



**Sylvia**  
Lacroix

The development of inhibitors, a serious complication of hemophilia, affects 25-50% of hemophiliacs with severe FVIII deficiency and 1.5-5% of FIX-deficient hemophiliacs. The Sainte-Justine children's hospital (along with its partner for adult patients, Maisonneuve-Rosemont Hospital) is currently the only Reference Centre for the treatment of patients with coagulation inhibitors, as designated by ministerial order in April 2000. In this care context, telemedicine could ease case management of patients despite their geographic remoteness or isolation by allowing transmission of medical data to and from the Reference Centre. Setting up such a system will enable individuals with inhibitors in Quebec or their family to transmit real-time images of a bleeding episode for which they currently consult by telephone. The ultimate goal of this initiative would be to optimise product use and improve quality of life in this patient population.

We assume that this real-time image transmission

## Telemetry in the service of hemophilic patients with coagulation inhibitors in Quebec

technology would make it possible to:

- Collect relevant data and promote better-informed medical case management
- Practice early intervention, the cornerstone of treatment in this target population
- Dispense quality care while reducing the cost associated with in-hospital procedures (e.g. travel, parking, babysitting, meal expenses)
- Give the patient/family a greater role in the care and treatment decision process
- Reduce traffic in already overextended hospital departments
- Document the use of coagulation products in real time

According to the experts consulted, the technology is straightforward and easily accessible. The required equipment consists of a video-type Polycom camera linked to the user's personal computer, and access to a high-speed Internet interface. The patient could then email the images captured during the bleeding episode to the telemedicine portable station, and simultaneously contact the Reference Centre by telephone to discuss the proposed treatment plan with a member of the medical staff. The latter could track the episode's progress and document each consultation/intervention in the patient's file. The confidentiality of the information transmitted would be ensured by the RTSS system already implemented in Quebec.

The hospital proved favorable to this type of approach and the targeted group of patients is small (n=10). The appearance of coagulation inhibitors is a serious

problem that requires special care. As proposed, the project is bold and innovative in that it allows for direct intervention between the treatment centre and the patient. To date, such projects have been documented only in the maritime field or between specialists and general practitioners. This initiative is not a substitute for interactive relation with the team of caregivers but would be in addition to the service already available.

The integration of recently diagnosed hemophilic patients could, in the short term, serve as a tool to reassure them and support them during their period of self-care learning. The structure of hemophilia treatment centres in Canada, which is based on a unique model, would also pave the way for implementing this approach in centers across Canada.

“

*The system will enable individuals with inhibitors in Quebec or their family to transmit real-time images of bleeding episodes for which they currently consult by telephone*

”

Hôpital Sainte-Justine  
Canada