

Correlation between Hemophilia joint health and Patient's Quality of life

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Introduction:

The focus of Hemophilia treatment for the past years was on the improvement of the physical health condition to extend life expectancy for PWH. With the availability of more clotting factors and the improvement of care, more attention was shifted toward improving not only the survival of the patient but care went more into upgrading the patient's quality of life.

This development introduced the concept of health-related quality of life (HRQoL) problems.

Many factors influence the patient's QoL and they are thought to be linked together and affect each other:

- Patient's functional status
- Perceived health
- Physical status
- Social and psychological concerns

All these outcomes should be assessed and monitored to provide wider angle of care for patients.

Aim and objectives:

The assessment aimed to check the link between patients' physical condition and their QoL from the patient's perspective to see to what extent these 2 factors can affect and relate to each other, and to check how patients cope with their condition.

Methods:

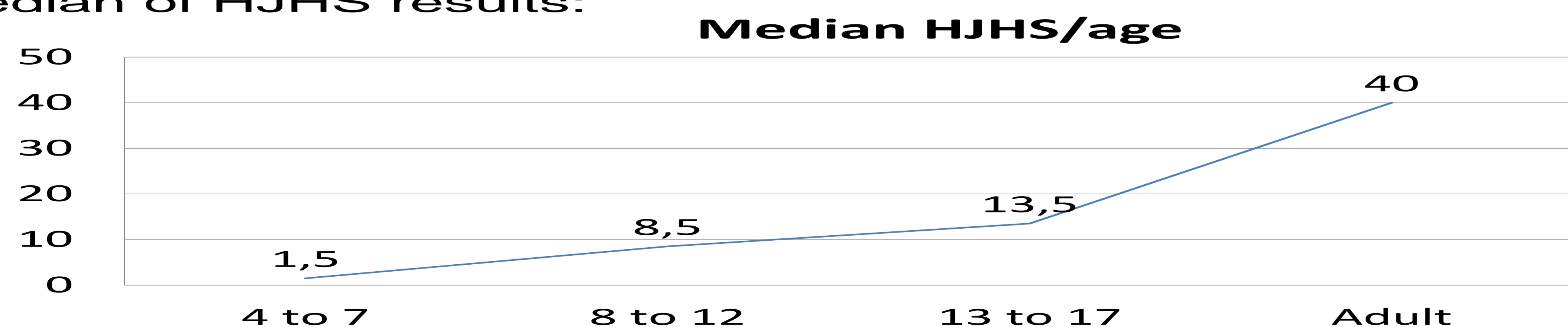
- Patients from the Lebanese registry were called for a regular physical assessment
 - 140 PWH A
 - 43 PWH B
- Estimated 450 PWH A and B in Lebanon
- Assessment took place from November 2013 till January 2015
- Patients were assessed using the Hemophilia Joint Health Score HJHS and Haemo QOL questionnaire was given it is a self reported questionnaire that tests the Quality of Life of PWH divided into different domains covering all aspects of hemophilia health related QoL.

Results:

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

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

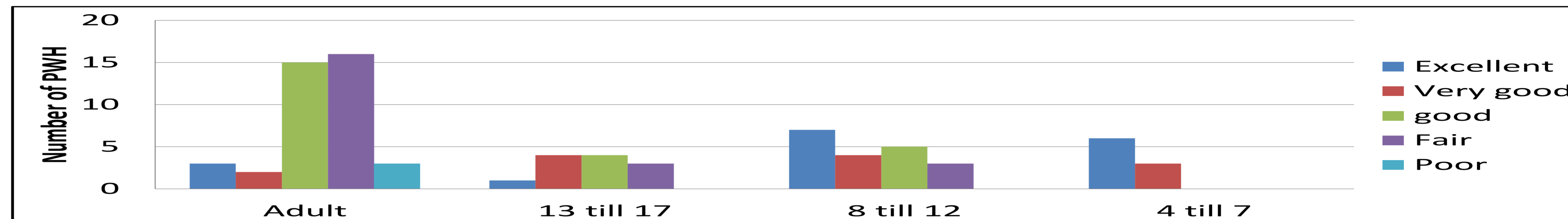
Median of HJHS results:



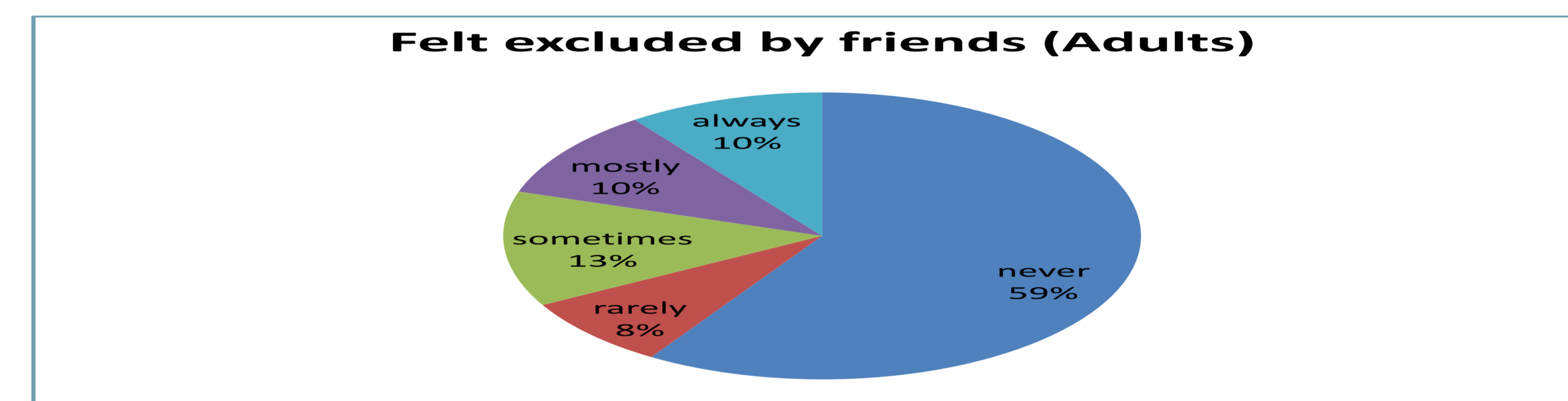
Most affected joint based on the HJHS for all age groups is left knee with a mean score of 4.42/20 followed closely by both elbows then Right Knee and Ankle.

Musculoskeletal complications started with swelling and synovitis at a very young age then problems worsen to turn into chronic synovitis and arthropathy for patients even under 18 YO.

General Health condition:



When patients were asked if they felt excluded by their friends:



Correlation between HJHS and QoL:

- HJHS & if Hemophilia made their life more difficult : 0.49
- HJHS & how patient felt because of his Hemophilia : 0.39
- HJHS & how does Hemophilia affect his view of yourself : 0.52
- HJHS & Sport / recreational Activities : 0.58
- HJHS & Work and School : 0.57
- HJHS & Future plans : 0.44

From these results we can understand that there is NO strong correlation between the patient's physical health and their QoL.

Discussion:

When Patients With Hemophilia were interviewed about their QoL specially with poorer health condition patients surprisingly reported good QoL. The impact of Hemophilia on QoL was expected to be lower than the actually achieved scores, but because patients develop coping strategies, the impact of Hemophilia was reduced.

Patients perceive disability as a non tragic act with it being acknowledged and distinguished as an integrated part of the self. Therefore patients response to illness will be associated with their emotional state, belief system, coping strategies and support mechanisms but will also be related to the seriousness of their physical condition.

Although patients may report negative perceptions related to chronic illness including difficulty coping with unpleasant symptoms, depression, loss of self esteem, uncertainty about the future, loss of job and social isolation, they often regard their illness positively. Patients reported accepting their condition as a part of normal life.

A number of explanations why people might describe chronic illness as a positive experience have been proposed. These include improving relationships, benefits from developing social networks by assisting others with similar problems and reevaluating priorities and personal values.

