

Development of annual joint bleeds and factor consumption during the last 6 years in 14 hemophilia centers

- real life data from electronic documentation smart medication

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Background and Objective

Electronic diary has shown to be a valuable tool for analysis of annual joint bleeding rate (AJBR) and annual factor VIII/IX consumption (AFC) in real life setting. What has changed over a six-year period?

Methods

AFC and AJBR among 391 patients with hemophilia A/B from 14 hemophilia centers in 2019 were compared to data to prior years (277 patients from 9 centers in 2017, both gradually increasing since then) according to electronic documentation smart medication.

Results

Looking at five consecutive years, the average AFC (IU/kg BW) was 2442, 2701, 2575, 2670, 2924 and 2847 the average AJBR 2.1, 2.5, 2.3, 2.2, 1.9 and 1.7 between 2014 and 2019, respectively. Four groups, comparing above or below average AFC and AJBR, were compared between 2014 -2019: The majority (45%/40%/44%/45%/40%/42%) had an AJBR of ≤ 2 with less than average AFC, followed by a group (31%/35%/32%/32%/29%/28%) with ≤ 2 AJBR but above average AFC. A minor group (14%/11%/15%/15%/14%/14%) had an AJBR > 2 and more than average AFC. Only few (10%/14%/8%/8%/17%/15%) had an AJBR > 2 but less than average AFC.

Conclusion

In 2019 the AJBR was slightly lower, the AFC slightly higher compared to all prior years. Whether this reflects changes in treatment or is due to an increasing number of participating patients and centers needs to be further analyzed. With the introduction of extended half-life products, the future bleeding and factor consumption may change, demonstrating the necessity for ongoing electronic surveillance in hemophilia care.

TAB. 1 NUMBER OF PATIENTS, ALL BLEEDS, JOINT BLEEDS AND AVERAGE UNITS/BODY WEIGHT/YEAR ACCORDING TO GROUP

	Patients	All bleeds	Joint bleeds	IU/kgBW/y	IU
A	165	368	41	1377	18,7 Mio
B	112	143	25	4537	37,7 Mio
C	55	470	271	5008	21,0 Mio
D	59	561	323	1502	7,6 Mio
SUM	391	1542	660	-	85,0 Mio
Average					2847 (\pm 2528)

FIG. 1 PATIENTS WITH ABOVE OR BELOW AVERAGE AJBR AND AVERAGE AFC

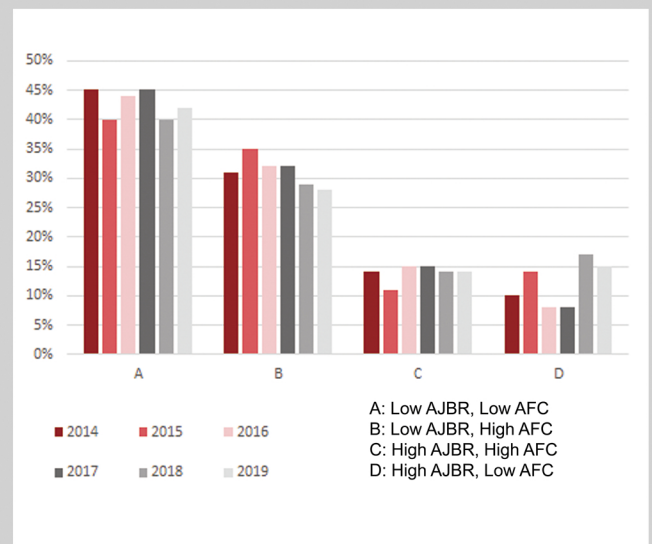


FIG. 2 AJBR VS. AFC AMONG 391 HEMOPHILIA A/B PATIENTS IN 14 GERMAN HEMOPHILIA CENTERS

