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Introduction

Older persons with haemophilia (PWH) often suffer from hemophilic arthropathy (HA) in more than one joint. HA resembles degenerative joint disease and is characterised by pain, loss of range of motion and strength (body level). HA in the lower extremities reduces essential physical activities, i.e. walking (activity level), resulting in less ability to function in their society (participation level).

Orthopaedic surgery in our hospital was expanded since 1995 from single procedures towards multiple joint procedures (MJP), in order to optimally restore activities. MJP is defined as any combination of Total Knee (TK), Total Hip (TH) or Ankle Arthrodesis (AA) during one in-hospital stay, performed during one session or staged.

We described this particular group to define clinical guidelines on rehabilitation (Haemophilia 17 (6), 2011; 971-8). Unfortunately a standard set of measurement tools was lacking completely.

The aim of this study is to define an adequate set of measurement tools to describe the population of PWH who underwent a MJP. Objectives are needed to decide the optimal moment of surgery, and to perform an adequate follow-up, both short and long term. Only in this way we will be able to describe the benefits as well as complications and get insight how to optimize the results for this very specific group of PWH, who made an enormous investment by undergoing an MJP.

Patient characteristics	Frequency (percentage)
Type	
Hemophilia A	48 (90,6)
Hemophilia B	4 (7,5)
Hemophilia B Leyden	1 (1,9)
Severity	
Severe	49 (92,5)
Moderate	1 (1,9)
Mild	3 (5,7)
Age (average)	
On date first operation	47 [42-52.5]

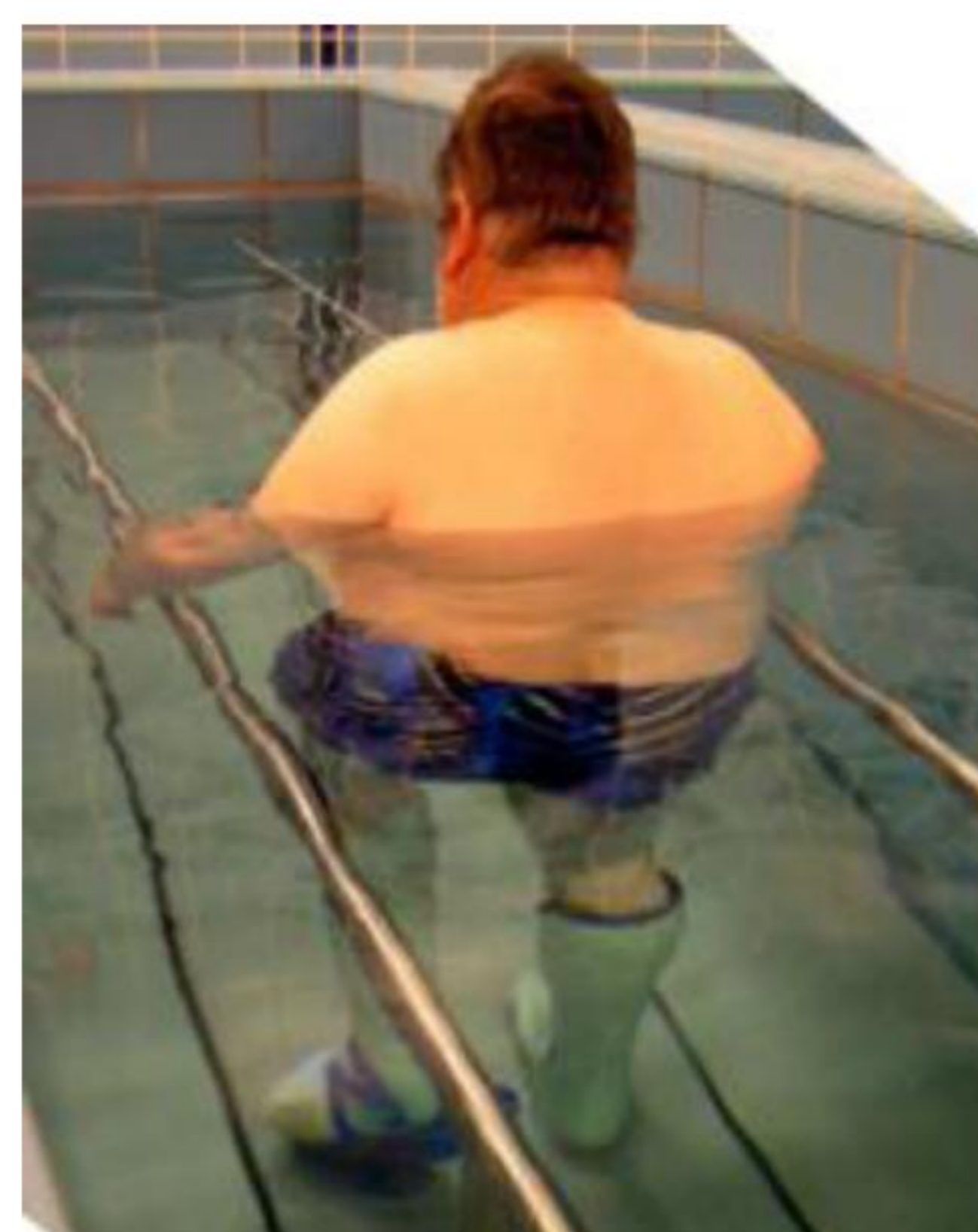


Table 1 Group characteristics (n=53)

Methods

Pre operatively the range of motion and pain (WFH score) was measured (body level) of 19 patients. The MACTAR, a semi open interview, results in 0-5 items PWH indicate they do perform, but which are limited by pain. This instrument was only used at a few patients.

This lack of information, a consequence of just routine check ups, made us decide to explore this group. Besides the measurements mentioned, we tried to measure both pre and postoperatively (retrospective) body functions as pain (WFH score and VAS), range of motion (goniometry), activities (HAL, MACTAR) and participation (SF 39 and EQ-5D).

Results

From 1995 till today 53 PWH underwent 56 MJP of their lower extremities, see table 1. They were all clinically rehabilitated in the UMCUtrecht, the Netherlands. Eight patients passed away, and another eight patients were excluded: three were lost for follow up, 5 had complications of which one MJP related.

Of the remaining group of 37 patients 22 were included and measured. From that group a pain reduction was found both by making use of the WFH score as well as using VAS (figure 1 and 2). The range of motion did not increase. The MACTAR indicates the most limited activities of this group (table 2). The HAL showed an average sum score of 46, being very sensitive in differentiating between upper and lower extremities, but also between basic and complex lower extremities. The SF 36 results in an average health of 69,3 (15,6) and discriminates role limitation physically (39,5) from emotional (73,7) and social functioning (69,7) quite well. The EQ 5D resulted in a mean of 0,72 (0,19).

It was, unfortunately, not possible to compare pre and post operative values in all cases. Especially pain, measured both by the WFH score as VAS and MACTAR could not be used for this purpose. The time gap between measurements both pre and post operative was large, see fig 1 and 2 and table 1.

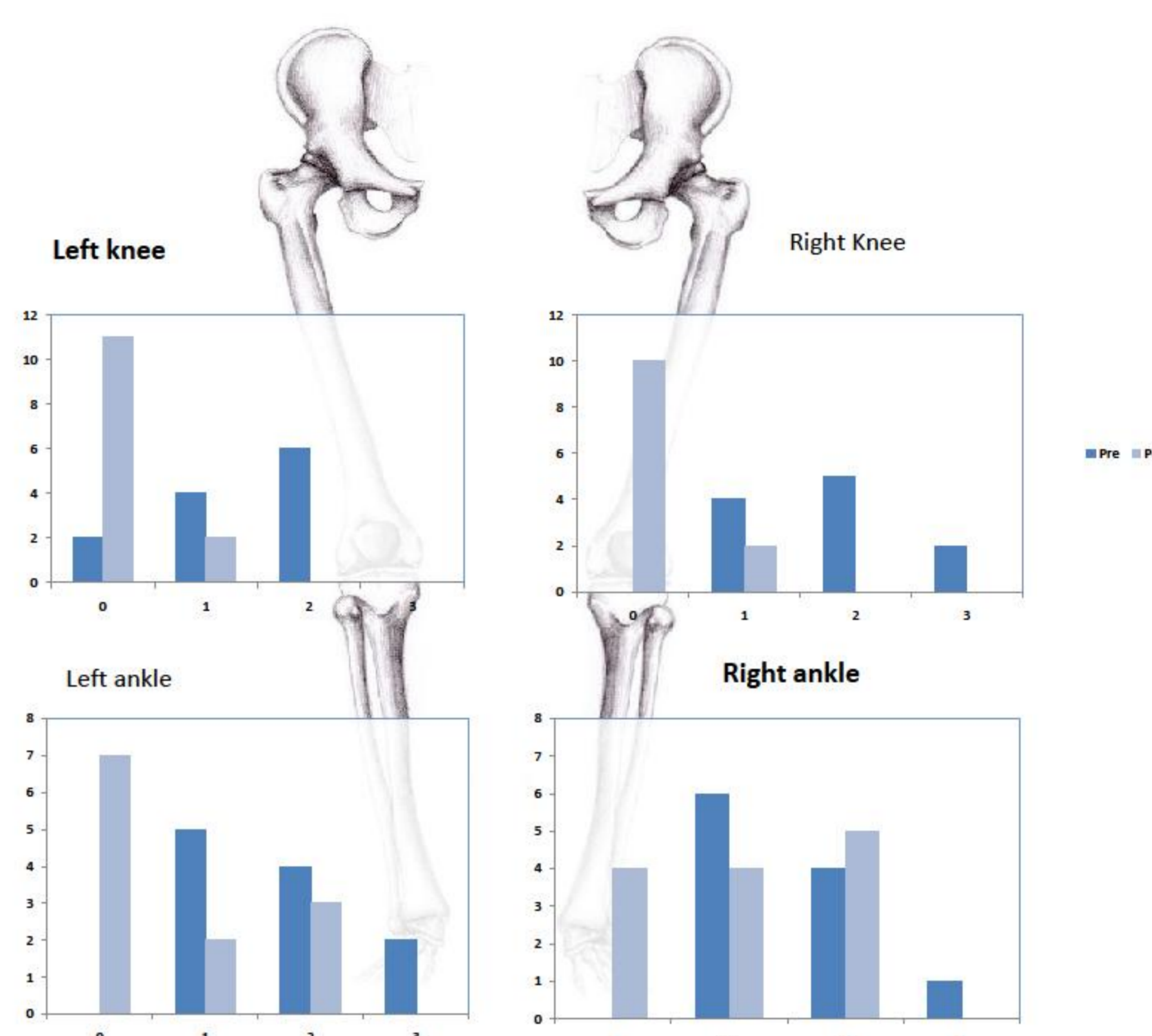


Fig. 1. WFH pain score pre/postoperative left knee (n=12/n=13), right knee (n= 11/n=12), left ankle (n=11/n=12) right ankle (n=11/n=13). Data presented as frequency scores. Time between pre and operation in years M= 1.6 [0.4 - 3.6] and between operation and post M= 12.2 [6.8 - 13.5].

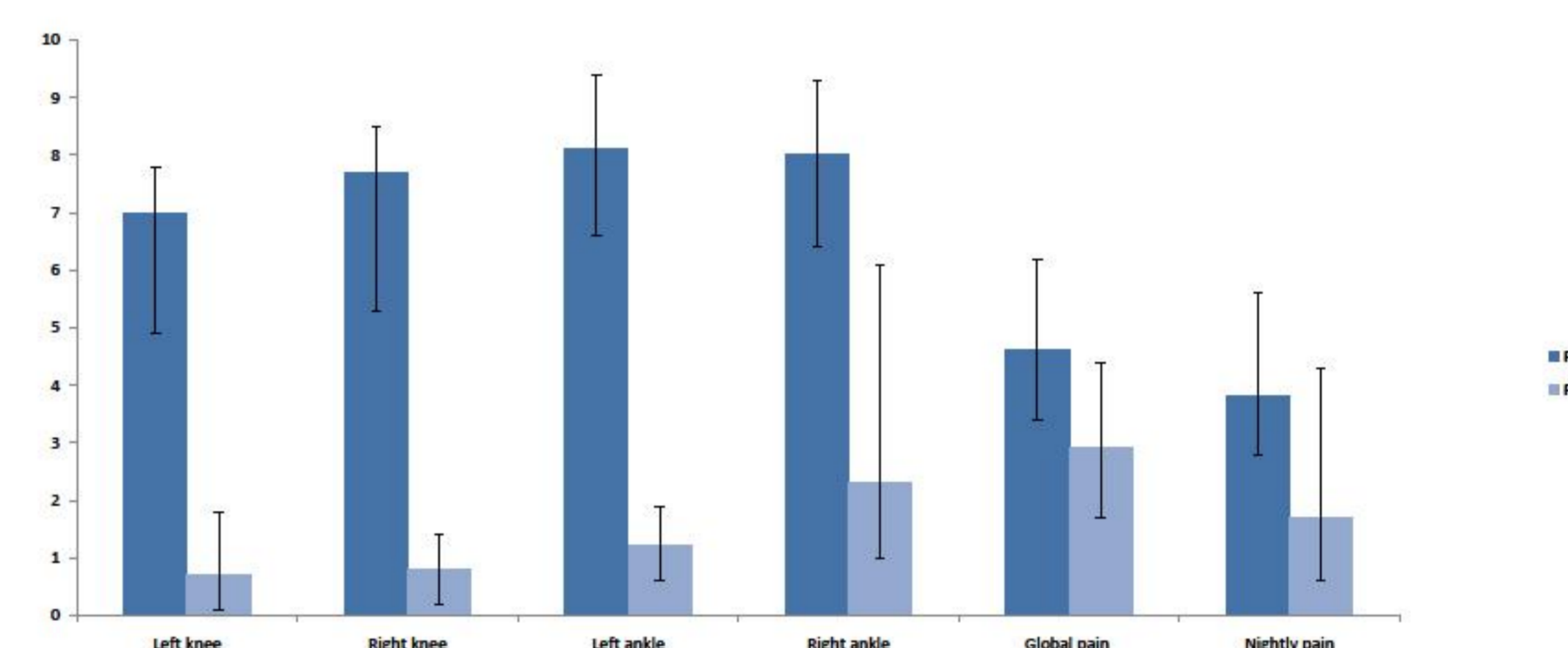


Fig. 2 VAS pain score pre/postoperative left knee (n=13), right knee (n=12), left ankle (n=12) right ankle (n=13), global pain (n=19), nightly pain (n=19). Data presented as median [IQR]. Pre- and postoperative measured retrospective. Time between measurement retrospective and operation in years M= 12.2 [6.8-13.5].

	MACTAR pre operative	MACTAR post operative
1	Walking short distances*	Walking short distances*
2	Maintaining a standing position	Driving a bicycle
3	Driving a bicycle	Maintaining a standing position
4	Climbing	Walking long distances**
5	Parent child relations	Maintaining dwelling and furnishings

* = Shorter than 1 km, ** = Longer than 1 km.

Table 2 MACTAR - Five most impaired activities pre/postoperative (pre n=19, post n=19). Pre- and postoperative measured retrospective. Time between measurement retrospective and operation in years M= 12.2 [6.8-13.5].

Conclusion (preliminary)

Measurement tools recommended for long term follow up of MJP:

1. Body level
 - Range of motion
 - VAS - pain
 - Pain per joint
 - Overall pain
 - Nocturnal pain
2. Activity level
 - HAL
 - Figure 8
 - 50 Meter walking test at preferred speed
 - 6 Minute walking test
3. Activity and Participation level
 - SF 36

