Interprofessional Workshop Series

Implementing Best Practices

Pediatric Diabetes in BC: A Public Health Perspective Workshop

November 14 & 15, 2008

Vancouver BC

November 14, 2008 marked the 17th annual World Diabetes Day, where the theme was diabetes in children and adolescents.

November 27, 2008

revised Jan 2010

Executive Summary

On November 14 & 15, 2008 Child Health BC, in partnership with the BC Children's Hospital Endocrinology & Diabetes Unit, hosted a consultation workshop on pediatric diabetes in BC. The purpose of the workshop was to initiate the planning and implementation of a BC pediatric diabetes program designed to meet provincial and national standards.

The workshop focused on the following five themes:

- A *public health approach* to pediatric diabetes
- The landscape of pediatric diabetes in BC
- Professional best practice
- Diabetes education programs and the role of the diabetes team
- Needs assessment by regional health authority

The five key objectives of the workshop were to:

1. Define the current context of pediatric diabetes in British Columbia.
2. Review the recently published 2008 Canadian Diabetes Association Clinical Practice Guidelines.
3. Discuss the role of the diabetes team and describe best practices, innovations and challenges in pediatric diabetes education programs.
4. Engage in collaborative dialogue on the successes and barriers to pediatric diabetes care in various regions of BC focusing on: identifying gaps and barriers to the provision of standards of care and formulating solutions to facilitate the implementation of an effective provincial pediatric diabetes program in BC.
5. Build regional team capacity and interprofessional relationships for continued contact and collaboration.

Representatives from BC's health authorities and BC Children's Hospital Endocrinology & Diabetes Unit provided detailed information regarding the current strengths and challenges throughout the province for children and youth with diabetes.

The following were identified as first steps towards developing a more unified provincial program:

1. The development of a provincial educational resource for newly diagnosed children with diabetes
2. The organization of regional diabetes workshops to help unify pediatric diabetes within each regional health authority
3. The exploration of existing provincial and national databases that may facilitate the evaluation of health and non-health outcomes in children with diabetes living in BC.

Introduction

About Child Health BC

Child Health BC is a network of the province's five geographic health authorities, the Provincial Health Services Authority, Ministry of Health Services, Ministry of Children and Family Development, health professionals and care facilities dedicated to excellence in the care of infants, children and youth in BC. Child Health's vision is the best health for infants, children and youth in BC. The mission is to build an integrated and accessible system of care for the purpose of improved health status and health outcomes for BC's infants, children and youth and the mandate is to bring together partners from the health authorities, the Ministry of Health Services, the Ministry of Children and Family Development, and other provincial agencies and services to optimize the health of children and youth and to improve access to high quality clinical health services.

Through cooperative partnerships; regional subspecialty programs; education and dissemination; research; monitoring quality and performance; and developing standards, protocols and guidelines, Child Health BC is creating an integrated, standardized and accessible system of care available to all children in British Columbia.

About BC Children's Hospital Endocrinology & Diabetes Unit

The BC Children's Hospital Endocrinology & Diabetes Unit is a diagnostic, treatment and education centre for children and families affected with diabetes and other endocrine conditions. The endocrine conditions include variations and abnormalities of normal growth and puberty, as well as both over- and under-production of thyroid, parathyroid, adrenal, and antidiuretic hormones. Through its affiliations with the University of British Columbia (UBC) Faculty of Medicine / Department of Pediatrics, the UBC School of Nursing, and the UBC Faculty of Land and Food Systems / Food, Nutrition and Health Program, the Unit serves as an academic resource centre for pediatricians and other physicians and health-care professionals serving children affected with diabetes and hormone problems in BC.

Workshop Purpose & Objectives

The purpose of the workshop was to initiate the planning and implementation of a pediatric diabetes network in BC designed to meet provincial and national standards of diabetes care. Figure 1 illustrates the five workshop objectives:

Figure 1: Workshop Objectives

1. Define the current context of pediatric diabetes in British Columbia.
2. Review the recently published 2008 Canadian Diabetes Association Clinical Practice Guidelines.
3. Discuss the role of the diabetes team and describe best practices, innovations and challenges in pediatric diabetes education programs.
4. Engage in collaborative dialogue on the successes and barriers to pediatric diabetes care in various regions of BC focusing on: identifying gaps and barriers to the provision of standard of care, and formulating solutions to facilitate the implementation of an effective provincial pediatric diabetes network in BC.
5. Build regional team capacity and interprofessional relationships for continued contact and collaboration.

Workshop Highlights

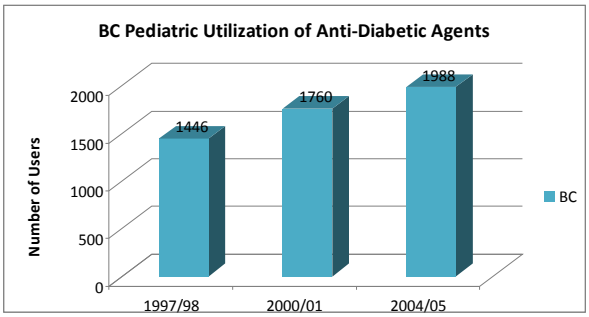
A Public Health Approach to Pediatric Diabetes Care

Lead: Shazhan Amed, MD, MSc,
Clinical Assistant Professor, Department of Pediatrics, UBC
Endocrinologist, BC Children's Hospital

Dr. Amed spoke of the significance of November 14th – World Diabetes Day. Research indicates that globally, Type 1 Diabetes is increasing by 3% per year in children and adolescents and 5% per year in preschoolers. Type 2 Diabetes is also growing at alarming rates in children and adolescents - parallel to increasing rates of childhood obesity. Dr. Amed emphasized the need to work together on challenges and develop strategies to create a provincial pediatric diabetes network. This network would enable equitable access to diabetes care and education, and will ensure that necessary supports are available closer to home for **all** children with diabetes living in BC.

Dr. Amed spoke about the prevalence of chronic disease – affecting approximately 20% of children and accounting for up to 80% of expenditures on child healthcare. Pediatricians in BC report the health care system needs to be more responsive to children with complex chronic disease (CCD). Pediatricians in BC suggest improving access to medical specialists and community-based services as well as implementing innovative, alternative models of care. Diabetes is a common pediatric CCD which requires child-specific comprehensive care with coordination between various health and non-health sectors, including primary and tertiary health care providers, health and education systems, and community-based support services.

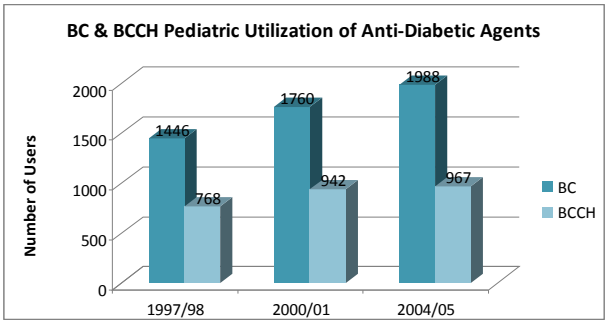
Data from the last five years indicates that about 60% of children with diabetes in BC were seen at the Endocrinology & Diabetes Unit at BC Children's Hospital.



Prosser B, Carleton B, et al 2008
Anti-diabetic Agents = insulin, metformin, glyburide, rosiglitazone

This indicates that more than a third of children with diabetes may not have access to specialized diabetes care. Consequently, Child Health BC and the Endocrinology & Diabetes Unit at BC Children's Hospital are working together to unify pediatric diabetes care into a comprehensive provincial health care model. This model will: (i) provide equitable and high quality, evidence-based diabetes care to all children in BC, (ii) provide reasonable ad timely access to comprehensive, community based diabetes care, and (iii) will promote the best possible long term health outcomes in children and youth with diabetes.

Dr. Amed represented this health care model as a Pediatric Diabetes Network in BC that links existing and/or new pediatric diabetes programs in each of the 5 Regional Health Authorities.



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Initial goals would be to: (i) build capacity within existing and/or new community pediatric diabetes programs, (ii) to coordinate services and develop formal linkages between community programs and tertiary level care, (iii) foster the development of communities of

practice and professional partnerships, and (iv) monitor and evaluate the activities, efficacy and efficiency of a Pediatric Diabetes Network in BC.

Childhood and Adolescent Obesity: From a Tertiary Care Institution to the Community

Lead: Jean-Pierre Chanoine, MD, PhD
Clinical Professor and Head of Endocrinology and Diabetes Unit, Children's Hospital BC

Jean-Pierre Chanoine provided an overview of demographics in BC and spoke about the impact of ethnicity on the increased risk of diabetes. Dr. Chanoine reviewed the importance of lifestyle factors in an "obesogenic environment" and spoke about the impact of the complications of Type 2 Diabetes from a public health perspective. There is an increasing need to educate patients and families. There is also a growing movement toward collaboration with community partners to prevent obesity. For example, non-medical resources exist in the form of pamphlets distributed in schools and activities. Dr Chanoine is also a principal investigator of "Healthy Buddies", a peer-led curriculum aiming at preventing the development of overweight in elementary school children.

Childhood and adolescent obesity has become a major public health problem in Canada. In BC, the Centre for Healthy Weights (Shapedown BC) opened in 2006 at BC Children's Hospital. The goal of the centre is to establish a seamless referral assessment and treatment model with children dealing with obesity in BC. The specific intervention program has already seen close to 200 children/adolescents and their families (living close enough to access BC Children's Hospital) and includes a comprehensive screening program for metabolic complications of obesity such as Type 2 Diabetes and hyperlipidemia.

Dr. Chanoine presented the existing infrastructure for obesity intervention in BC and potential future models of care. The presentation was concluded by emphasizing the need for much more work in this area – understanding what types of care are needed, closing the gaps through increased collaboration and identifying how Child Health BC's provincial focus of ensuring equitable access will improve diabetes care to all children and youth in BC.

Clinical Diabetes Association 2008 Clinical Practice Guideline: Type 1 Diabetes

Lead: Daniel Metzger, MD, FAAP, FRCPC
Pediatric Endocrinologist, Endocrinology & Diabetes Unit, BC Children's Hospital

Dr Metzger reviewed the recommendations from the Canadian Diabetes Association's *2008 Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada* relating to the care of children with Type 1 Diabetes. Key messages from these guidelines are three-fold:

- Suspicion of diabetes in a child should lead to immediate confirmation of the diagnosis and initiation of treatment to reduce the likelihood of diabetic ketoacidosis (DKA).
- Management of pediatric DKA differs from DKA in adults because of the increased risk for cerebral edema. Pediatric protocols should be used.
- Children should be referred for diabetes education and ongoing care to a diabetes team with pediatric expertise

The review of the guidelines served as a framework for discussions about how best to ensure availability, consistency and quality of care to children with Type 1 Diabetes across the province.

[Note to the reader: the DKA Protocol is currently under review. The BC Children's Hospital DKA Protocol is available online http://endodiab.bcchildrens.ca]

Clinical Diabetes Association 2008 Clinical Practice Guideline: Type 2 Diabetes

Lead: Dina Panagiotopoulos, MD, FRCPC
Assistant Professor, Department of Pediatrics, UBC; Endocrinologist and Director, Type 2 Diabetes/Insulin Resistance Program, BC's Children's Hospital

Dr Panagiotopoulos reviewed the *Canadian Diabetes Association 2008 Clinical Practice Guidelines for Type 2 Diabetes in Children and Adolescents*, for which she is the co-author. In addition, an overview of the structure of the Type 2 Diabetes/Insulin Resistance Clinic at BC Children's Hospital was provided. Other provincial initiatives such as diabetes screening in remote First Nations communities were highlighted. Key messages from these guidelines are as follows:

- Anticipatory guidance regarding healthy eating and active lifestyle is recommended to prevent obesity.
- Regular targeted screening for Type 2 diabetes is recommended in children at risk.
- Children with Type 2 diabetes should receive care in consultation with an interdisciplinary pediatric diabetes healthcare team.
- Early screening, intervention and optimization of glycemic control are essential, as onset of Type 2 diabetes during childhood is associated with severe and early onset of microvascular complications.

Dr Panagiotopoulos spoke about the objectives of the Type 2 Diabetes/Insulin Resistance Clinic at BC Children's and the need to: (a) develop a tertiary care model for management of Type 2 diabetes that would serve as a model for the province, (b) develop a comprehensive curriculum, (c) identify priorities and develop educational resources (d) continue to liaise with the ministry for provincial collaboration.

Managing Pediatric Diabetes Outside the Tertiary Care Centre

Lead: Sue Stock, MD
Pediatric Endocrinologist and Clinical Instructor at the University of British Columbia; Community-based Pediatric Endocrinologist

In the last several years there has been much advancement in the care of children with diabetes in BC, specifically regarding the level of service in outlying regions and the resulting reduced travel time for patients and their families. Dr Stock, by way of a case study, compared the treatment of a patient in Nanaimo in 2001 to current treatment in 2008.

Previously, a patient would need to travel to BC Children's hospital for treatment and follow up. Today the patient is able to receive these services on Vancouver Island between Victoria General Hospital and clinics in Nanaimo. Although many children with diabetes continue to travel to BC Children's Hospital for appointments, the number has been greatly reduced. Today over 500 children with diabetes are seen in their local communities.

With increased access to regional specialty diabetes clinics, the number of children traveling to BC Children's Hospital should continue to decrease, with the goal of no patient being required to travel out of their community for treatment and support.

Dr Stock detailed several critical success factors for community diabetes care:

1. Tap into existing resources/space (eg. adult diabetes centre staff/space, pediatric clinic nurses/space)
2. Engage discussions with key stakeholders (eg. adult diabetes clinics, local physicians, laboratory services, health authorities)
3. Start small and grow with time, recognizing that any local support is better than none
4. Recognize unique needs and strengths for your clinic
5. Ask for help/funding when needed

6. Encourage autonomy among families (eg. train them to become more independent in diabetes management, recognize that they usually have more knowledge than we think)

Diabetes Education: An Interdisciplinary Overview

Led by: Heather Nichol, RN, MScN, CDE, Clinical Nurse Specialist, Diabetes Program, Endocrinology and Diabetes Unit, BC Children's Hospital

Ms Nichol provided an overview of best and promising practices in diabetes education, based on a literature review and target audience needs. Key documents were highlighted including national and international standards for diabetes education, a new chapter on Self-management education which has been included in the 2008 edition of the Canadian Diabetes Association Clinical Practice Guidelines, and ISPAD Clinical Practice Consensus Guidelines for pediatric diabetes education (2007). Discussion points covered characteristics of quality education and the challenges associated with providing education and care in the community – including the provision of timely services and equitable access. To be effective, self management education needs to be multidimensional.

Education is not only about developing knowledge, but also includes interventions that focus on physical, behavioural, psychological and social management of diabetes. Effective self management education must be individualized to patients/families. Education is most effective when ongoing diabetes education is timely and part of a comprehensive healthcare plan.

Ongoing education can be organized to address three levels of learning: survival, intermediate and advanced knowledge, skills and motivation. Several innovative and promising practices for self management education were reviewed along with characteristics of effective resources and educational interventions.

Promising Practices in Diabetes Education

- Social coping skills for adolescents (problem-solving, role play, behavioural practice)
- Cognitive reframing/behavioural therapy
- Enhancing diabetes specific self- management

A Family Experience Case Study

Lead: Mark Lund, MD
Pediatrician in Campbell River

Dr Mark Lund graciously shared his experiences as an individual diagnosed with Type 1 diabetes in the BC health care system. Dr. Lund has been dependent on insulin since he was 20 years of age. Dr. Lund talked about the challenges of living with diabetes without guidance – being left to navigate the system as a "therapeutic orphan".

Dr Lund stressed the importance of individualized care from the healthcare community, particularly upon initial diagnosis. There is a need to ensure that the information and necessary follow up is presented and "sold" in a personalized way so that each and every patient feels comfortable and willing to follow professional guidance. Dr. Lund spoke about managing issues of specific concern for adolescents (i.e. weight gain with too much insulin and acne) and the importance of taking the time to present the necessary guidance and to enable patients to self manage their day-to-day care.

Challenges & Opportunities

Representatives from BC's health authorities and BC Children's Hospital Endocrinology & Diabetes Unit provided detailed information regarding the current strengths and challenges

throughout the province for children and youth with diabetes.

Speakers included: Heather Nicol, Huguette Cloutier, Jana Wong, Patty Phillips, Louise Lefebvre, Brenda McDougall, Tamara Robertson, Suzanne Bourgh, Cathy Wilson.

Key themes are outlined below:

Challenges

Geographical Restrictions

Without satellite clinics around the province, particularly in the Northern areas of BC, the Interior, and Vancouver Island, patients and their families are forced to travel great distances for consultation and follow up. Patients require care closer to home.

In addition, the educational resources for patients and families vary from region to region. Consequently, if families move or are treated in other regions information and communication can be confusing.

Health Human Resources: Social Workers and Mental Health Professionals

There is inadequate social and mental health support for families who are dealing with pediatric diabetes. Attention needs to be paid to multidisciplinary care – both at tertiary sites and in the community.

Education

There is an increased need for education to support treatment closer to home. Regional clinics require:

- Knowledgeable pediatricians
- Accessible pediatricians
- Diabetes nurse educators
- Dieticians
- Point of care for A1c machines
- Insulin pump trainers
- Mental health/social workers

Length of Stay

Length of stay in hospital for newly diagnosed patients can be as long as 7 days in some centers. Other centers provide diabetes education in the outpatient setting to medically stable newly diagnosed patients. With the ideal support systems in place, the length of time in the hospital could be reduced significantly and/or diabetes education can be provided in an outpatient setting. Not only does decreased length of stay reduce healthcare costs, it also enables patient/family centric care.

Communication

Currently a Pediatric Diabetes database does not exist in BC, nor is there a database that identifies the specialists and support systems throughout the province. The need for an online communication tool for both patients and families was identified to facilitate information sharing and promote collaboration.

Coordination with Schools

Coordination with the Ministry of Education regarding diabetes education in the school system is just beginning to emerge. Gaining the support of school districts to assist with children who are required to test and/or take insulin daily will be of significant benefit to patients and families across BC's communities.

Transition from Pediatric to Adult Care

The transition from pediatric to adult care will be an ongoing challenge unless support systems are developed. Collaboration across the continuum of care, at all levels of healthcare providers and professionals is essential.

Funding

Always a challenge - funding is required for ongoing and sustainable staff and patient education. Innovative initiatives to encourage multidisciplinary community based care will be important.

Opportunities

Growth through Networking

Practitioners in BC are genuinely passionate about their work with pediatric diabetes. Each region has valuable promising practices to share in the design of a consistent and fluent process

of pediatric diabetes care throughout the province. It is important to harness this knowledge and grow by facilitating effective networking.

Improving the Utilization of Existing Resources
Many resources and facilities already exist in BC for the treatment of adults with diabetes (i.e. nursing staff, clinic space, and lab services). Increasing the effective utilization of these resources for pediatric services will help to enable cost-effective solutions.

Moving Forward

Building on the challenges and opportunities identified above, workshop participants identified the following initiatives as first steps towards developing a more unified provincial pediatric diabetes program:

1. A "*Provincial Pediatric Diabetes Education Committee*" will be assembled with representation from each regional health authority. As a first step, this committee will be responsible for developing a provincial pediatric diabetes education resource which will be provided to families of <u>all</u> children with newly diagnosed diabetes in BC and will be used by <u>all</u> pediatric diabetes centers across the province for pediatric diabetes education.

2. As a first step in developing a Pediatric Diabetes Network in BC, individual Regional Health Authorities will organize (with the support of Child Health BC) regional pediatric diabetes workshops in order to enhance an integrated regional program and develop valuable linkages between other regional pediatric diabetes programs.

3. Members (S. Amed, D. Metzger, J.P. Chanoine) of the Endocrine & Diabetes Unit at BC Children's Hospital are in the process of exploring the feasibility of using existing administrative health databases to evaluate the quality of pediatric diabetes care in BC and measure outcomes in children and youth with diabetes living in BC. Additionally, this work will help to identify the need for complementary data collection in order to develop a comprehensive "diabetes registry" comprising of valuable information that will facilitate communication between tertiary care diabetes specialists and pediatricians and/or general practitioners, and diabetes health professionals who provide essential diabetes care in the community.

Acknowledgements

Child Health BC and its partners gratefully acknowledge participants from BC Children's Hospital, Canadian Diabetes Association, Vancouver Costal Health Authority, Northern Health Authority, Interior Health Authority, Fraser Health Authority, Vancouver Island Health Authority and the BC Children's Hospital Foundation for their participation and contributions.

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