

Haemophilia & Exercise Project (HEP): Subjective and objective physical performance in adult haemophilia patients after one year sports therapy programme

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"[...] I would also like to thank you once again. Since I have been a part of the camp and have been doing sports regularly, I have been feeling great. I have had less bleeding, a better feeling of the body and much more motivation." (Patient's comment B.D., September 2010)

Introduction:

Bleeding events in people with haemophilia (PWH) are associated with a reduced activity level and consequently with limitations in physical performance. Until today, there is little experience in effects of sports therapy on PWH. Within the scope of the 'Haemophilia & Exercise Project' (HEP) (www.haemophilia-exercise.de) PWH participated in a special model of "Programmed Sports Therapy" (PST).

Aim of this study was to investigate subjective and objective physical performance in PWH after annual PST.

Subjects & Methods:

Forty-eight adult subjects - 46 with haemophilia A, of whom 43 were severely affected and two with severe haemophilia B - were compared to each other regarding their physical performance (PP) before and after PST (Figure 1). PP was assessed subjectively with HEP-Test-Q and objectively relating to mobility (range of motion), strength and coordination (one-leg-stand) and endurance (12-minute walk test). PST included two collective instructive sports camps per year together with a supervised selfemployed home training. Participants documented their training and evaluated their activity level. In addition, 43 controls without haemophilia and without training were examined.

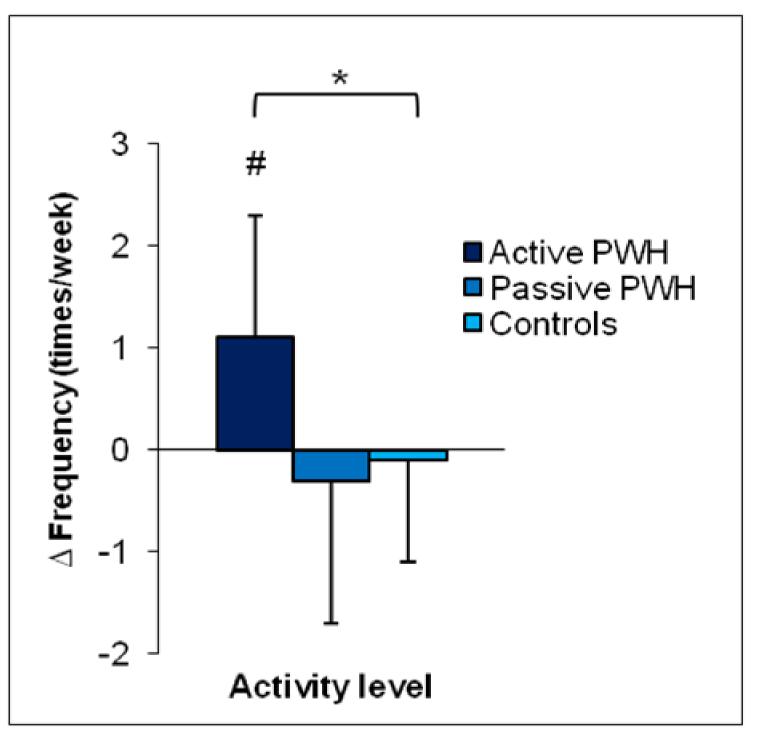




Fig. 1. Concept and contents of the "Programmed Sports Therapy"

Fig. 2. Changes in activity level after one (n=13) and passive (n=12) people with haemophilia (PWH) and controls (n=19); Kruskal-Wallis-test; *p≤0.05, #p≤0.05 (active PWH versus passive PWH and controls); positive values im-ply an increase of the activity level.

Tab. 1. Clinical data; subgroups of peo-ple with haemophilia (PWH) and con-trols; OJS Orthopaedic Joint Score

(modified WFH-Score), n.s. = not significant; † Univariat ANOVA, the others with Kruskal-Wallis-test; *p≤0.05 (dropped out PWH versus passive PWH and controls); ***p≤0.001 (controls versus active PWH, passive PWH and dropped out PWH).

Active PWH	Passive PWH	Dropped out	Controls	p-value
(n=13)	(n=12)	PWH (n=23)	(n=19)	
45 ± 5	36 ± 15	48 ± 9 *	39 ± 11	0.006†
(36 to 55)	(19 to 65)	(29 to 61)	(23 to 59)	
26.2 ± 5.2	22.6 ± 3.6	26.3 ± 4.6	25.9 ± 2.9	n.s.
(20.8 to 37.7)	(18.3 to 28.7)	(19.2 to 38.6)	(17.6 to 29.6)	
32 ± 10	26 ± 10	29 ± 9	4 ± 3 ***	≤0.001
(18 to 48)	(10 to 47)	(8 to 43)	(0 to 10)	
	$\begin{array}{c} \textbf{(n=13)} \\ 45 \pm 5 \\ (36 \text{ to } 55) \\ 26.2 \pm 5.2 \\ (20.8 \text{ to } 37.7) \\ 32 \pm 10 \end{array}$	(n=13)(n=12) 45 ± 5 36 ± 15 $(36 \text{ to } 55)$ $(19 \text{ to } 65)$ 26.2 ± 5.2 22.6 ± 3.6 $(20.8 \text{ to } 37.7)$ $(18.3 \text{ to } 28.7)$ 32 ± 10 26 ± 10	(n=13)(n=12)PWH (n=23) 45 ± 5 36 ± 15 48 ± 9 *(36 to 55)(19 to 65)(29 to 61) 26.2 ± 5.2 22.6 ± 3.6 26.3 ± 4.6 (20.8 to 37.7)(18.3 to 28.7)(19.2 to 38.6) 32 ± 10 26 ± 10 29 ± 9	$\begin{array}{c ccccccccccccccccccccccccccccccccccc$

Results:

Data are presented as mean values \pm standard deviation (min to max). Out of 48 PWH, 13 performed a regular training (active PWH). Twelve HEP-participants were constantly passive over time (passive PWH). Twenty-three PWH and 24 controls dropped out because of incompleted data (Table 1). The activity level increased by 100% in active PWH and remained unchanged in passive PWH and controls (p≤0.05) (Figure 2). The mobility of the right knee was significantly improved in active PWH (+5.8° \pm 5.3°) compared to passive PWH

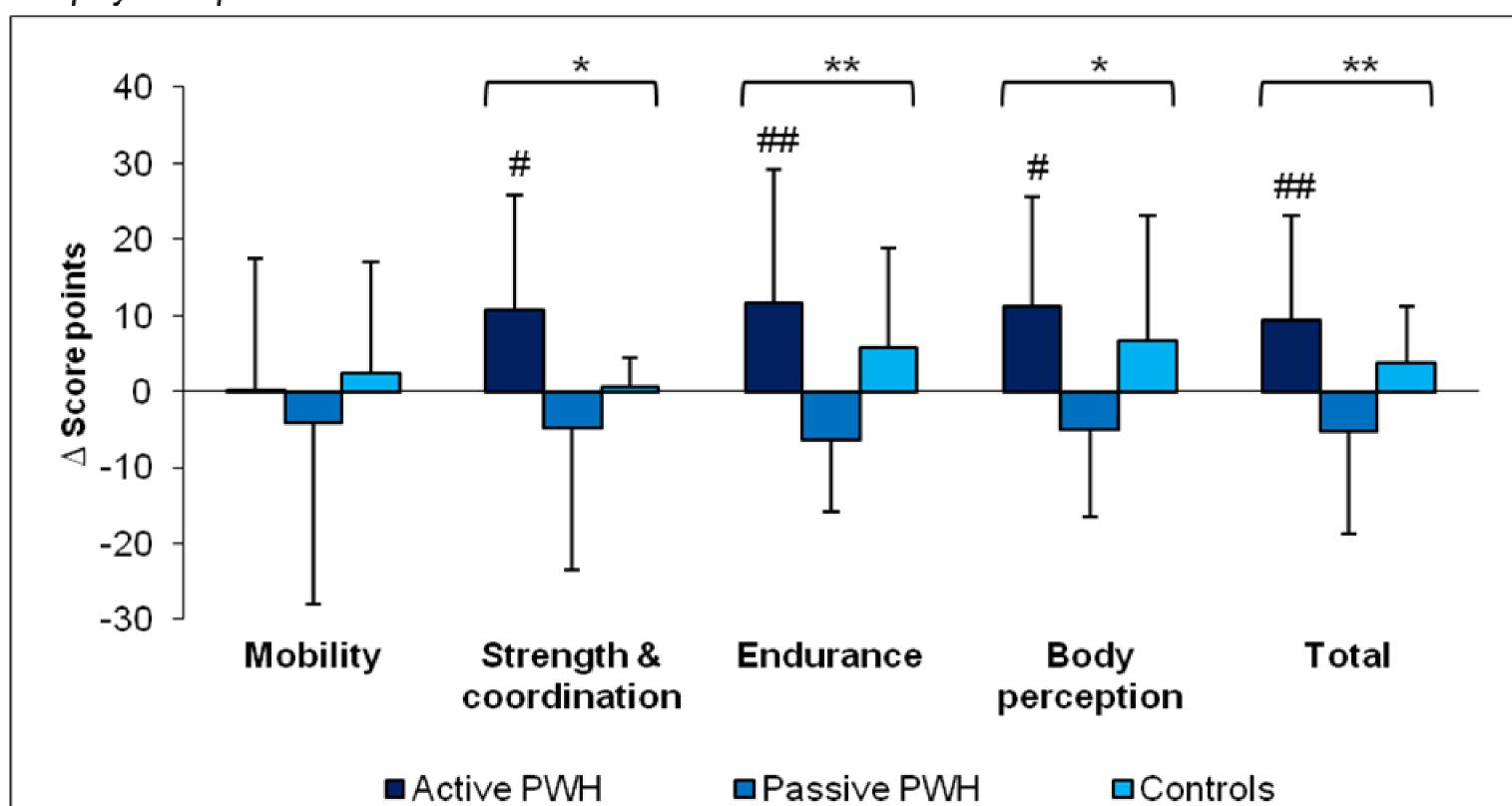
 $(-1.3^{\circ} \pm 8.6^{\circ})$. The mobility in the other joints as well as the one-legstands were the same. 12-minute walk test proved a significant lon-ger walking distance for active PWH (+217 ± 199 meters) compa-red to controls (-32 \pm 217 meters). Active PWH reported a significant better subjective physical perfor-mance in the HEP-Test-Q do-mains 'strength & coordination', 'endurance' and the total score (+9.4 \pm 13.6) compared to passive PWH (-5.3 \pm 13.5) and controls (+3.7 \pm 7.5) (Figure 3).

Conclusion:

Sports therapy affects positively the activity level and the physical performance of haemophilia patients, whereby objective effects were not always in agreement with subjective assessments.

Fig. 3. Changes in subjective physical performance (HEP-Test-Q) after one year sports therapy programme; active (n=13) and passive (n=12) people with haemophi-

year sports therapy programme; active lia (PWH) and controls (n=18, one control did not fill out the HEP-Test-Q during the first examination); domains 'mobility' and 'strength & coordination' with Kruskal-Wallis-test, the others with univariat ANOVA; *p≤0.05, **p≤0.01; #p≤0.05 (active PWH versus passive PWH); ##p≤0.01 (active PWH versus passive PWH); positive values imply an increase of the physical performance.



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