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Successful implementation of telemedicine in hemophilia

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Hemophilia A is an X-linked, recessive disorder caused by deficiency of functional plasma clotting factor VIII (FVIII), which may be inherited or arise from spontaneous mutation. To prevent patients with hemophilia from spontaneous and life-threatening bleedings substitution with FVIII-concentrates are essential. In accordance with §14 of the German Transfusion act, patients are obligated to document each factor substitution. Usually this is done by a paper based substitution calendar. Since 2007 an electronic substitution diary that works on the basis of a Personal Digital Assistant, offers another option for the documentation of factor consumption for hemophilia patients in Germany. The electronic patient diary records details of FVIII infusions like total dose, time of infusion, brand name and reason for infusion and bleeding with bleeding location. In our centre 36 patients switched to electronic documentation and we see similar compliance compared to the paper based documentation. The physicians receive information's about suspicious bleeding quickly and they can control the therapy compliance easily. This offers an opportunity to optimize therapies easily and it helps to eliminate distance barriers. For our patients it is easy to use. But elderly patients seem to be not qualified for using it as this generation is mostly not so experienced in the use of modern electronic devices. Since recently one system is available in Spain and shortly in more European countries. This would be a chance to reduce paper based documentation in the following decades.

Biography

Manuela Siebert is a Clinical Research Coordinator at the CRC-Coagulation Research Centre GmbH in Duisburg, Germany. Her research interests are focused on treatment options of hemophilia with special interest in cases of von Wille-brand diseases and rare bleeding disorders. She is a Member of the World Federation of Hemophilia (WFH) and Member of the scientific committee of the European Hemophilia Nurses Network (EHNN).

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