Pain and treatment related to joint bleeds – comparison of data between 2017 and 2018 according to electronic diary smart-medication™


Background:
Joint bleeds in patients with hemophilia A/B may cause severe pain leading to immediate or delayed factor treatment, as well as different dosing in home settings.

Methods:
Results from 359 patients from 13 hemophilia centers during 2018 were analyzed according to electronic data from smart medication™. Severity of pain (SP) on a scale of 0 (no pain) or 1 (very mild) to 10 (very severe) was related to the respective initial treatment dose, annual consumption and annual joint bleeding rate (AJBR).

Results:
AJBR was 1.96 in 2018. A majority of patients rated pain due to joint bleed between 2 and 6. Average consumption for severe pain as well as light pain was low. The single treatment dose and annual consumption was not correlated with severity of pain due to joint bleeds.

Discussion:
In 2018 a lower AJBR was seen in comparison to previous years. The only change according to the smart medication™ data base was the introduction of extended half life products, which may be the reason for less bleeds. Only few patients recorded no or low intensity pain as the result of joint bleeds demonstrating joint bleeds still as one of the major burdens in hemophilia life. However, high intensity pain did not lead to an increase of dosing. The overall rate of factor consumption for high intensity pain was rather low. This may be the result of early treatment in case of suspected joint bleed and thus avoiding further pain development. However, only 30% recorded a time gap of less than one hour between symptoms of bleed and treatment, 20% waited more than 4 hours until treatment. In spite of the recommendation for early treatment, a considerable rate of patients seems to follow a watch and wait strategy in order to avoid unnecessary treatment.