



Bleeding vs. Factor VIII/IX consumption – comparison of annual real-life results between 2014 and 2016 according to electronic diary smart-medication[™]

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Background:

Bleeding frequency and factor VIII/IX consumption differ widely among patients with severe haemophilia. Year to year patterns among individual patients and centers may, however, be similar.

Methods:

Annual factor VIII/IX consumption and joint bleeds were compared among 246 patients with haemophilia A/B from 9 Haemophilia centers between 2014 and 2016 according to electronic documentation smart medication[™].

Results:

The average factor VIII/IX consumption (IU/kg BW/year) was 2,442 (±2,038) in 2014, 2,701 (±1.837) in 2015 and 2,575 (±1,877) in 2016. The average number of documented joint bleeds was 2.1 (±3.9), 2.5 (±4.9) and 2.27 (±7.3), respectively. Four groups, comparing above or below average factor consumption and joint bleeds, were compared between 2014, 2015 and 2016 (Fig. 1 and 2): The majority (455%/40%/44%) had 2,25 or less joint bleed (A) with less than average factor consumption, followed by a group(31%/35%/32%) who also had 2,25 or less joint bleed and more than average factor consumption (B). A minor group (14%/11%/15%) had more than 2,25 joint bleed and more than average factor consumption (C) and was similar in size to a group (10%/14%/8%) who had more than 2,25 joints bleeds but less than average factor consumption (D). This stratification may in future be implemented into an online hemophilia center surveillance tool (Fig. 3).

FIG. 1 AVERAGE JOINT BLEEDS AND FACTOR CONSUMPTION AMONG 246 PATIENTS (%) WITH HAEMOPHILIA A/B IN 9 HAEMOPHILIA CENTERS





Conclusion:

Between 2014 and 2016 a majority (76%/73%/76%) of patients (A) documented 2,25 or less joint bleeds per year and yet low factor consumption as a result of optimal home treatment. Patients with high bleeding frequency in spite of above average factor consumption (C) revealed a small (14%/11%/15%) but important group requiring intensified medical attention. Treatment dose may be reduced in patients with above average consumption and low bleeding frequency (B) and vice versa may be increased in patients with high bleeding frequency and low factor consumption (D). The results were consistent comparing three consecutive years. The electronic diary smart medicationTM is suitable to online focus on groups of patient which may require more or less factor treatment or need otherwise intensified treatment. It is under investigation, whether online stratification into group A to D may provide intensified and yet simple surveillance of haemophilia home treatment.

FIG. 2 ANNUAL RATES OF JOINT BLEEDS AND FACTOR CONSUMPTION COMPARING THREE CONSECUTIVE YEARS (2014 – 2016)



FIG. 3 ONLINE SURVEILLANCE OF PATIENTS WITH HAEMOPHILIA A/B , THE LAST COLUMN IS NOT YET IMPLEMENTED BUT UNDER INVESTIGATION

Patient	Days since last entry	IU in stock	IU infused in 2016 (2015)	Bleeds in 2016 (2015)	Joint Bleeds last 3 months	Bleeds last 7 days	Kategorie 2017 (2016)
1001	0	12.000	120.000 (175.000)	4 (8)	2	1	B (B)
1002	3	5.000	85.000 (120.000)	O (1)	1	0	A (A)
1003	2	42.000	165.000 (150.000)	6 (1)	0	0	C (A)
1004	5	2.000	24.000 (36.000)	2 (8)	0	0	A (D)