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The treatment of hemophilia requires vast economical and human resources. Comprehensive hemophilia care requires not only medical treatment, but psychological support and counselling. Hemophilia physicians must be assisted by psychologists, social workers and nurses. The importance of nurses in hemophilia treatment is already recognised in some countries such as the United Kingdom, where an organization for hemophilia nurses has been established (www.hemophilianurse.org). However, in other countries, such as Italy, hemophilia specialist nurses are lacking.

The aim of this project is to develop a training program for nurses wishing to specialize in hemophilia care. This training program should increase the knowledge and social competence of nurses caring for people with hemophilia.

Separate focus groups, involving persons with hemophilia, hemophilia physicians and nurses working in the field of hemophilia, will be

Specialization programme for hemophilia nurses in Italy (SPHINX)

used to collect different perspectives of relevant problems in hemophilia treatment. On the basis of these results, a modular training program will be developed to meet the needs of physicians, nurses and patients. The training programme will be evaluated for quality, practicality and complexity by a group of hemophilia experts. At the beginning of the training program the nurses will undergo a test in order to investigate their knowledge of hemophilia. These results will be used to determine areas of focus in the following training programmes. At the end of the training workshop they will perform the test again in order to evaluate the effectiveness of the program.

The program will be developed in Italy, where specialized nurses are almost completely lacking. It is expected that the program will result in greater awareness of the importance of nurses in hemophilia care, involving new forces, and perhaps creating an organization that can continue the training program in the future. This training program, which can be subsequently extended to other countries, is expected to support nurse professional development and qualification, and improve information, psychosocial support and ultimately the quality of life of patients and their families.

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