

Patient Organization Assessment of Care Delivery in Canadian Treatment Centres

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INTRODUCTION AND OBJECTIVES

In 2013-14, with no formal accreditation or audit process in place to evaluate the level of services delivered in the Canadian network of 25 Inherited Bleeding Disorder Comprehensive Care Centres (IBDCCCs), the national patient organization, the Canadian Hemophilia Society (CHS), conducted its own assessment of the centres' human and physical resources.

The goals were to:

- evaluate each centre's capacity to respect the *Canadian Comprehensive Care Standards for Hemophilia and Other Inherited Bleeding Disorders* adopted in 2007;
- provide recommendations to centre staff, hospital administrations, and regional and provincial health authorities;
- provide CHS provincial chapters with evidence-based information about centre resources that they could use to advocate on behalf of their members.

METHODS

The assessment was in two parts:

- tour of the centre and in-person interviews, lasting 1 to 4 hours, with core members of the comprehensive care teams, either individually or in small groups, based on a standardized questionnaire, conducted by CHS staff;
- patient satisfaction survey. A random selection of 3,000 patients who had been seen in clinic in the last two years was made using the Canadian Hemophilia Registry (CHR) database. Questionnaires were sent by mail by the centre staff and returned to the CHS national office for compilation. Responses were anonymous.

Draft reports were shared with each centre director to ensure accuracy of information, and then approved. Final reports were made available to the centre staff, CHS chapter boards and local health officials. A national report entitled *Penny Wise, Pound Foolish* was published in May 2015. A summary of this report was published in *Haemophilia* in March 2016.

Centre participation was voluntary, but supported by the Association of Hemophilia Clinic Directors of Canada.

RESULTS

Twenty-four of the 25 centres agreed to meet the assessors. Interviews were held with 162 program staff, including: 51 physicians, 37 nurses, 23 physiotherapists, 17 social workers, 15 data entry personnel, and 19 others.

Twenty of the 25 Canadian centres distributed the patient satisfaction survey. It is not possible to state with any accuracy the number of questionnaires distributed; however, 347 were completed and received by the CHS.

All 25 centres provided up-to-date information on the numbers of patients registered and on the staffing levels of core team members.

Key findings were the following:

1. Patients and their families expressed very strong appreciation for the competence and dedication of the health care providers who work in the IBDCCCs across Canada, and for the comprehensive care model that has evolved over the last four decades.
2. However, despite dedicated and well-trained staff, the programs are experiencing serious resource deficiencies. Twenty-three of the 25 programs lack human resources in one or more of the core disciplines. In nine of the 25 programs, no resources are allocated to certain core disciplines, notably physiotherapy and social work. These shortcomings affect the ability of some programs to respect certain standards of care. **See Tables 1 and 2.**

An additional 21.1 FTEs were considered necessary to help program staff meet the current challenges of increasing numbers of patients and an ageing population. At an average of \$70,000 per FTE, this represents a national investment of less than \$1,500,000, or approximately one-half of one percent (0.5%) of the 2014 budget of \$270,000,000 for the care of people with inherited bleeding disorders. Ninety-three percent (%) of this expenditure was the cost of clotting factor concentrates; only 7% was spent for all other aspects of care delivery.

3. Support is needed to run the Canadian Bleeding Disorders Registry (CBDR), currently being implemented. This information system has the potential to significantly improve home infusion reporting, data collection and health monitoring by centre staff, and health outcomes. It will attain these goals, however, only if the CBDR is adequately funded in the medium to long term. The cost is estimated at \$600,000 per year to house, maintain and develop the registry, and an additional \$300,000 per year for additional data entry resources in the centres. This represents approximately one-third of one percent of the total cost of coagulation therapies.

In all, 25 recommendations were made to improve adherence to Standards of Care.

CONCLUSIONS

This project showed that it is possible, even in a country as large as Canada, for a patient organization to conduct a rigorous evaluation of centres of care. This requires:

- strong, trusting relations between the patient organization and the centres across the country;
- trained assessors;
- the financial and human resources to conduct the time-consuming interviews, analysis of patient surveys and preparation of professional reports.

The reports have already influenced health care decision-making and resulted in added human and physical resource allocation.

Ideally, an accreditation system can be put in place which will be recognized by hospital administrations and whose recommendations will have force.

Table 1: Full-time equivalents (FTEs) per 100 hemophilia A and B patients in all centres

Centre	Nursing	Physiotherapy	Social work	Admin/data	Comments
1	1.5	0.4	0.3	0	These are pediatric centres
2	1.0	0.2	0.3	0.6	
3	1.0	0.3	0.2	0.14	
4	0.9	0.1	0.2	1.1	
5	1.6	0.4	0.4	1.0	
6	0.6	0.2	0.2	0.2	These are adult centres
7	0.6	0.1	0.1	0.6	
8	0.4	0.1	0.01	0.2	
9	0.4	0	0	0.2	
10	0.6	0	0.1	0.1	
11	1.2	0.14	0.2	0.5	These are combined pediatric / adult centres
12	0.5	0.2	0.05	0.6	
13	0.8	0.2	0.3	0.8	
14	0.5	0.1	0.1	0.6	
15	1.5	0.25	0.1	0.4	
16	0.6	0.1	0.05	0.01	
17	1.0	0.1	0	0.6	
18	1.3	0	0	0.6	
19	1.4	0.4	0.4	1.8	
20	1.0	0.05	0	0	
21	0.6	0.1	0	1.0	
22	1.0	0.25	0.02	0.25	
23	1.1	0.07	0.07	0	
24	0.2	0.01	0.01	0.1	
25	0.4	0.01	0	0.4	
Total	21.7	3.88	3.11	12.36	
Mean	0.87	0.15	0.13	0.47	

Table 2: IBDCCC current FTEs and recommended additional staffing (in brackets)

Centre	Hemophilia A and B patients	Nursing	Physiotherapy	Social work	Admin/data
1	Pediatric	103	1.6 NP	0.4	0.3
2	Pediatric	63	0.6 (1.0)	0.15 (0.3-0.4)	0.2
3	Pediatric	167	1.6 (2.0)	0.5 (1.0)	0.33 (1.0)
4	Pediatric	56	0.5 (0.7)	0.05 (0.2)	0.1 (0.2)
5	Pediatric	57	0.9 (1.1)	0.2 (0.4)	0.2 (0.3)
6	Adult	215	1.3 (2.0)	0.4 (0.8)	0.4 (0.8)
7	Adult	175	1.0* (1.6)	0.2 (0.4)	0.2 (0.4)
8	Adult	404	1.5 (2.0)	0.4 (0.6)	0.1 (0.2)
9	Adult	184	1.0	0 (0.2)	0 (0.2)
10	Adult	118	0.7 (1.0)	0 (0.2)	0.1 (0.2)
11	Ped./adult	196	1.5** (2.0)	0.3 (0.4)	0.4 (0.8)
12	Ped./adult	245	1.2	0.6 (1.0)	0.1
13	Ped./adult	60	0.5 (1.0)	0.1 (0.2)	0.2 (0.4)
14	Ped./adult	174	0.8	0.2	0.2
15	Ped./adult	158	2.3	0.4	0.2 (0.3)
16	Ped./adult	179	1.0	0.2	0.1
17	Ped./adult	104	1.0	0.1	On call (0.2)
18	Ped./adult	40	0.5 (1.0)	0 (0.2)	0 (0.2)
19	Ped./adult	139	2.0	0.5	0.6
20	Ped./adult	62	0.6	0.025 d/y (0.2)	0 (0.1)
21	Ped./adult	211	1.4	0.2	0 (0.2)
22	Ped./adult	396	4.0	1.0	0.1 (0.5)
23	Ped./adult	134	1.5 (2.0)	0.1 (0.2)	0.1 (0.2)
24	Ped./adult	89	0.2 (0.5)	0.008 (0.1)	0.008 (0.1)
25	Ped./adult	56	0.2	0.008 (0.2)	0 (0.1)
Total		3,785	28.4 (5.6)	5.9 (3.7)	3.9 (4.1)
					14.0 (7.7)

NP - Nurse Practitioner*
1.6 for all blood/immune disorders**
2.5 for all blood/immune disorders

References/Bibliography

1. Penny wise, pound foolish: an assessment of Canadian Hemophilia/Inherited Bleeding Disorder Comprehensive Care Program Services and Resources D. PAGE,* S. CRYMBLE,† K. LAWDAY,* M. LONG,* J. STOFFMAN,‡ L. WATERHOUSES and P. WILTON*
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2. A National Assessment of Hemophilia/Inherited Bleeding Disorder Comprehensive Care Program Services and Resources, Canadian Hemophilia Society, May 2015, bit.ly/29EF80o



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Care Delivery
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