

IMPACT OF ACUTE AND CHRONIC PAIN IN PEOPLE WITH SEVERE HAEMOPHILIA ON THE EQ-5D: INSIGHTS FROM THE PROBE STUDY

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Table 1: Summary Characteristics of patients reporting acute and chronic pain

	No Pain (AP)		Acute Pain (AP)		Chronic Pain (CP)		Acute and Chronic Pain (A/CP)	
	N / Mean	% / SD	N / Mean	% / SD	N / Mean	% / SD	N / Mean	% / SD
n	85		110		111		376	
Age Mean (SD)	27.6	18.3	24.8	15	39.2	15.5	37.6	16.2
Weight Mean (SD)	65.5	25.8	62.6	23.4	76.8	16.9	73.1	19.2
Treatment Regimen								
Episodic ("on-demand")	6	7.4	25	23.6	23	20.9	98	27.8
Intermittent prophylaxis	8	9.9	11	10.4	12	10.9	62	17.6
Regular prophylaxis	67	82.7	68	64.2	74	67.3	189	53.7
Immune tolerance induction	0	0	2	1.9	1	0.9	3	0.9
Bleeds in the last 12 months								
0 Bleed	21	25.6	6	5.5	18	16.4	8	2.2
1 Bleed	18	21.9	9	8.2	8	7.3	12	3.3
2-3 Bleeds	22	26.8	21	19.1	23	20.9	49	13.3
4-7 Bleeds	9	11	21	19.1	20	18.2	58	15.8
8-10 Bleeds	5	6.1	8	7.3	10	9.1	43	11.7
11-15 Bleeds	2	2.4	12	10.9	7	6.4	49	13.3
16-30 Bleeds	2	2.4	13	11.8	8	7.3	56	15.2
>30 Bleeds	3	3.7	20	18.2	16	14.6	93	25.3
Frequency of Pain Medication Use								
Never	45	53.6	18	16.5	17	15.5	35	9.4
Rarely	14	16.7	39	35.8	28	25.5	67	18
Occasionally	20	23.8	19	17.4	28	25.5	90	24.2
Sometimes	3	3.6	21	19.3	14	12.7	65	17.5
Frequently	1	1.2	8	7.3	13	11.8	55	14.8
Very Frequently	1	1.2	3	2.8	5	4.6	39	10.5
Always	0	0	1	0.9	5	4.6	21	5.7
No. of activities of daily living effected Mean (SD)								
1	1	2.6	2.1	4	4.2	4.6	6.6	5.9
Employment								
Working Full-Time	21	42	28	43.7	58	70.7	153	64.2
Long Term Disability	4	5.06	4	3.7	5	4.5	34	9.2
Sick Days	7.9	17.9	22.1	54.8	18.4	37.3	49.9	91
Target Joint Mean No. of Target Joints per PwSH								
31	31	37.8	68	63	65	60.8	277	77.8
0.9	0.9	1.4	1.5	1.6	1.6	1.5	2.3	1.7
Joints with reduced range of movement Mean No. joints with reduced range of movement per PwSH								
36	36	44	66	61	96	89	342	96
1.5	1.5	2.1	1.6	1.9	3.1	2	3.4	2
VAS Utility								
0.838	0.838	0.183	0.766	0.197	0.694	0.166	0.662	0.206
EQ-5D Utility								
0.914	0.914	0.116	0.827	0.210	0.750	0.174	0.656	0.260

ACKNOWLEDGEMENTS

We thank the participating patient organizations: Fundación de la Hemofilia (Argentina) Cordoba Chapter; Hemophilia Foundation Australia (Australia); Federação Brasileira de Hemofilia (Brazil); Canadian Hemophilia Society (Canada); Association Française des Hémophiles (France); Deutsche Hämophiliegesellschaft (Germany); Magyar Hemofilia Egyesület (Hungary); Irish Haemophilia Society (Ireland); Federazione delle Associazioni Emofilici (Italy); National Hemophilia Network of Japan (Japan); Federación de Hemofilia de la República Mexicana (Mexico); Nederlandse Vereniging van Hemofilie- Patiënten (The Netherlands); Haemophilia Foundation of New Zealand (New Zealand); Haemophilia Foundation of Nigeria (Nigeria); Polish Hemophilia Society (Poland); Federación Española de Hemofilia (Spain); The Haemophilia Society (United Kingdom); National Hemophilia Foundation (United States); Asociación Venezolana para la Hemofilia (Venezuela) and Vietnamese Hemophilia Association (Vietnam).

PROBE is an independent investigator led research project with grant / research support from: Baxalta, now part of Shire; Bayer; Bioerativ, a Sanofi Company; CSL Behring; Novo Nordisk, Roche and Sobi and the collaboration of the US National Hemophilia Foundation.

BACKGROUND

Acute and chronic pain as well as the potential access to medications, including haemophilia specific products, significantly impact the quality of life of people with severe haemophilia (PWH). Generic questionnaires such as the EQ-5D are used to measure the impact of the condition on life experience. EQ-5D in particular is designed to record the individual experience on the day of completion. There is little information on how the response to the pain domain in EQ-5D is driven by acute or chronic pain. The Patient Reported Outcomes, Burdens and Experiences (PROBE) is a questionnaire developed by patients to measure what matters to them in a way that allows comparison with people without bleeding disorders.

METHODS

This analysis examines people with severe haemophilia (PwSH) and hypothesized that joint analysis of EQ-5D and PROBE measures would allow deeper understanding of the impact of acute and chronic pain on the respective scores. Descriptive and correlation analysis were performed.

RESULTS

- Data from 686 participants with severe haemophilia and their responses are characterized in Table 1.
- As shown in Figure 1, respondents reported
 - No Pain (NP) 12.46%
 - Acute Pain (AP) 16.13%
 - Chronic Pain (CP) 16.23%
 - Acute and Chronic Pain (A/CP) 55.13%
- The mean (SD) ages for NP, AP, CP and A/CP were 27.5 (18.3), 24.8 (15.0), 39.2 (15.57) and 37.6 (16.0), respectively
- The mean (SD) EQ-5D utility values for NP, AP, CP and A/CP were 0.91 (0.12), 0.82 (0.21), 0.75 (0.17) and 0.65 (0.28), respectively
- Weak correlation between chronic (CP) and acute pain (AP) ($r=0.21$, Pearson)

CONCLUSION

Acute pain has a significant impact on the quality of life of PWH. This is further exacerbated by the presence of chronic pain and the combination of both leads to the greatest decrease in quality of life. The EQ-5D does discern a difference between both types of pain. However, if chronic pain only is present at the time the EQ-5D is administered, the result may mask the full extent of the impact on the utility value unless the context and timing of using these generic tools is understood. It may lead to a misrepresentation of the true nature of pain within the severe haemophilia population.

Figure 1: Responses of PwSH to the pain domain of the EQ-5D

