

Monitoring pain and joint health in patients with haemophilia

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Introduction

Patients with haemophilia experience joint bleeds and develop chronic joint disease and pain leading to reduced mobility. Prophylaxis in patients with severe haemophilia to avoid any bleeding is standard of care. Patient reported outcome is crucial to optimize treatment. We developed a simple questionnaire to assess pain and joint health to investigate the current status of our patients and the possibility for treatment optimization.

Methods

All patients with haemophilia A or B (severe and mild/moderate) received the questionnaire during a personal visit at our haemophilia treatment center. The following items were asked: presence and location of pain and pain intensity in the last four weeks, triggering factors, physical activity and therapeutic interventions. The patient charts were evaluated for type and severity of haemophilia and treatment regimen.

Results

159 patients (pts) returned at least one questionnaire including 139 (87%) pts with haemophilia A (HA), 20 (13%) with haemophilia B (HB). The average age at the time of the first questionnaire was 38 years. 127 (80%) pts were treated with prophylaxis, 96 (60%) patients reported regular physical activity.

Pain in the last four weeks before the visit date was stated by 119 (75%) pts. The ankle joint (n = 74, 47%), knee joint (n = 46, 29%), elbow joint (n = 40, 25%), followed by shoulder joint (n = 27, 17%) and hip joint (n = 14, 9%) were the reported joints with decreasing frequency. 30 (19%) pts reported pain in other parts of the body. As a trigger for pain 93 (58%) pts mentioned extended physical activity and 44 (28%) pts a bleed. 57 (36%) pts reported pain without an identified trigger and 26 (16%) pts reported constant pain. The mean severity of pain on the numeric analog scale (1 no pain and 10 worst pain) was 3.26. For the treatment of joint pain 86 (54%) pts used factor replacement, 93 (58%) pts pain medication and 62 (39%) pts used conservative measures like immobilization and cooling. 40 (25%) pts performed physiotherapy regularly and 10 (6%) pts were treated by a pain specialist. 104 (65%) pts reported that the used treatment was successful.

Conclusions

In addition to the medical visit the questionnaire detected relevant information about pain and joint health in pts with haemophilia. The majority of patients had pain in the last 4 weeks. Factor replacement and pain killers were used predominantly to treat pain. Despite significant improvements in the treatment of haemophilia patients and nearly all pts with severe haemophilia on prophylactic factor replacement pain and joint health need further treatment optimization. Especially physiotherapy was only done regularly by a quarter of our patients. Standardized patient reported outcome could add relevant input to improve joint health and pain management in the future.

	N (%)
Haemophilia A and B	159 (100%)
Haemophilia A (HA)	139 (87%)
Haemophilia B (HB)	20 (13%)
mild/moderate HA and HB	32 (20%)
mild/moderate HA	27 (17%)
mild/moderate HB	5 (3%)
Severe HA and HB	127 (80%)
severe HA	112 (70%)
severe HB	15 (10%)
<i>Treatment all patients</i>	
on demand	32 (20%)
prophylaxis	127 (80%)
<i>regular physical activity</i>	96 (60%)
<i>pain in the last four weeks (more than one answer)</i>	
shoulder joint	27 (17%)
elbow joint	40 (25%)
hip joint	14 (9%)
knee joint	46 (29%)
ankle joint	74 (47%)
other parts of the body	30 (19%)
no pain	40 (25%)
<i>trigger for pain (more than one answer possible)</i>	
no trigger identified	57 (36%)
physical activity	93 (58%)
bleeding	44 (28%)
constant pain	26 (16%)
<i>mean severity of pain (numeric analog scale 1-10)</i>	3,26
<i>treatment of pain (more than one answer possible)</i>	
factor replacement	86 (54%)
immobilization/cooling	62 (39%)
physiotherapy	40 (25%)
pain specialist	10 (6%)
pain medication	93 (58%)
<i>treatment success</i>	104 (65%)