

Fostering collaboration in hemophilia care

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Approach to hemophilia care in the developing world

The effectiveness of a multidisciplinary approach to hemophilia care has been well established in hemophilia treatment centers around the world. Patients with bleeding disorders have unique and complex needs which are best addressed by a team of experts working in cooperation. For treatment centers in the developing world, creation of a collaborative multidisciplinary team has been shown to be an important factor in improving outcomes for patients with hemophilia.

Challenges of hemophilia care in India

Health care in India is divided among various centers, including autonomous institutions such as academic health care facilities, private hospitals, government-funded centers, and non-governmental organizations (NGOs). Patients with hemophilia may need to visit several facilities to access the medical and support services that they require. Hemophilia Society [Delhi] (HSD) started providing comprehensive care as an NGO in 1987, when such treatment was not otherwise available in Delhi. For the past three years, government centers have provided factor replacement therapy, free of cost, under specific conditions. Financially, HSD is unable to provide this, but continues to offer consultation, counseling, laboratory support, and physiotherapy. The situation seems complementary, but this complicated provision of care can be confusing for patients and families, and may lead to critical gaps in effective management of the acute and chronic issues these patients face.

Solutions through cooperation and collaboration

Through the World Federation of Hemophilia Twinning partnership between Delhi, India and Winnipeg, Canada, we are attempting to address and streamline this complex process. With the input from key representatives of the different institutions, we can identify the unique services that are available from each center. In cooperation with local government to address the infrastructural issues, we hope to be able to encourage the development of a collaborative network within Delhi for hemophilia care. Ultimately, this will enhance care available to persons with hemophilia throughout Delhi, and can become a model for other developing programs.

