Progress in Comprehensive Care for Rare Blood Disorders

Progress and Lessons Learned

Standards of Care for Hemophilia and Other Inherited Bleeding Disorders

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Previous milestones

1970s: Self/family administration of clotting factors (cryoprecipitate & concentrates)
Previous milestones

1976: First Canadian Hemophilia Registry (managed by CHS)
1978: Winnipeg Conference to establish model for comprehensive hemophilia care
1980s: Creation of network of 25 Hemophilia Treatment Centres in 9 provinces
Previous milestones

- 1990s: Creation of 4 professional groups
  - Association of Hemophilia Clinic Directors of Canada (AHCDC)
  - Canadian Association of Nurses in Hemophilia Care (CANHC)
  - Canadian Physiotherapists in Hemophilia Care (CPHC)
  - Canadian Social Workers in Hemophilia Care (CSWHC)
Previous milestones

1998: Winnipeg II

A second conference to establish standards for hemophilia care
Previous milestones

1999: Publication of *Clinical Practice Guidelines* for hemophilia and von Willebrand disease by Association of Hemophilia Clinic Directors of Canada

www.ahcdc.ca/
Why standards?

**Fig. 1.** Chances of avoiding hospitalization for bleeding complications according to home therapy and haemophilia treatment centre (HTC) use among 2950 males with haemophilia identified by a six-state surveillance system and followed for up to 4 years. *Soucie et al, Haemophilia 7:198, 2001*
## Why standards?

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Deaths</th>
<th>Mortality Rate*</th>
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<tbody>
<tr>
<td><strong>Non-HTC</strong></td>
<td>971</td>
<td>86</td>
<td>38.3</td>
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<tr>
<td><strong>HTC</strong></td>
<td>1979</td>
<td>149</td>
<td>28.1</td>
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* Deaths per 1000 person-years;
  Soucie et al, Blood 2000; 96:437
Development of Standards

• 2004: AHCDC creates multi-disciplinary working group to develop standards

• 2007: First edition of standards is presented at AHCDC/CHS Medical and Scientific Symposium

• 2007: all 4 professional groups and patient organization endorse the standards document
Previous milestones

2007: Quebec City

Adoption of Canadian Comprehensive Care Standards for Hemophilia and Other Inherited Bleeding Disorders

CANADIAN COMPREHENSIVE CARE STANDARDS FOR HEMOPHILIA AND OTHER INHERITED BLEEDING DISORDERS

First Edition
June 2007

Authored by the Canadian Hemophilia Standards Group

1 A committee of the Association of Hemophilia Clinics Directors of Canada in collaboration with the Canadian Hemophilia Society (CHS), the Canadian Association of Nurses in Hemophilia Care (CANNHC), Canadian Physiotherapists in Hemophilia Care (CPHHC), and Canadian Social Workers in Hemophilia Care (CSWHC).
Standards of Care

Aims

Intended for use by Hemophilia Treatment Centres, hospital administrations, and provincial Ministries of Health.

To provide comprehensive care to all individuals with inherited bleeding disorders, guided by clear standards, facilitated by engagement with stakeholders, and driven by needs and best practice, resulting in best outcomes.
Focus of standards

On the *structural and resource requirements* necessary for a Hemophilia Treatment Centre to effectively provide care, and on its *functions and responsibilities*. 
Purpose of Standards

• Achieving recognition of Hemophilia Treatment Centres by hospital and provincial authorities
• Assuring equitable access and quality evidence-based care across Canada
• Establishing a reference for future advances and needs
• Establishing a focus and unifying force for staff of various disciplines
• Promoting discussion and research regarding optimal ways to deliver care
• Providing the basis for design of clinics, for accreditation, and for audit and evaluation
Effective programs...

- deliver comprehensive care through an integrated, multi-disciplinary team.
- partner with patients to foster and facilitate self-management and independence.
- have the capacity to tailor management to the individual’s needs and abilities.
- adhere to guidelines and standards.
- regularly participate in quality assurance.
- consult with other programs.
- participate in collaborative research.
Structure of Standards Document

Scope of Care: To describe which bleeding disorders are to be addressed by the HTC, the required staff, and the administrative structure and responsibilities

& Key Indicators

Quality Measures: To describe expected activities of an HTC that contribute to the quality of both the individual centre and the Canadian HTC network

& Key Indicators

Therapeutic Services: To describe the actions required of an HTC in the direct delivery of therapeutic services

& Key Indicators
1. Establish correct **diagnoses**.
2. Establish and maintain a full complement of **core team members**.
3. Develop **visibility**.
4. Strive to **enrol** all members of the target population.
5. Establish a **collaborative relationship** among core team members.
6. Establish a routine for patient access to regular and **emergency care**.
7. Establish a process for **referring** patients to services not provided within the program.
8. **Register** patients in CHARMS and CHR databases.
9. Provide the patient with **documentation** that identifies his/her bleeding disorder and recommended treatment.
10. Provide **education** to affected individuals, family members, health care givers and others.
11. Have a **home infusion program**, including prevention and recognition of bleeds.
12. Provide **prophylaxis** regimens.
13. Provide **early intervention** and follow-up care to reduce long-term complications.
14. **Network** with outside agencies.
15. Encourage & facilitate eligible members to participate in **professional activities**.
Quality Measures

1. Participate in **data collection** and submission to CHARMS including patient demographics and factor utilization.
2. Maintain **health records** according to legislation.
3. Submit **anonymous data** to the Centre Point module of CHARMS and to the CHR.
4. Adhere to provincial health information **privacy protection** acts.
5. **Be supported** by its host hospital and the provincial Ministry of Health.
6. Accept **accountability** for the appropriate use of all **factor concentrates** distributed within its catchment area to registered patients.

7. Participate in a formal **accreditation** and evaluation process once it is established.

8. **Mentor**, where possible, students and trainees in the health professions.

9. Establish mechanisms to acknowledge and review compliments, **complaints** and special requests.
1. Provide the appropriate **professional care**.
2. Provide a comprehensive **assessment** at least annually for adult patients and semi-annually for children.
3. Provide **assessments** from each core team member at least annually.
4. Provide **emergency departments and family physicians** with diagnosis and treatment recommendations. Arrange for qualified **24-hour medical coverage** and consultative services.
5. Educate patients and families on the best way to advocate for and to access **emergency care** and other services.
6. Utilize **clinical practice guidelines** published by AHCDC and other expert bodies.
7. Establish **formal links** to provide access to special hemostasis testing, genetic testing, and treatment.
8. Work in **collaboration** with patients and their families to promote health and to enhance ability to cope with a chronic health condition.
9. Provide **education** and recommendations to other community professionals who provide services to patients.
10. Provide **prophylaxis** to patients in accordance with AHCDC recommendations and best practice.
11. Provide a **home therapy program** to all appropriate patients and monitor its effectiveness.
12. Provide injection equipment and other supplies to patients.
13. Provide management for patients with inhibitors.
14. Be located in a facility that should be readily accessible.
15. Be located within an Ambulatory Clinic area to facilitate prompt assessment and treatment.
16. Be located in a facility that has or is linked with an Emergency Department where patients can obtain treatment outside of regular hours.
Full Standard

• The full standard, including performance indicators, is available at:

Subsequent Steps

- 2008: Development of an anonymous, voluntary self-administered survey for HTCs based on the standards
- Spring 2009: Survey carried out in 23 of 25 HTCs
- Autumn 2009: Results collated and analyzed
- 2010: Standard revised (if necessary)
- 2010: Creation of external audit process
- 2010: First audits of HTCs
- 2011-2013: Rollout of audit process across Canada
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