Canadian Comprehensive Care Standards: results of a self-assessment survey of the Standards by 24 Canadian hemophilia treatment centres.

Summary

HTC performed a self-assessment survey to validate the Canadian standards[1]. This expectation was largely realized: the average adherence by all clinics to all standards was 92% (standards being adhered to by an average of 22 of 24 HTC[2]). Adherence levels below 83% (20 of 24 HTC) were observed for only 4 standards; for two of these standards the low adherence was due to a lack of core team members, particularly social workers and physiotherapists but possibly administrative staff as well. A lack of any of these team members is particularly serious considering their importance, as indicated by statements from the World Federation of Hemophilia and by the Canadian standards. Lack of complete adherence to other standards was due to a variety of reasons, in most cases either easily explainable or spurious. No correlation was found between the level of adherence to the standards and any one of a variety of HTC descriptors. The general level of acceptability of the standards is high; most clinics (20 of 24, 83%) thought the standards were useful and 22 of 24 clinics (92%) expressed their willingness to participate in evaluation and accreditation processes once these are established.

Canadian standards can now be used by the hemophilia community for the purpose of external accreditation of Canadian HTC. However, it will be important to judge application of the standards flexibly; the relative importance of individual standards has not been graded, and adherence to all standards will for some HTC be neither possible nor necessary. With the guidance of the results of this survey, together with the comments received, it would be appropriate now to revise the existing standards to a Second Edition.

Introduction

In 2009, in response to a request from AHCDC executive, the Standards group[3] initiated a self assessment survey among Canadian Hemophilia Clinics. The goal was to validate the Canadian clinic standards by assessing acceptability and adherence.

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[1] Canadian Comprehensive Care Standards for Hemophilia and other Inherited Bleeding Disorders, First Edition, June 2007 (available at www.hemophilia.ca and http://www.ahcdc.ca)

[2] HTC: Hemophilia Treatment Centre (or Centres)

[3] Members: Dorothy Barnard (recent past member), Morna Brown, Maureen Brownlow, David Page, Victoria Price, Erica Purves, Julia Sek (past), Connie Shrubsole, Mary Jane Steele, Jerry Teitel (co-chair), Irwin Walker (co-chair), Margaret Warner, Braden Waters, Pam Wilton.

As a result, clinics would be able to compare their own practices on each standard against those of all clinics, find out about new ways in which standards can be attained, and hence raising their own standards and, finally, use the results locally to bolster their case for new resources. In turn, members of the hemophilia health care organizations, and CHS[4], would become more knowledgeable about hemophilia care across Canada, would be able to highlight national successes, develop new ways to achieve standards, become aware of weaknesses in the system and be better able to work towards closing gaps in care. Finally (deleted indents), the national database would stand as a baseline to compare future practices.

Methodology

A web-based survey was designed. Centres could respond by completing the survey online, or provide answers on paper. The latter was preferred as clinics had been encouraged to include all core team members in the process of self-assessment. In the end, responses were received from all clinics except one which gave advance notice that they would not be able to reply, there having been recent and major staff reductions. Funding was obtained through CHS, and <company > was commissioned to design the website and collate the data in a form suitable for analysis.

Clinics were asked about their ability to attain each standard, how they demonstrate adherence, and were invited to provide suggestions and examples. Responses were kept anonymous, one member of the Standards committee applying a code for each clinic's responses. A collated report would be prepared.

Results

For each standard the responses were collated and summarized. For each standard the degree of adherence was the primary interest; secondarily, the degree of adherence was sub-tabulated according to the following variables: Size of clinic according to patients numbers, number of severely affected cases, type of clinic (pediatric, adult, combined), average distance of patients from clinic, funding (provincial, hospital, other) and according to whether the clinic considered the standard to be useful. Because of the small differences and small numbers of the subgroups, only where outstanding differences appeared were these subcategories commented on.

The results are summarized in the following paragraphs, following the order of the standards in the Standards monograph. The standards have also been numbered in ascending order for ready reference to figure 1.

[4] AHCDC: Association of Hemophilia Clinic Directors of Canada; CANHC: Canadian Association of Nurses in Hemophilia Care; CAPHC: Canadian Physiotherapists in Hemophilia Care; CSWHC: Canadian Social Workers in Hemophilia Care; CHS: Canadian Hemophilia Society.

Summary of responses to survey questions relating to "Scope of Care" standards (Section 1)

Overall, adherence to the standards regarding "Scope of Care" was high: 92% (22 of 24) of responding HTC are able to adhere to 12 or more of the 15 standards. Four of six adult only clinics compared with 17 of 18 pediatric and combined clinics were able to adhere to at least 12 of the 15 standards.

Standard 1-1 (1): Most (22 of 24) HTC can establish an accurate diagnosis, while all HTC had documented factor levels on their patients. Comment: This seems contradictory, however a few disorders present problems in diagnosis and may need to be referred.

Standard 1-2 (2): Only 14 of 24 HTC have a complete complement of core team members as listed in the standards. This is most notable in the largest clinics, of which only 2 of 7 adhere to the standard, as compared to 12 of 17 of the remainder. Comment: Lack of full complements of core team members is a widespread problem; this standard is one of the least adhered to.

Standard 1-3 (3): Most HTC (21 of 24) feel they have high visibility in the bleeding disorder and medical communities, maintain regular communication with the CHS (22 of 24), and are open to contact for information (23 of 24). Proactive communications to outside agencies regarding current events/workshops and conferences is less common (14 of 24).

Standard 1-4 (4): Twenty of 24 strive to enroll all patients in their region or and are aware of factor concentrate utilization regionally.

Standard 1-5 (5): There is a high level of collaboration among team members of nearly all HTC (22 of 24), referring presumably to clinical care. There is also a high frequency of collaboration, though less (20 of 24), in the development of policies, procedures and standards.

Standard 1-6 (6): There is almost universal (23 of 24) ready access to care and follow up of acute bleeds, and availability of ambulatory facilities outside emergency rooms. Policies and procedures for care have been developed by only two thirds of HTC (16 of 24).

Standard 1-7 (7): HTC almost universally (23 of 24) have procedures for referring patients to services not provided within the program, and all team members are knowledgeable about these procedures. HTC less often have specific lists of secondary team members to refer to. Only half of HTC invite secondary team members to educational workshops and activities.

Standard 1-8 (8): Ninety-six percent of HTC (23 of 24) have CHARMS available in their clinic and register their patients into CHARMS, and into CHR. However in only 12 HTC do all core members have access to CHARMS. Clerical work for data entry is kept current by only 17 of 24 HTC (71%).

Standard 1-9 (9): All HTC provide patients with wallet cards outlining their diagnoses and treatment recommendations.

Standard 1-10 (10): HTC do provide education to affected individuals, family members, health care givers and others as necessary and have access to educational resources (23 of 24). Written policies and procedures for delivering such education is less widespread (14 of 24, 58%).

Standard 1-11 (11): Home infusion programs are available universally (23 of 24), and HTC keep lists of participating individuals. Formalization is less widespread, with policies and procedures existing in only 18 of 24 HTC, and documentation of participation in the health record by only 15 HTC.

Standard 1-12 (12): All HTC provide programs for prophylactic concentrate infusion programs and most (21 of 24) have lists of patients on these programs.

Standard 1-13 (13): HTC provide early intervention and follow up care (22 of 24), and have access to special coagulation and transfusion medicine laboratories, and to diagnostic imaging. Nineteen of 24 HTC have a procedure for assigning priority for new patient referrals.

Standard 1-14 (14): Contact information for all HTC is currently listed with CHS and all HTC network with outside agencies.

Standard 1-15 (15): There is strong encouragement for core team members to participate in activities of AHCDC, CANHC, CPHS, CSWHC and other relevant HTC working groups (23 of 24 HTC), and in 22 of 24 HTC members are participating members of such working groups.

Summary of responses to survey questions relating to "Quality Measures" standards (Section 2)

Overall, adherence to the standards regarding "Quality Measures" was uniformly high: over 90% (22 of 24) of responding HTC are able to adhere to 7 or more of the 9 standards. Although numbers were small, it appears that HTC servicing very large catchment areas may have somewhat more trouble adhering to some of these standards.

Standard 2-1 (16): There is near universal adherence to standards relating to record keeping (24 of 24), with the exception of telephone advice, which is less well documented (18 of 24).

Standards 2-2 and 2-3 (17&18): There is nearly universal ability to seek assignment of CHR numbers to new patients (22 of 24), and to collect data and enter it into CHARMS (23 of 24). There is very good but a somewhat lower degree of adherence to routinely submitting these data to the Centrepoint module (18 of 24), and to using it locally e.g. factor utilization reports (20 of 24), and monitoring expiry dates (18 of 24)).

Standard 2-4 (19): HTC nearly universally report adherence to provincial privacy legislation (22 of 24) and have the ability to store patient data with appropriate security (23 of 24).

Standard 2-5 (20): There is variable participation by HTC in peer evaluation activities at present. A substantial proportion of HTC have not identified mechanisms to seek resources necessary to provide services to their patients (not identified by 10 of 24). This is particularly true for HTC which are funded through hospital global budgets, fewer than half of which are able to adhere to this standard; this is in contrast to an approximately 80% adherence among HTC funded directly through Ministries of Health. The interpretation is that HTC do not feel well supported by their hospitals.

Standard 2-6 (21): A large majority of HTC (22 of 24) feel confident in their ability to accept accountability for factor concentrate distributed to patients registered in their Programs.

Standard 2-7 (22): Almost all HTC (22 of 24) express their willingness to participate in evaluation and accreditation processes, once these are established.

Standard 2-8 (23): Nearly all HTC (23 of 24) participate in mentoring and continuing education activities directed to various health professions.

Standard 2-9 (24): There is variability (18 of 24) in the ability of HTC to collect, document and review feedback from patients and other stakeholders. Adherence to this standard tends to be higher for HTC with larger numbers of registered patients.

Summary of responses to survey questions relating to "Quality Measures" standards (Section 3)

Overall, adherence to at least 13 of the 16 standards (81%) in this category was achieved by 22 of 24 (92%) HTC. Adherence was achieved to this degree by all pediatric and combined pediatric clinics but by only 2 of 6 adult-only clinics.

Standard 3-1 (25): All 24 HTC assessed themselves as being able to provide the appropriate professional care for their patients, recognizing the need for pediatric and adult medical expertise as appropriate

Standard 3-2 (26): Only 20 of 24 (83%) of HTC provide a comprehensive evaluation (including lab testing) at least annually for adult patients and semi annually for children, this frequency being recommended for those with higher bleeding risk. A possible explanation is provided by one of the key indicators, responses indicating that for 4 HTC the number of assessment clinics offered is insufficient to meet this standard. This was the case for 3 of 6 adult-only clinics compared with 1 of the 18 remaining HTC.

Standard 3-3 (27): Only 17 of 24 HTC (71%) provide assessments from each core team member at least annually. This was the case in only 1 of 6 adult-only clinics and 16 of the other 18 HTC.

Standard 3-4 (28): Twenty of 24 clinics feel that they meet this standard, which relates to promoting care beyond the HTC, particularly to family physicians and emergency rooms. Interpretation is difficult

because the standard has three components. All clinics provide treatment recommendations to their ERs and patients' family doctors but other resources are not otherwise provided by 4 HTC.

Standard 3-5 (29): All clinics feel that they educate patients and families on the best way to advocate for and to access emergency care and other services. Not all core team members may be involved in this process.

Standard 3-6 (30): Nearly all HTC (23 of 24) utilize clinical practice guidelines for the management of bleeding episodes, inhibitors and special or surgical procedures.

Standard 3-7 (31): Nearly all HTC (23 of 24) have formal links to specialized services such as special hemostasis laboratories and genetic services.

Standard 3-8 (32): All HTC feel that they work collaboratively with patients and families in providing services and ensure safety when participating in clinical trials, and nearly all provide business cards with contact information.

Standard 3-9 (33): Nearly all HTC (22-23 of 24) provide education and recommendations to other community professionals, offer education to communities, and transfer patients from one HTC to another in a formal manner.

Standard 3-10 (34): All HTC provide prophylactic programs according to recommendations and have reference materials available.

Standard 3-11 (35): This is a complex standard regarding the provision of a home therapy program for patients, to which 23 of 24 centres adhere. Existence of evaluation is achieved by a lower proportion (21 of 24).

Standard 3-12 (36): At 3 HTC injection equipment and supplies are not provided free of charge.

Standard 3-13 (37): Only 20 of 24 HTC provide management for patients with inhibitors with reference to guidelines issued by the AHCDC and other expert bodies, though reference materials are available at all HTC. The explanation for the less than universal provision of services may lie in the fact that not all HTC have patients with inhibitors.

Standard 3-14 (38): Twenty-one HTC are located in a facility that should be readily accessible to people with disabilities, and 6 HTC feel that physical clinic space is not appropriate for people with disabilities or mobility aids.

Standard 3-15 (39): Twenty-two of 24 HTC are located within an ambulatory clinic area to facilitate prompt assessment and treatment of acute bleeding episodes. A few HTC feel that these facilities need improvement.

Standard 3-16 (40): All HTC are located in a facility that has, or is linked with, an ER where patients can obtain treatment outside of regular hours. Twenty of 24 HTC have provided to these ERs treatment guidelines for registered patients.

Comments Received

There were many comments received, the list filling 26 pages. These comments will be very useful in further interpreting the data and in revising each standard but are too numerous to detail here. The comments provide valuable insight into how clinics operate and many of the reasons for non-adherence, but they do not influence the overall results and conclusions of this survey.

Prediction of Adherence

Analysis was carried out to determine associations between the level of clinics' adherence to standards and clinic descriptors, these being total patients, number of patients severely affected, type of centre (pediatric, adult etc), University affiliation, funding source, territory size, and whether or not clinics found guidelines to be helpful). No significant associations were found between levels of adherence and these descriptors.

Overview

Each and every standard was adhered to by a majority of HTC, adherence ranging from 14 (58%) to 24 (100%) of HTC (see Figure 1).

The average adherence across all standards was 22 (of 24 HTC, 92%), and the median was also 22, indicating a tight cluster at a high level of adherence. As seen in Figure 2, for 73% of standards (29 of 40) adherence was claimed by 22 of 24 HTC (92%), or more. For only 10% of standards (4 of 24) did adherence fall below 83% (20 of 24).

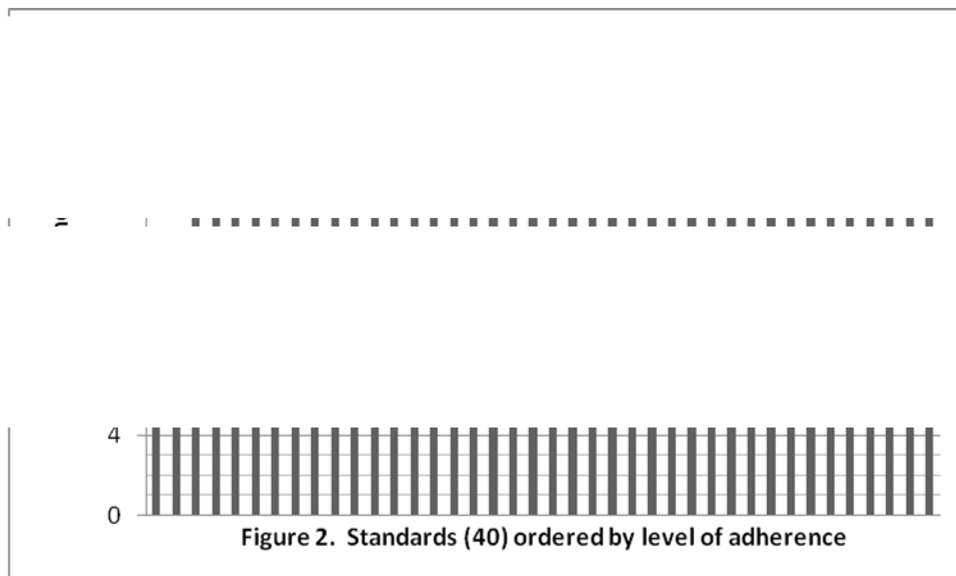

Figure 2. Standards (40) ordered by level of adherence

Focus on Standards with Lowest Levels of Adherence.

Four out of 40 standards (10%) had adherence lower than 83% (20 of 24 HTC). See Figure 1.

Standard (2): Adherence by 14 of 24 HTC. This indicates that many clinics lack a full complement of core team members as specified in the standard. Comments refer particularly to Social Workers and Physiotherapists, but as well in one case to an Administrative Assistant.

Standard (20): Adherence by 14 of 24 HTC A substantial proportion of HTC have not identified mechanisms to seek adjustment to the resources necessary to provide services to their patients. Centres funded from their MOH appear more able to adhere (8 of 10 HTC) than those funded by their hospital global budget or other source (6 of 14 HTC).

Standard (27): Only 17 of 24 HTC (71%) provide assessments from each core team member at least annually. Comments received confirm that this is partly due to the lack of core team members (Standard 2, see this section above). The lack of adherence is due also to a difference in approach, some clinics tending to involve social workers and physiotherapists only “when necessary”.

Standard 2-9 (24): There is variability (adherence by 18 of 24) in the ability of HTC to collect, document and review feedback from patients and other stakeholders. The level of adherence is open to interpretation. In many cases such feedback may be handled on an ad hoc basis; in addition, comments received suggest that feedback is handled by procedures set up by the hospital for all departments.

Commentary

This survey was designed to assess the acceptability of the standards, by testing the level of adherence and by inviting comments. This process is an iterative one, a “back and forth” dialogue: HTC have for many years strived to provide best care which they have derived from a combination of published evidence, collaboration with colleagues across the world, and their own experience; the members of the standards committee are themselves members of the HTC and bring to the committee the knowledge of HTC practice; thus, HTC practice determines the standards, rather than the other way round. Rather than being paradoxical, it is the norm; firstly it follows the actual chronology, secondly it follows the process of standard development in areas beyond hemophilia and medicine. For example, members of committees of the Canadian Standards Association (CSA) that determine standards for industries and professions are largely those practicing in the areas for which standards are being developed. Standards are thereby established by those most knowledgeable and experienced, these standards then coming to represent the opinion of that industry or profession as a whole. Individual members of that industry then strive to maintain or attain the levels of practice prescribed by the standards.

Standards recognize various levels of requirement for adherence, some subsections requiring absolute adherence, being preceded by “must”, “will” or “shall”, while other subsections may be assigned a lesser

requirement, reflecting either applicability only under particular conditions or reflecting a state that is merely optimal or desirable (preceded by "should", "may" or "ought"). Thus, there is no *a priori* requirement or expectation that the present survey should have resulted in 100% compliance.

In addition to the above considerations, the stated level of compliance, when less than universal was often open to interpretation and may not reflect true non-adherence. In some cases lack of adherence to one standard may influence adherence to another e.g. one reason for poor adherence to Standard 3-3 (27) may in part be a consequence of poor adherence to Standard 1-2 (2). In other cases the standard may be unnecessarily detailed, involving a number of components, thereby increasing the likelihood of incomplete compliance e.g. Standard 3-4 (28). An apparent lack of adherence may be spurious as in Standard 3-13 (37) where the failure to provide care to patients with inhibitors may reflect the lack of inhibitor patients at those sites. Finally, variation in adherence may reflect different ways of thinking by HTC.

Recommendations

1. That the Canadian Standards, First Edition, be used for purposes of external accreditation of Canadian HTC, qualified by the limitations set out in the Summary of this report.

2. That the Canadian Standards be revised and upgraded to a Second Edition, guided by the results of this survey, including the comments received, the objectives being to grade the importance, and where necessary qualify, each standard.

3. That mechanisms to correct deficiencies in staffing be investigated.