

When should we interfere to prevent joint damage in Lebanese PWH?

World Hemophilia congress - Orlando 2016

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Introduction:

Musculoskeletal Health is an important challenge in Hemophilia care especially in countries with inadequate clotting factor resources.

Evaluation based on objective measurement tools are mandatory for comprehensive care in Hemophilia and helps building tailored rehabilitation programs for the patients towards a better follow up and a good functional recovery.

Aims and objectives

The assessment aimed to help upgrading the effectiveness of physiotherapy for PWH in Lebanon by inspecting the age where joint damage starts to occur, this helps directing our work and prevent early irreversible damage through:

- Assessing the MSK status of Lebanese PWH (and keeping records) using International assessment tools
- Achieving higher level of awareness about the importance of physiotherapy
- Offering individualized Rehabilitation plans based on results and the patients' age

The project was realised through a fund from Bayer Hemophilia caregiver award

Methods:

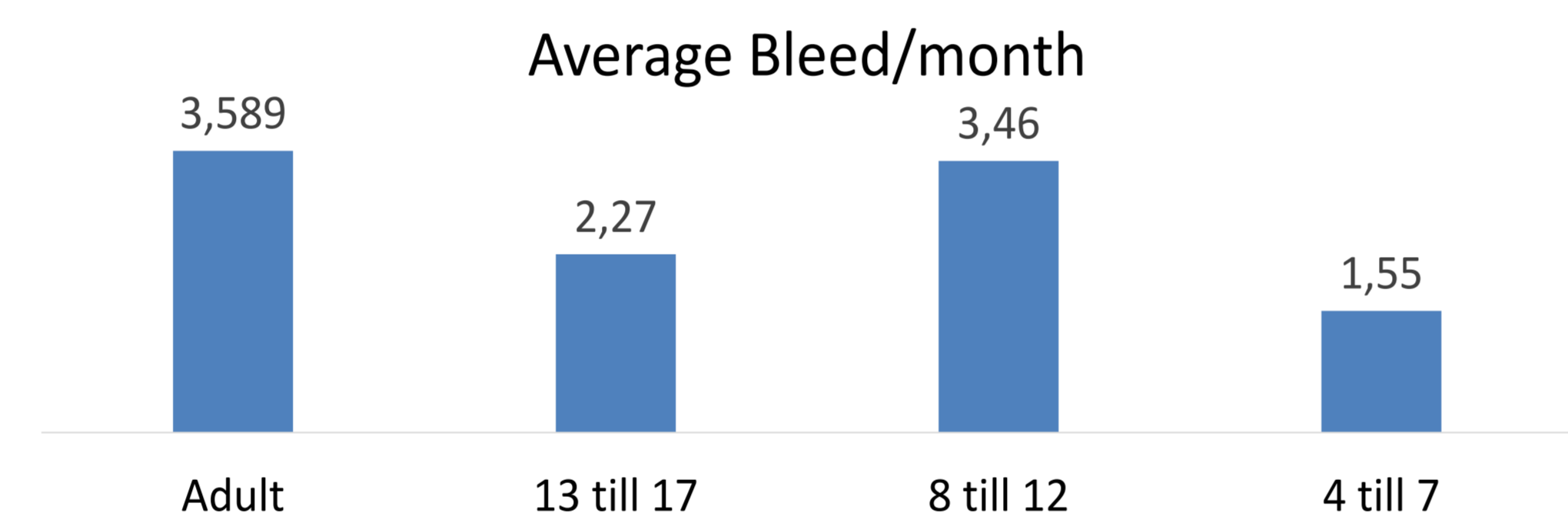
Project took place from November 2013 till January 2015, Using the following steps:

- Assembling the assessment forms that have been used (HJHS, FISH, Pain core, Hemo-QoL, HAL)
- Translating Hemophilia Activity list HAL questionnaire into Arabic and testing its clarity
- Contacting registered PWH out of the 450 estimated in the Country for regular check ups
 - 140 PWH A
 - 43 PWH B
- Making first assessment and developing tailored rehabilitation programs
- Planning workshop to train other local and regional physiotherapists

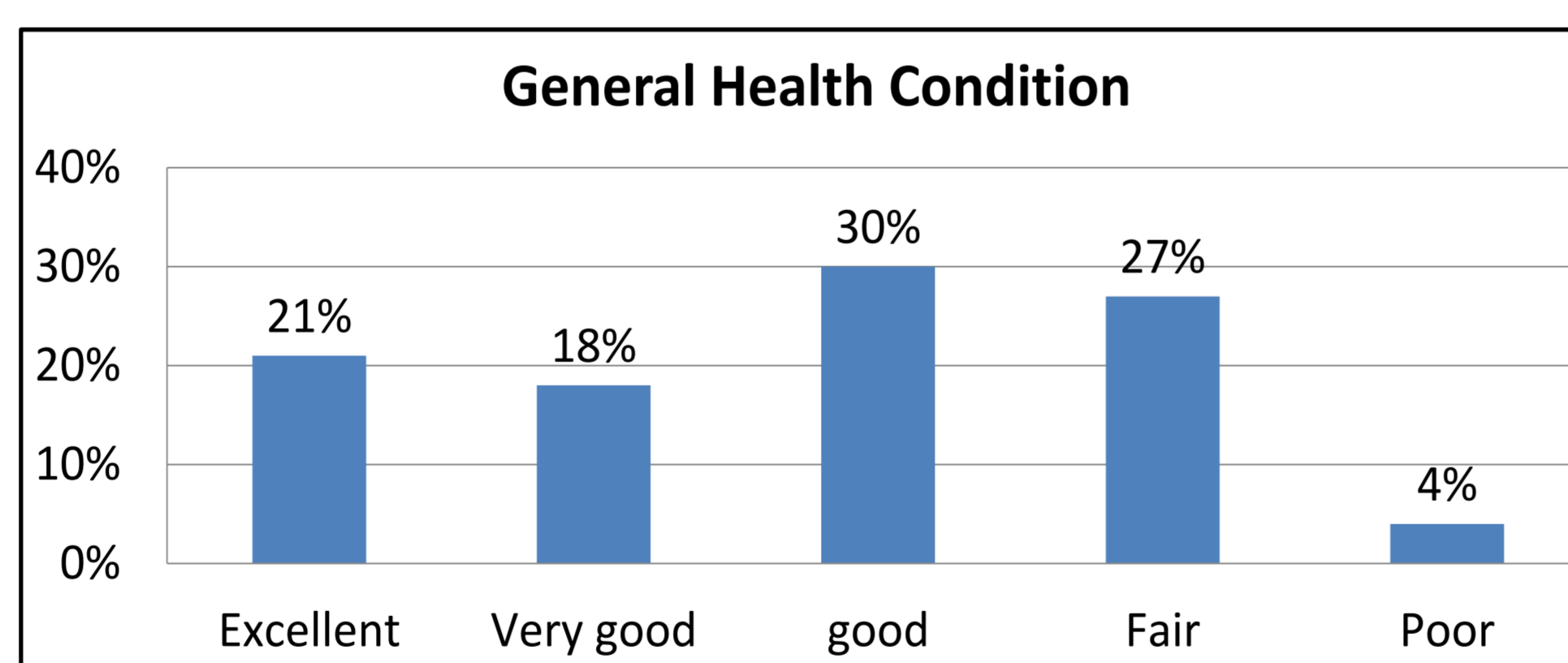
Results:

79 PWH A and B were assessed aged between 4 and 57:

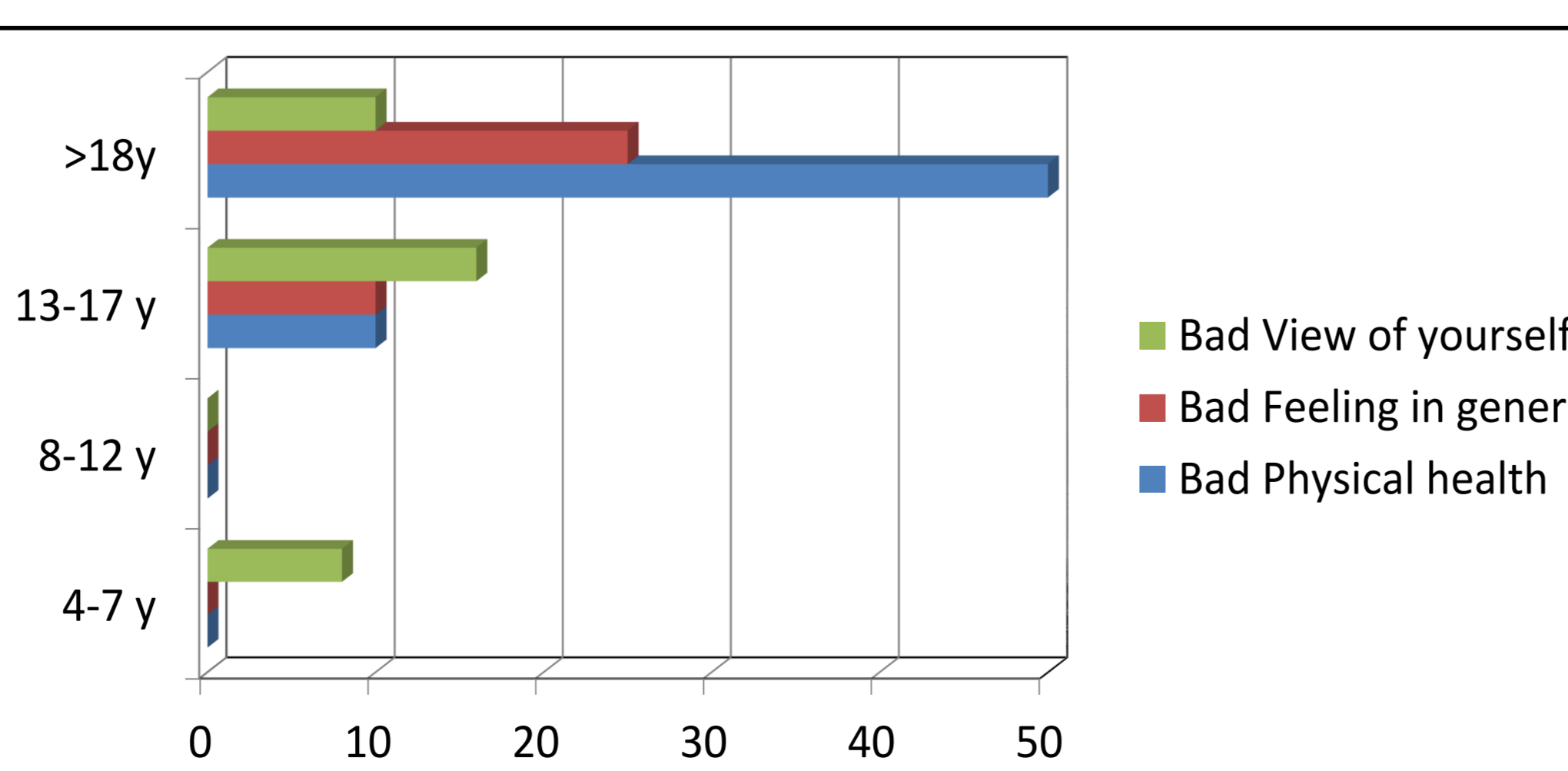
	Median (IQR) or %
N.	79 PWH
Hemophilia A	78%
Age at evaluation	18 (11.5 – 29.5)
Adult	49%
Severe Hemophilia	91%
On prophylaxis	13%
Start of prophy.	Secondary low dose Twice or 3x/week depending on availability
Bleed/month as reported by patient/parent	3 (1.5 – 4) bleed/month



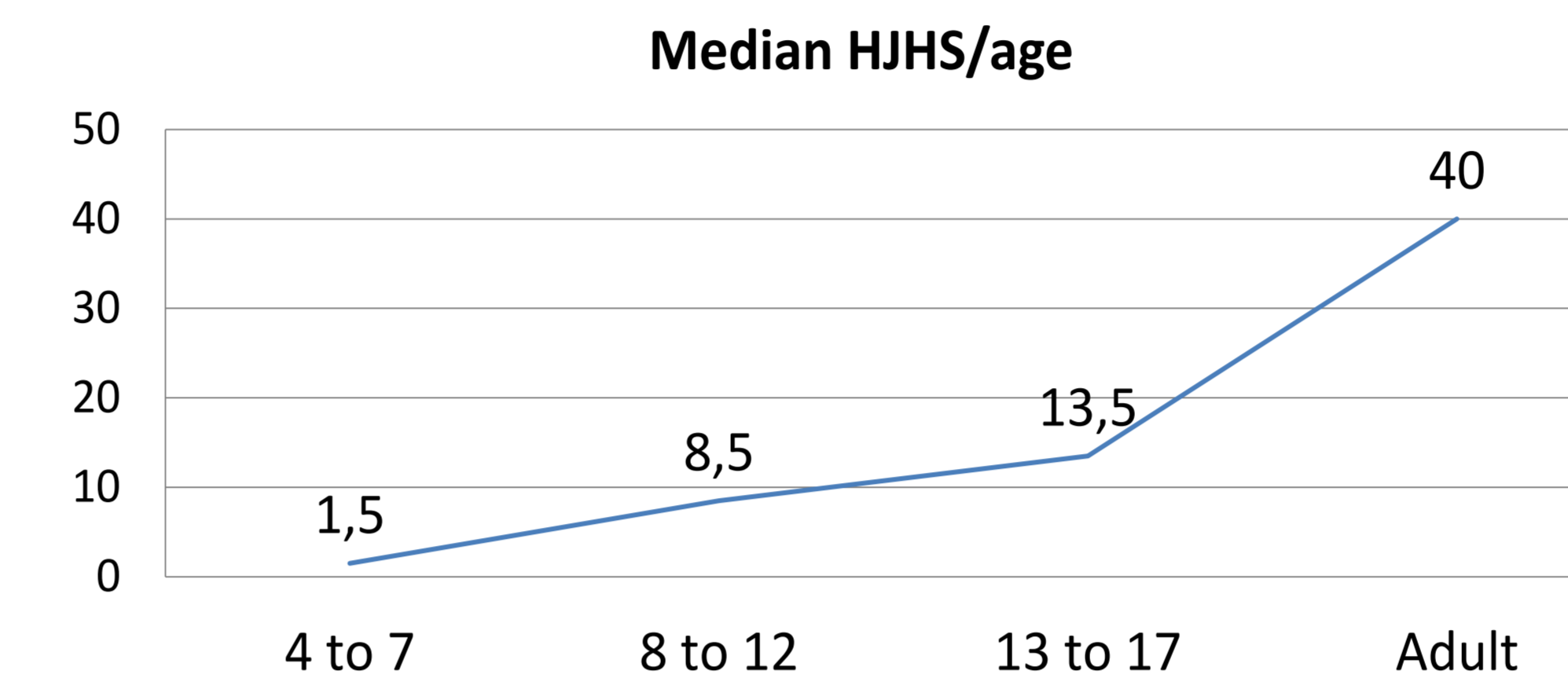
When asked about their general health condition:



- Adult patients tend to have poorer self satisfaction

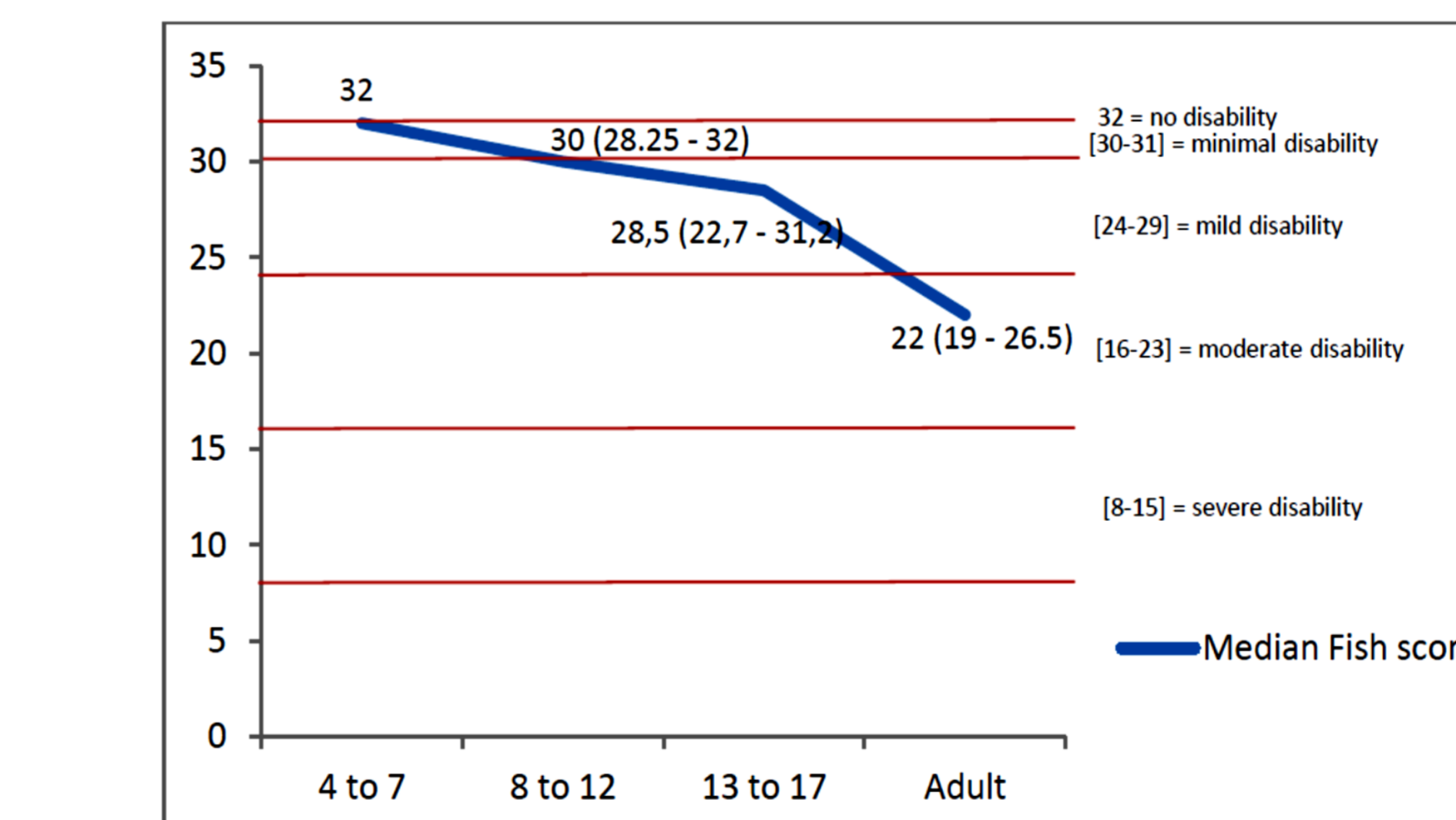


Results of Hemophilia Joint Health Score HJHS 2.1:



Most affected joint based on the HJHS for all age groups is left knee with a mean score of 4.42/20 followed closely by both elbows then Right Knee and Ankle. Complications starts with swelling and synovitis at a very young age then it develops to become chronic synovitis and arthropathy for patients even under 18 YO

Results of the Functional Independence Score FISH:



After assessing the patients' functional abilities, results shows rapid functional loss with age progression. When compared to normal values, our adult patients scores 22.92/32 have moderate disabilities.

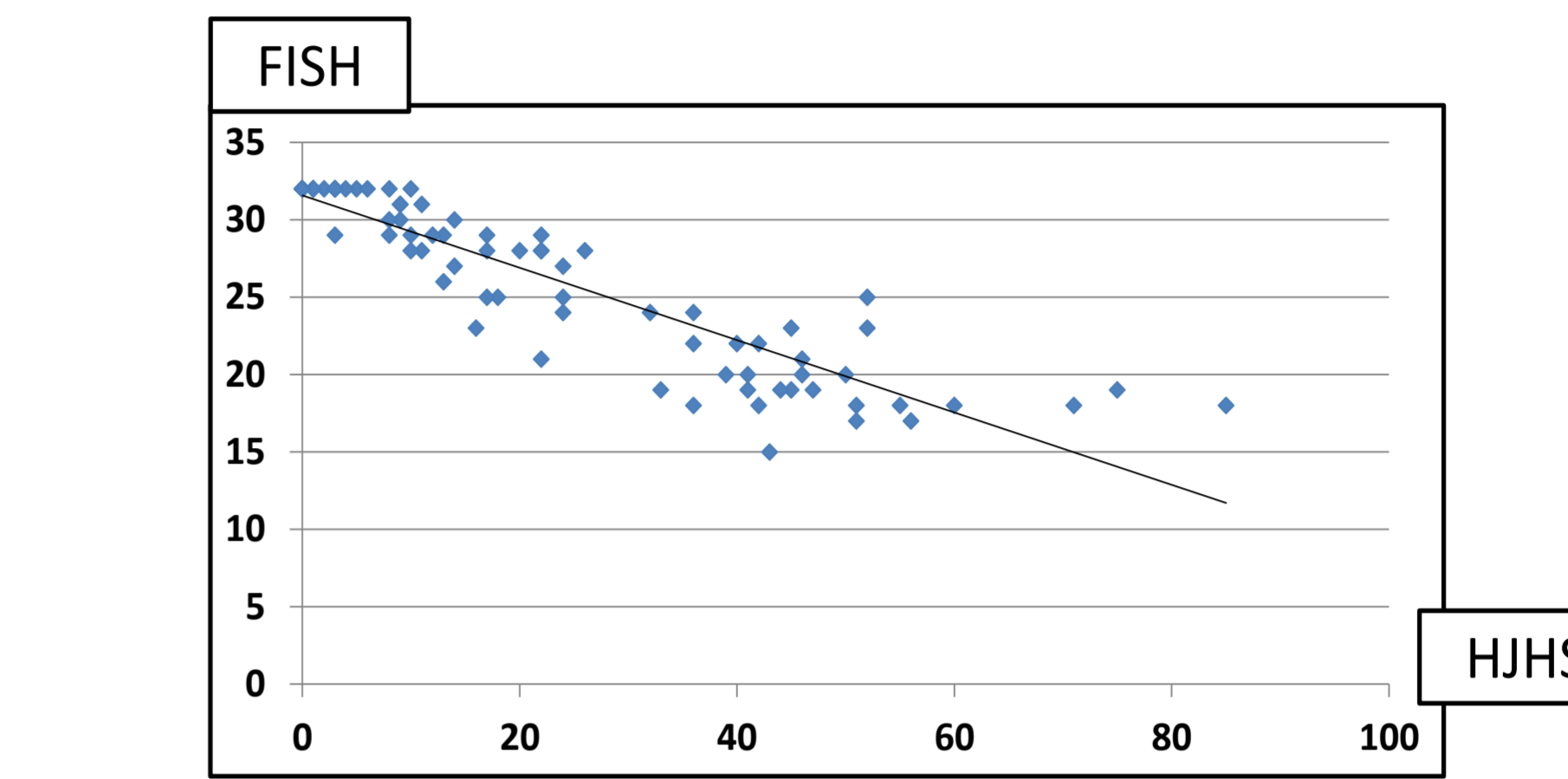
Most challenging functions affected transfer and locomotion like squatting, stairs and running.

Results of pain score:

- 34% with no painful joints
- 51 % between 1 and 5 joints
- 16% more than 5 painful joints

Most reported painful joints are knees
 Highest average pain is for left elbows : 5.79/10
 55% reported that the most frequent reason for pain is Bleeding while 26% is for chronic joint pain

Correlation between HJHS and FISH:



Correlation coefficient : -0.91 shows a strong negative correlation between HJHS and the FISH score

Rehabilitation plan:

- Regular follow ups with some of the patients was made
- Phone contact to adjust exercise plan for patients living far
- Sport sessions were induced with a PWH trainer

Conclusion:

Based on the results, Hemophilia patients starts having severe joint problems at very young age, in addition after the age of 12 problems worsened rapidly leading to irreversible complications. Therefore prophylactic treatment and physiotherapy guidance should be started as early as possible. This study supported the positive effect of physiotherapy in Lebanon in acute and chronic situations

- More adapted assessment tools should be studied specially for children to discover silent symptoms
- Adapted rehabilitation plans based on results and re-assess to check improvements
- Ways to involve more physiotherapists in Hemophilia care to promote better follow ups



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