹ Institute of Medical Psychology, University Medical Centre, Hamburg, Germany

² Department of Sports Medicine, University of Wuppertal, Germany

³ Haemophilia Centre, Great Ormond Street Hospital for Children NHS Trust, London WC1N 3JH, UK

⁴ RUSH Hemophilia and Thrombophilia Center, RUSH University Medical Center, Chicago, IL USA

Introduction:

One of the most frequent complications of recurrent bleeding into joints is arthropathy. Therefore the assessment of orthopaedic joint score (OJS) and physical functioning in people with haemophilia (PWH) is quite important. Besides objective measures subjective measures are also available. The HEP-Test-Q assesses subjective physical performance and was originally developed and validated in Germany [1]. The aim of this study was to linguistically validate and psychometrically test the English version of the HEP-Test-Q for use in English-speaking PWH.

Methods:

The HEP-Test-Q consists of 25 items pertaining to four subscales 'mobility', 'strength & coordination', 'endurance' and 'body perception' (high scores indicating good physical performance) (see Fig. 1). The forward/backward translated English version of the HEP-Test-Q was administered to patients from the UK and the US. Clinical data such as type and severity of haemophilia, bleeding frequency and OJS were collected by haemophilia specialists.

Fig. 1. Excerpt of the HEP-Test-Q, items of the two subscales, 'strength & coordination' and 'endurance'

| Questionnaire | | HEP-Test-Q | | | | |
|--|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 3. We would like to know what you think about your STRENGTH & COORDINATION | | | | | | |
| In the past 4 weeks ... | | never | seldom | sometimes | often | always |
| 1. | ... I had a lot of energy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. | I felt secure walking | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. | I had problems climbing stairs | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. | it was difficult for me to climb stairs without holding onto something | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. | I had problems walking downstairs | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. | ... I had difficulty lifting or carrying heavy things | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. | I had problems with keeping my balance on rough ground | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. what about your ENDURANCE? | | | | | | |
| In the past 4 weeks ... | | never | seldom | sometimes | often | always |
| 1. | ... I could cover far distances (about 30 minutes or 2 km) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. | ... I was exhausted after physical activities of medium difficulty (e.g. climbing stairs and carrying shopping) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. | ... I was easily out of breath | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. | ... I could do physical activities longer than usual | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. | I was easily tired | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. | I could carry out exhausting activities (e.g. walking fast, cycling) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. | I did a lot with others | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. | I was physically more active than usual | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Tab. 2. Psychometric characteristics of the HEP-Test-Q

| Dimension | No of items | Min | Max | Mean | SD | Cronbach's α |
|-------------------------|-------------|------|-----|------|------|--------------|
| Mobility | 4 | 0 | 100 | 71.2 | 26.9 | .891 |
| Strength & coordination | 8 | 28.1 | 100 | 81.0 | 16.0 | .794 |
| Endurance | 8 | 31.3 | 100 | 67.1 | 16.9 | .729 |
| Body perception | 5 | 0 | 100 | 78.8 | 23.2 | .885 |
| HEP-Test-Q | 25 | 32 | 100 | 74.6 | 15.7 | .916 |

References

[1] Von Mackensen, S., Czepa, D., Herbsleb, M., & Hilberg, T. (2010). Development and validation of a new questionnaire for the assessment of subjective physical performance in adult patients with haemophilia - the HEP-Test-Q. *Haemophilia*, 16(1), 170-178.

Results:

A total of 38 PWH completed the questionnaire, clinical data are shown in Tab. 1. Patients needed 9.4 ± 4.7 minutes to complete the HEP-Test-Q and reported no problems with the questions or answer categories. Psychometric characteristics of the newly translated HEP-Test-Q showed good values for internal consistency (see Tab. 2). Known groups validity of the HEP-Test-Q was tested comparing PWH with a low (<3) vs. a high (≥3) OJS based on the median split (see Fig. 2) and PWH reporting pain vs. no pain (see Fig. 3) and PWH having limitations in mobility vs. PWH without limitations (see Fig. 4). In all clinical subgroups significant differences were found for almost all dimensions of the HEP-Test-Q, but for the dimension 'perception'. PWH reported in general a good subjective physical performance, but had the highest impairments in the dimension 'endurance' and 'mobility' (Fig. 5).

Conclusion:

The English version of the HEP-Test-Q has proven to be a reliable and valid instrument for the assessment of subjective physical performance for use in English-speaking PWH.

Tab. 1. Clinical data of the English-speaking haemophilia patients

| Clinical Data | Adults (n=9) | Children (n=29) | TOTAL (n=38) |
|-------------------------------|------------------------|------------------------|------------------------|
| | M ± SD (range) | M ± SD (range) | M ± SD (range) |
| Age [years] | 29.8 ± 10.2 (19-48) | 11.5 ± 3.4 (4-17) | 15.8 ± 9.7 (4-48) |
| BMI [kg/m ²] | 30.0 ± 9.4 (14.3-47.2) | 21.5 ± 6.0 (14.2-40.0) | 23.5 ± 7.7 (14.2-47.2) |
| Total bleeds [last 12 months] | 10.9 ± 13.3 (1-40) | 5.2 ± 14.3 (0-72) | 6.6 ± 14.1 (0-72) |
| Joint bleeds [last 12 months] | 8.0 ± 10.2 (0-30) | 1.4 ± 2.2 (0-8) | 2.8 ± 5.7 (0-30) |
| OJS [Score] | 9.4 ± 10.7 (0-34) | 2.8 ± 4.5 (0-17) | 4.3 ± 7.2 (0-34) |
| | N (%) | N (%) | N (%) |
| Type of haemophilia | | | |
| A | 7 (77.8%) | 26 (92.9%) | 34 (89.5%) |
| B | 2 (22.2%) | 2 (7.1%) | 4 (10.5%) |
| Severity | | | |
| severe | 7 (77.8%) | 24 (85.7%) | 31 (81.6%) |
| moderate | - | 2 (7.1%) | 2 (5.3%) |
| mild | 2 (22.2%) | 2 (7.1%) | 5 (13.2%) |
| Treatment | | | |
| prophylaxis | 6 (66.7%) | 26 (89.7%) | 32 (84.2%) |
| on-demand | 3 (33.3%) | 3 (10.3%) | 6 (15.8%) |
| Pain | | | |
| yes | 6 (66.7%) | 10 (34.5%) | 16 (42.1%) |
| Limitations in mobility | | | |
| yes | 5 (55.6%) | 5 (17.2%) | 10 (26.3%) |

Fig. 5. Dimensions of the HEP-Test-Q compared between children and adults

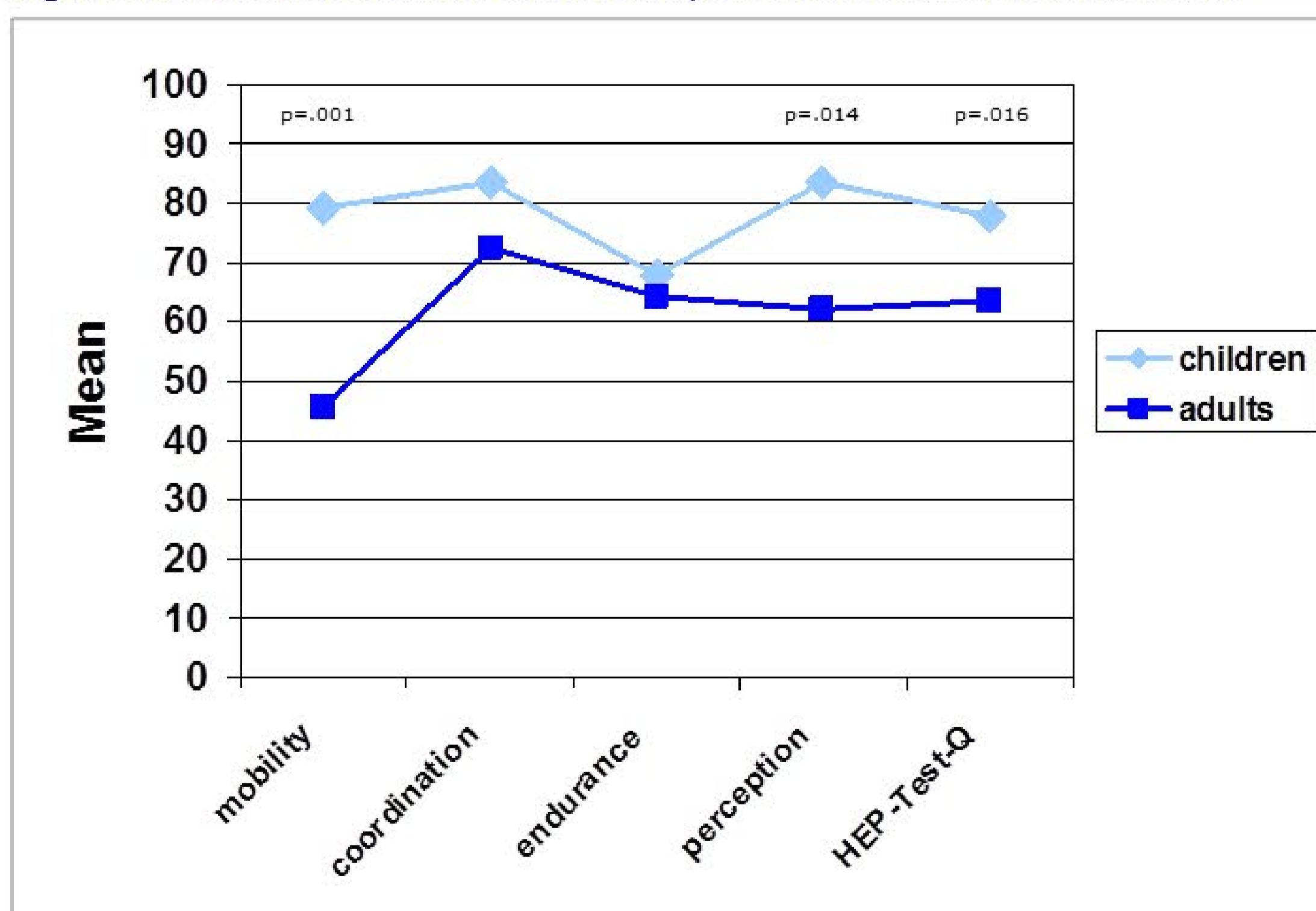


Fig. 2. Differences in HEP-Test-Q related to Orthopaedic Joint Score (OJS)

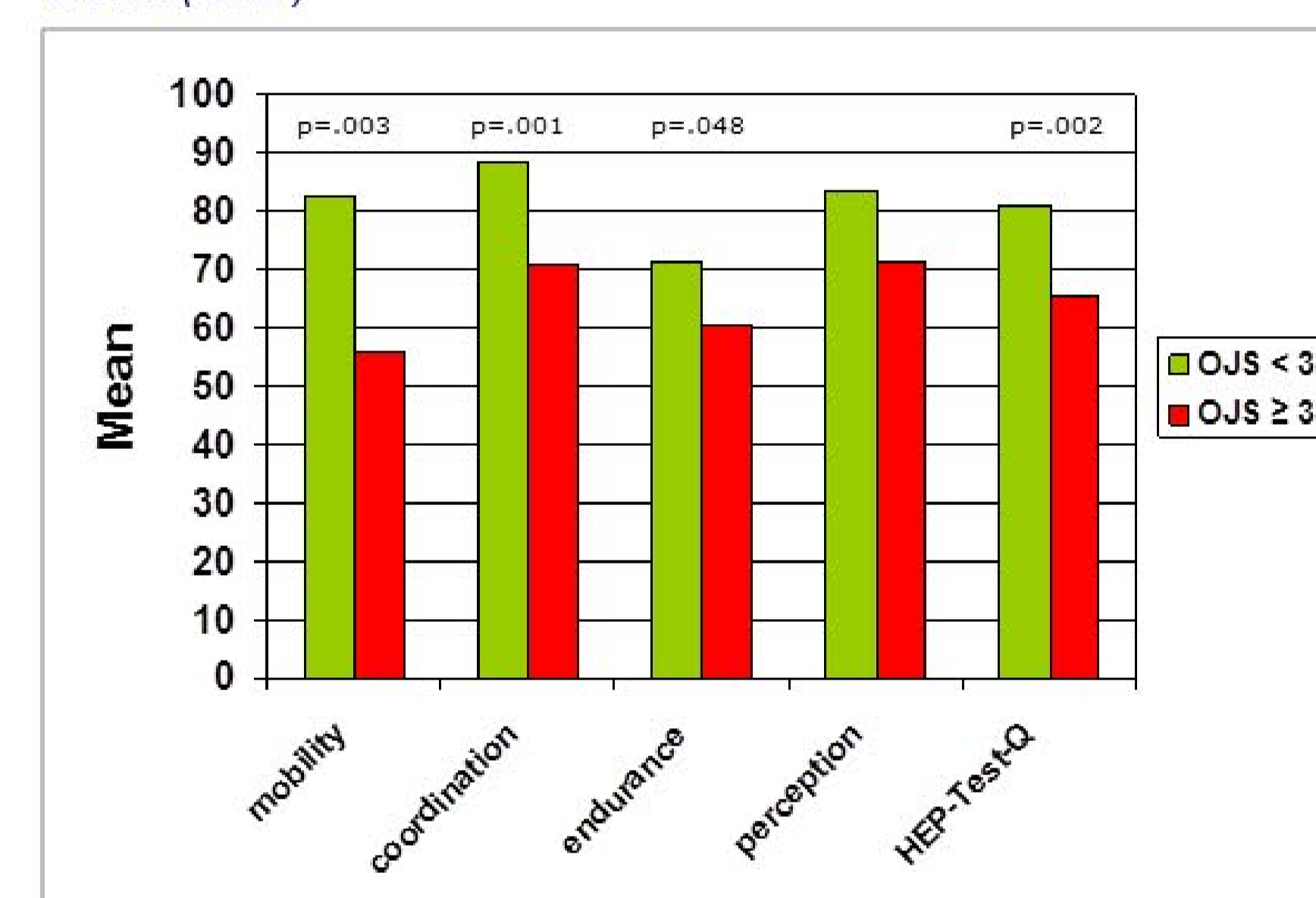


Fig. 3. Differences in HEP-Test-Q related to Pain

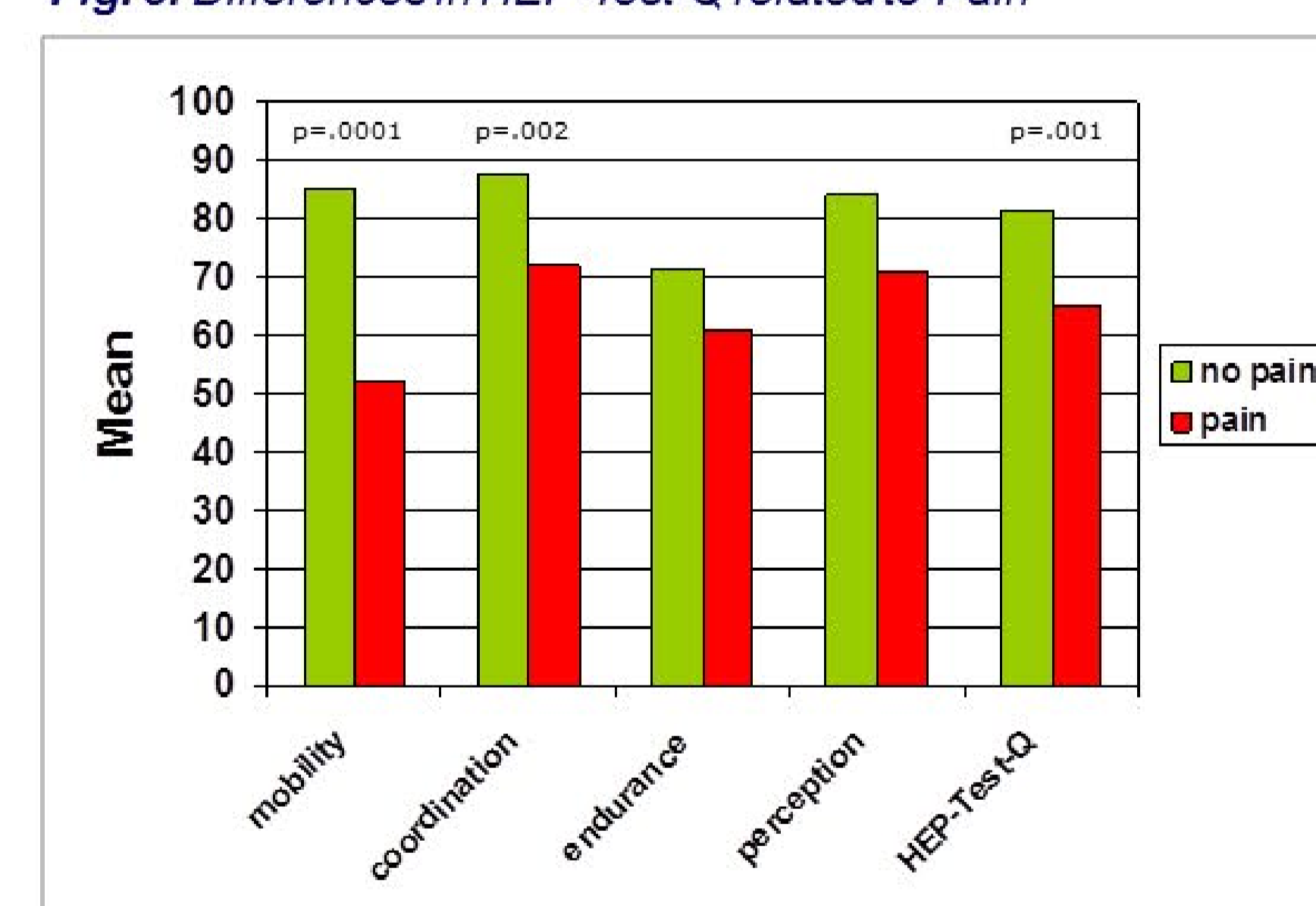


Fig. 4. Differences in HEP-Test-Q related to Limitations in Mobility

