

A WEB SITE TO IMPROVE MANAGEMENT OF PATIENTS WITH INHERITED BLEEDING DISORDERS IN THE EMERGENCY DEPARTMENT: RESULTS AT 2 YEARS

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Background: treatment of patients with inherited bleeding disorders (IBD) in the emergency department (ED) is a challenge because haemorrhages can be underestimated and their management is not well known by emergency physicians. At present there are only guidelines from the National Haemophilia Foundation limited to patients with haemophilia and rarely applied in our ED. In 2008, the EAHAD recommended development of a policy to manage these patients. In 2010 a project was started involving all 8 haemophilia centres (HC) (organized since 2002 according to a "hub and spoke" network) and all 44 ED of the Region of Emilia-Romagna (RER) in north Italy to find solutions to this problem.

Methods: The project is based on a web-based platform dedicated to IBD and involving the information technology already developed in RER (web-clinical record and web-IBD regional registry) and a new web-site for bleeding emergency management in these patients (Figure 1).

The principle steps of the project were:

- guidelines for emergency treatment;
- education for ED medical and nurses staff;
- a dedicated web-site supporting treatment decisions and sharing data with the patients' electronic clinical records.

Fig. 1: Web-based platform developed in RER



EMARTRO Consiglio terapeutico	
Dati inseriti dall'operatore	
Altre informazioni sull'evento:	
Diagnosi:	dolore
Età:	difficoltà a muovere l'articolazione
Peso:	Emofilia B grave
Presenza di inibitore:	40 anni
Trattamenti precedenti con concentrato:	70 Kg
Farmaco selezionato:	Nu
	SI
	BENEFIX
Consiglio terapeutico elaborato dal software	
Farmaco:	BENEFIX
Dose consigliata:	3000 UI

Fig. 2: An example of the algorithm suggesting the first infusion for a joint bleed

Results: guidelines for emergency treatment, containing practical instructions for managing patients in the ED, were produced and shared by HC and ED and published on the web-site www.emofiliarer.it in February 2011, and a pocket guide for all ED physicians was completed in June 2011.

The web-site, which has a private area for doctors and a simplified public area, enables easy access to descriptions of diseases and drugs, contains address of all HC and ED in the RER (by Googlemaps) and instructions for treating bleeds and critical injuries. An algorithm suggests the first dose of concentrates for every type and severity of bleed and trauma. Furthermore, all RER patients with IBD have a personal web-identity (an USB device) by which they can access their own main clinical data stored in the region's web-based clinical records and enter themselves bleeding episodes and home treatments. These data can be processed immediately by the ED web-based site enabling optimal, tailored emergency treatment (Figure 2).

After on-site training courses in each ED, the network has been active since June 2011. Up to 2013 the ED had accessed the web-site **1885** times and used the algorithms **764** times (mostly for joint bleeds 215, mucosal bleeds 181, head injuries 86, muscle bleeds 73). Finally, there were **112** accesses by subjects who consulted the public area.

Conclusion: to our knowledge this is the first example of a network, involving HC, ED and patients, for managing bleeding emergencies in IBD with the support of dedicated web-based software. The main advantages of this system are better management of patients in ED (shortening the time between triage and therapy administration) and improved collaboration between HC and ED. The most critical point is staff turnover in ED, which necessitates continual training.