

Introduction

• Hemophilia treatment in Brazil is largely performed in blood banks. In 2011/2012, with the implementation of primary (PP) and secondary (PS) prophylaxis programs and immune tolerance induction (ITI), patients needed more clotting factor infusions, however requiring support of Primary Care Health System to perform treatment. Knowledge of protocol programs, PP, PS and IT by the Family Health team help on adhesion of and monitoring those patients. This project was developed in partnership with Novo Nordisk Foundation and the Brazilian Federation of Hemophilia.^{1,2,3,4}

Objectives

- To train health professionals, active in Primary Care Health System, to care for patients with hereditary bleeding disorders;
- To educate patients and parents on topics relevant to treatment of coagulation disorders.

Methods

• The project was designed to last nearly 2 years. Actions were initiated in August of 2013, after approval by the Novo Nordisk Foundation, the funding of the project. A multidisciplinary team of HEMOES applied the training in larger cities. The contemplated cities were Linhares, Vitória, São Mateus, Cachoeiro do Itapemirim and Colatina, from North to South of Espirito Santo state, Brazil. Six trainings were scheduled for healthcare professionals and 3 for patients/parents per years (18 training/two years). A previous survey was performed to find out the number of hemophilia patients by region. The training consisted of a theoretical part (first phase), addressing the most relevant issues in hemophilia: 1- What is hemophilia?; 2- Home treatment; 3- The distribution of concentrate factors and other drugs related to a haemostasis service; 4- Dental Care in patients with coagulopathies; 5- Primary and secondary prophylaxis in hemophilia; 6- Psychosocial care in hemophilia patients. 7- Emergencies in hemophilia patients. The second phase was a practical part, based on study of clinical cases. Several support materials were developed to be used in training: Treatment Handbook for Primary Care, Guidance Handbook for Patients, Emergencies in Hemophilia Posters, Infusion Diary and another guidance to health professionals who visit their houses.

Results

• 741 health professionals and 250 patients were trained. With regard to health professionals, 78% were college graduates and 22% high school graduates. A questionnaire was applied by phone on 20% of trained health professionals (168), to evaluate training impact. Only 52 (31%) of the professionals interviewed had previous knowledge of hemophilia. 98 (58.4%) professionals reported they had no confidence in patient care. After training, 153 (91%) professionals reported having improved knowledge and safety in patient care.



Figure 1 – Support materials developed to be used in training

Conclusion

- There was a reduction in the time spent for being assisted, with better support in maintaining the adherence to the prophylaxis and immune tolerance induction programs.
- Unfortunately, the constant changes of primary care professionals in the Primary Care System does not allow fostering the work, demanding frequent trainings.
- With better knowledge of hemophilia, there was an improvement in quality and better adherence to treatment. Moreover, early treatment of hemorrhagic complications reduces the number of joint sequelae and improves patients' quality of life.

References

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- [3] MINISTÉRIO DA SAÚDE, Portaria nº 364 de 06/05/2014. Protocolo Brasileiro de Profilaxia Primária para Hemofilia A grave, 2014.
- [4] MINISTÉRIO DA SAÚDE, Portaria nº 478 de 16/06/2014. Protocolo de Uso de Indicação de Imunotolerância para pacientes com Hemofilia A grave, 2014.

