

INCIDENCE AND SOME CHARACTERISTICS OF PATIENTS WITH HEMOPHILIA IN BOSNIA AND HERZEGOVINA

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Objectives:

➤ The objective of this paper is to show the data regarding the number of patients with Hemophilia A and B in the entire Bosnia and Herzegovina, together with their clinical characteristics, treatment options and annual clotting factor use.

Methods:

➤ We retrospectively analysed medical records of patients with congenital bleeding disorders in the largest children hospitals in two entities of Bosnia and Herzegovina - University Children Hospital Banjaluka in Republic of Srpska (RS) and University Children Hospital Sarajevo in Federation of Bosnia and Herzegovina (FBiH). The analysis was done according to type of bleeding disorder, level of inhibitors and treatment options.

➤ Also, we analysed the data from Health Insurance Fund of both entities regarding the annual clotting factor use in 2013.

➔ Bosnia and Herzegovina's Total Population: 3 791 662

➔ Number of registered patients with haemophilia (A and B): 181

Number of patients	
Hemophilia A	146
Hemophilia B	35
VWD	28
Other Bleeding Disorders	6
Total	215

Hemophilia A	Number of registered patients	%
Mild	37	25
Moderate	48	33
Severe	61	42
TOTAL	146	100

Classification of the patients according to the age (only Hemophilia A)	
Number of pts < 18 years	Number of pts > 18 years
52	94

Annual /2013/ Clotting Factor Use			
Type of factor	FVIII	IX	VII
Plasma derived	5 815 000 IU 83.42 %	827 000 IU 100%	/
Recombinate	1 155 500 IU 16.58 %	/	1 231.2mg
Total	6 970 500 IU	827 000 IU	1 231.2mg

	Consumption F VIII	Per capita
2003	723.000	0,2 IU
2013	6 970 500	2,4 IU

Level of inhibitors (BU)	Hemophilia A	Hemophilia B
Titre < 5BU	6	/
Titre ≥ 5BU	3	/
TOTAL	9	0

Results:

Treatment options:

- * Home treatment and self infusion
- * Delivery FVIII and IX - local pharmacy

Prophylaxis:

- Primary - only for children with severe hemophilia (start 1,5-2 y; depends of severity form of the disease)
- Secondary - for all children and adolescents with severe hemophilia -Mostly for all patients with severe hemophilia*
- Therapy on demand - for patients who are not on regular prophylaxis*

- * Intensified regimen of prophylaxis during physiotherapy and rehabilitation
- * Regular physiotherapy for all children with hemophilia
- * Rehabilitation + prophylactic treatment with CF - not available for all adults

Other services:

- Emergency medicine and acute surgery are available for patients
- Pediatrics +
- Infection and immunology (HIV, hepatitis) +
- Dentistry +
- Pain management + /_
- Social and psychological support - is not available for all patients

Management of inhibitors:

- Detection inhibitors
- Inhibition eradication with high dose of CF in low responders
- Other modalities of ITI are not performed
- Therapy on demand - first line treatment choice is rF VIIa
- There is no regular prophylaxis (only short term, e.g. before physiotherapy)

References:

1. Fischer K, Hermans C; The European Principles of Haemophilia Care: a pilot investigation of adherence to the principles in Europe. Haemophilia 2013; 19(1): 35-43.
2. O'Mahony B, Noone D, Giangrande PL, Prihodova L; Haemophilia care in Europe: a survey of 19 countries. Haemophilia 2011; 17(1):35-40.

Conclusions:

- Since Bosnia and Herzegovina is an European country, we intend to achieve European principles of hemophilia care.
- The introduction of home treatment and delivery of coagulation factors in local pharmacies are the most important results we have achieved in the introduction of regular prophylaxis for all children with severe hemophilia and most adult patients.
- Problems that we encounter: nonregistered patients

Top priorities:

- Establishing National Centre of Haemophilia
- Establishing National Register of Hemophilia Patients
- Establishing orthopedic surgery for patients with joint disabilities

