Establishing a regional haemophilia registry in southern Tunisia

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Introduction and Objective:

Creating a national registry for bleeding disorders is a major step in improvement of National Hemophilia Care Program. Therefore, a national haemophilia registry were lacking in our country, we establish a regional hemophilia register in our center which would contain accurate and regularly updated data for patients with hemophilia in southern Tunisia.

Materials and Methods:

❑ Our study included a cohort of patients with hemophilia (PWH) diagnosed in Department of hematology of Hedi Chaker Hospital in Sfax From Tunisia during a period of 32 years (January 1982-December 2014).

❑ We collected data on a listing document word including demographic, clinical, biologic, therapeutic data and outcome of our patients.

Results:

We collected data of PWH in electronic card. This card contains eight tabs:

The first tab: identification of the patient

The second tab: family history

The third tab: discovery circumstances

The fourth tab: hemostasis tests and viral serology

The fifth tab: bleeding events during the evolution

The 6th tab: therapeutic management

The 7th tab: outcome and complications

The 8th tab: social status of the patient

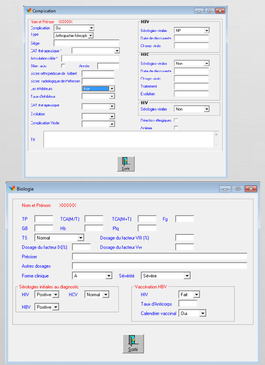

Figure : the 4th and 7th tabs

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❑ The table N°1 shows the data of the patients including in our regional registry.

Table n°1

		Number of patients (%)
	Hemophilia A	93 (87%)
	Hemophilia B	14 (13%)
	Severe form	65 (61%)
	Moderate form	30 (28%)
	Mild form	12 (11%)
Clinical manifestations	Hemarthrosis	86 (80%)
	Hematoma	80 (75%)
	Visceral hemorrhage	36 (34%)
Complications	Chronic arthropathy	45 (42 %)
	Inhibitors development	17 (20%)
	Viral infection :	
	HIV	2 (2%)
	hepatitic C	29 (31 %)

❑ All our PWH are treated on-demand, 13% of patients underwent secondary prophylaxis.

❑The mortality rate was 8%.

❑The current average age was 21 years.

❑ A third of our children with hemophilia are in school

❑ Nineteen adults with hemophilia have a profession.

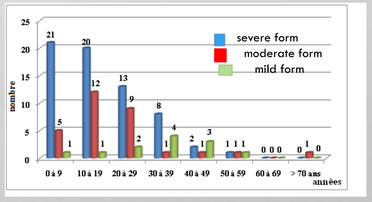

Figure : Current age of our patients

Conclusion:

Hemophilia continues to be a challenge for our health systems and remains a disabling disease in our country. It requires a multidisciplinary care to improve the quality of life of PWH.