

Linking Quality of Life Measures with the ICF/ICF-CY in Young People with Haemophilia

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Background:

The importance to address the patients' perspective and the patients' experience of functioning, disability and health is now commonly accepted. However, this topic is quite innovative in haemophilia research. This study describes health and functioning in children and adolescent with haemophilia in Europe based on the results of the linkage between the haemophilia-specific HRQoL questionnaire for children and adolescents (Haemo-QoL) and ICF/ICF-CY classification.



- Haemo-QoL is the first haemophilia-specific HRQOL questionnaire and it is available for three age group versions (I: 4-7 years, II: 8-12 years, III: 13-16 years) as self reports for children as well as three proxy versions for parents report respectively.
- It consists of 8 to 12 dimensions according to different age groups
- Domains: 'physical health', 'feeling', 'view', 'family', 'friends', 'others', 'sport and school' and 'treatment'. Age groups II and III have in addition the domains 'perceived support' and 'dealing with haemophilia' and for adolescents the domains 'future' and 'relationship' are added.
- It was originally validated in 6 countries (Germany, Italy, France, Spain, Netherlands, and the UK) and is currently available in 40 languages, from which 33 are linguistically validated.

Objective:

To measure health and functioning of children with haemophilia in Europe using ICF/ICF-CY as a frame of reference and items from health related quality of life instruments as a measurement tool within a European data set of 446 children.



Methods:

ICF/ICF-CY were created with the aim of covering all aspects of human functioning and disability that is health related, independent from a particular diagnosis. In order to describe functioning using ICF categories two steps are needed, first linking the measurement tool to specific ICF categories following the linking rules and second transforming information obtained from the measurement tool into ICF qualifiers based on ICF check list.

STEPS FOLLOWED:

- ✓ Items from the Haemo-QoL questionnaire have been linked to the ICF questionnaire following the established rules
- ✓ We selected two categories from 'Body function' and 'Body Structures' and from 'Activities and Participation' and one category from the 'Environmental factors', based on how frequently each category was linked to the items from the Haemo-QoL questionnaire
- ✓ The Likert-scaled response options from the Haemo-QoL were transformed into ICF/ICF-CY qualifiers in order to calculate the frequency of impairments, restrictions and barriers in the study population (qualifiers: 0 - no problem, 1 - mild problem, 2 - moderate problem, 3 - severe and 4 - complete problem)

Results:

More than 60% of the sample reported no or only minor impairments in the area of emotional functions (Body Functions: b152) indicating high emotional wellbeing. More impairments were found in the area of pain (Body Functions: b 280) [Table 1]. The major cause of pain in haemophilia is arthropathy in joints. As the level of arthropathy increases with time and with number of joint bleeds, older children and those receiving on-demand treatment are more impaired in this area. The restriction of functioning in relation to Recreation and Leisure (Activity & Participation: d 920) seemed to be most affected by receiving on-demand treatment even if they seemed to have fewer restrictions in the area of Informal social relationship (Activity & Participation: d750) [Table 2]. Finally, younger children (8-12 years) perceive more barriers in relation to the Individual attitudes of immediate family members (Environmental factors: e410) than older children (13-16 years) [Table 3].

Table 2. Frequency of reported restrictions in the area of sports related activities and communication with friends

ICF/ICF-CY qualifier	Haemo-QoL item "Because of my haemophilia I had to refrain from sports that I like" ICF-CY code "d920: Recreation and leisure"						Haemo-QoL item "I was able to talk to my friends about my haemophilia" ICF-CY code "d750: Informal social relationship"					
	Age group		Treatment		Severity of haemophilia		Age group		Treatment		Severity of haemophilia	
	8-12 (N=184)	13-16 (N=168)	On-demand (N=135)	Prophylaxis (N=156)	Mild and moderate (N=68)	Severe (N=193)	8-12 (N=180)	13-16 (N=150)	On-demand (N=134)	Prophylaxis (N=154)	Mild and moderate (N=97)	Severe (N=101)
0 - no restriction	38.00%	41.70%	35.0%	48.1%	43.0%	41.5%	20.00%	23.00%	38.0%	28.0%	42.3%	25.1%
1 - mild restriction	15.80%	13.10%	12.0%	14.7%	9.2%	16.1%	4.80%	11.00%	17.0%	21.4%	15.5%	22.0%
2 - moderate restriction	19.00%	15.00%	20.7%	16.7%	21.4%	17.1%	17.20%	17.00%	14.0%	20.1%	11.3%	20.9%
3 - severe restriction	14.10%	14.00%	14.8%	11.5%	12.2%	13.5%	24.20%	18.20%	9.0%	7.8%	5.2%	9.9%
4 - complete restriction	13.00%	14.60%	16.3%	9.0%	13.3%	11.9%	33.80%	28.30%	21.6%	24.7%	25.8%	22.0%

Table 1: Frequency of reported worries and pain in children and adolescents with haemophilia in Europe

ICF/ICF-CY qualifier	Haemo-QoL item "I was worried because of my haemophilia" ICF-CY code "b152: Emotional functions"					Haemo-QoL item "I had pain in my joints" ICF-CY code "b280: Sensation of pain"						
	Age group		Treatment		Severity of haemophilia		Age group		Treatment		Severity of haemophilia	
	8-12 (N=185)	13-16 (N=161)	On-demand (N=133)	Prophylaxis (N=155)	Mild and moderate (N=153)	Severe (N=135)	8-12 (N=183)	13-16 (N=162)	On-demand (N=132)	Prophylaxis (N=153)	Mild and moderate (N=95)	Severe (N=190)
0 - no impairment	63.24%	63.35%	56.4%	69.7%	62.7%	64.4%	44.30%	35.80%	42.4%	40.52%	52.6%	35.79%
1 - mild impairment	20.00%	14.91%	17.3%	17.4%	21.0%	12.6%	27.00%	27.20%	21.21%	29.41%	28.4%	24.21%
2 - moderate impairment	9.73%	13.66%	14.3%	9.7%	9.2%	14.8%	19.10%	26.50%	22.73%	24.84%	15.8%	27.89%
3 - severe impairment	6.49%	3.73%	7.5%	3.2%	5.2%	5.2%	5.50%	8.60%	11.36%	3.27%	2.1%	9.47%
4 - complete impairment	0.54%	4.35%	4.5%	0.0%	1.3%	3.0%	3.30%	1.90%	2.27%	1.96%	1.05%	2.63%

Table 3. Frequency of reported barriers in the area of parental protection and personal factors

ICF/ICF-CY qualifier	Haemo-QoL item "My mother protected me too much because of my haemophilia" ICF-CY code "e410: Individual attitudes of immediate family members"						Haemo-QoL item "Haemophilia made my life more difficult" ICF-CY domain "Personal factors"					
	Age group		Treatment		Severity of haemophilia		Age group		Treatment		Severity of haemophilia	
	8-12 (N=184)	13-16 (N=161)	On-demand (N=132)	Prophylaxis (N=154)	Mild and moderate (N=95)	Severe (N=191)	8-12 (N=185)	13-16 (N=161)	On-demand (N=133)	Prophylaxis (N=154)	Mild and moderate (N=96)	Severe (N=191)
0 - no barrier	28.80%	37.30%	29.5%	38.3%	40.0%	31.4%	47.03%	32.92%	41.4%	44.8%	53.1%	38.2%
1 - mild barrier	18.50%	20.50%	18.9%	22.1%	22.1%	19.9%	22.70%	33.54%	24.8%	29.9%	25.0%	28.8%
2 - moderate barrier	15.30%	18.60%	18.9%	15.6%	16.8%	17.3%	17.84%	16.77%	14.3%	16.2%	12.5%	16.8%
3 - severe barrier	9.50%	11.20%	9.1%	9.1%	7.4%	9.9%	7.57%	8.07%	10.5%	5.8%	4.2%	9.9%
4 - complete barrier	25.90%	12.40%	23.5%	14.9%	13.7%	21.5%	4.86%	8.70%	9.0%	3.2%	5.2%	6.3%

Conclusions:

Comparison between Haemo-QoL questionnaire and ICF/ICF-CY classification serves as an example of a cross walk between HRQoL and the ICF/ICF-CY approach measuring health, revealing strengths and possible limitations of both approaches and providing arguments that support the validity of the ICF/ICF-CY classification. Using items from quality of life instruments with ICF-CY as a frame of reference proved to be a useful approach for the assessment of health and functioning in children with haemophilia. This approach should be improved in routine haemophilia assessment.

References:

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