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ORIGINAL ARTICLES

Adherence to Clinical Practice Guidelines in the Management of Children, Youth, and Young Adults with Type 1 Diabetes—A Prospective Population Cohort Study

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Objective To describe adherence to clinical practice guidelines for the treatment of childhood type 1 diabetes and identify associated patient and system level factors.

Study design This prospective cohort study used population-based administrative data to describe individuals aged 1-24 years who had been diagnosed with type 1 diabetes at <20 years of age (1472 unique individuals and 5883 person-years over a 7-year period) living in British Columbia, Canada. The outcome measure was proportion 'at goal,' which was defined as having optimal adherence (3 diabetes-related physician visits/year, 3 hemoglobin A1c (HbA1c) tests/year, 1 glucagon prescription dispensed/year, and appropriate screening for diabetes-related comorbidity [ie, hypothyroidism] and complications [ie, retinopathy and nephropathy]), or good adherence to guidelines (2 diabetes-related physician visits/year, 2 HbA1c tests/year, and appropriate screening for diabetes-related comorbidity and complications). Statistical methods included descriptive statistics and logistic regression modeling.

Results Fifty-four percent person-years had poor adherence to guidelines (<2 diabetes-related physician visits and HbA1c tests/year) and 7.4% had optimal adherence. The proportion of person-years at goal was higher in females vs males (41.0% vs 37.6%; $P = .007$). Individuals 4-years post-diagnosis of diabetes were 78% less likely to be at goal compared with the year of diagnosis ($P < .0001$).

Conclusions The treatment of pediatric type 1 diabetes likely does not meet national and international standards. Future studies should explore facilitators and barriers to adherence to guidelines among health care providers, patients, and families, and whether adherence to guidelines is associated with glycemic control. *(J Pediatr 2013;163:543-8)*.

Rates of childhood type 1 diabetes are on the rise. European data predicts that, from 2005 to 2020, the incidence of type 1 diabetes will double in children <5 years of age, and prevalence will increase by 70% in individuals <15 years of age.[1] The result may be an increase in the number of young children with type 1 diabetes, longer duration of disease, and a subsequent increase in rates of short- and long-term diabetes-related complications. Childhood and adolescence are a crucial time for intensive diabetes management where optimal glycemic control is necessary for the best possible long-term health outcomes.[2]

Clinical practice guidelines exist to guide and standardize diabetes management[3] and to provide a set of processes that can be used to assess quality of pediatric diabetes health care services. Previously published studies using processes of care suggest that the quality of health care services for children with diabetes is suboptimal and does not meet the standard defined by guidelines. Christakis et al reported that in a single observational year, a cohort of children with type 1 diabetes receiving Medicaid were not receiving recommended care, with only 54%, 21%, and 43% having 1 hemoglobin A1c (HbA1c), 1 thyroid stimulating hormone test, and 1 ophthalmology assessment, respectively.[4] In a cross-sectional survey of youth with either type 1 or type 2 diabetes in the US, only 68% had at least 2 HbA1c measurements and 66% had 1 ophthalmology assessment over a period of 1 year.[5] These cross-sectional studies are limited in that they do not describe changes in the quality of care over time, from the year of diagnosis of type 1 diabetes onwards.

BCCH	British Columbia Children's Hospital
DAD	Discharge abstract database
GP	General practitioner
HbA1c	Hemoglobin A1c
MSP	Medical Services Plan
POC	Point-of-care

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In this study, we describe adherence to guidelines for the treatment of type 1 diabetes over a 7-year period in a prospective population-level cohort of individuals ages 1-24 years diagnosed with type 1 diabetes at <20 years of age living in British Columbia, Canada. A secondary objective was to identify patient- and health-system level factors associated with adherence to guidelines.

Methods

We used 4 population-based data sources: (1) British Columbia Medical Services Plan (MSP) database that captures fee-for-service billing and diagnostic codes from physician-patient encounters and laboratory investigations; (2) Canadian Institute of Health Information hospital discharge abstract database (DAD) that contains information related to acute care hospital admissions; (3) British Columbia PharmaNet database that collects information on every prescription dispensed from community pharmacies in the province; and (4) Client Registration and Premium Billing database that maintains client demographic information. All British Columbia residents have universal, publicly-funded health insurance for both outpatient physician visits and inpatient hospital care. Therefore all children and youth are registered with the Client Registration and Premium Billing database and their data are linkable across MSP, DAD, and PharmaNet datasets by a unique personal health number, with the exception of specific populations who receive federally funded health services (ie, Aboriginal children living on a reserve).

Ethical approval was obtained from the University of British Columbia's Children and Women's Hospital Research Ethics Board. Extensive privacy protection measures were taken to ensure that individuals and physicians could not be "personally" identified. Select co-investigators (K.N., P.M., and K.R.) had authorized access to the full dataset and the principal investigator (S.A.) and co-investigators received aggregate data only.

All community-based physicians (generalists and specialists) in British Columbia are fee-for-service and bill for diabetes-related physician visits where a diagnostic code is requisite. Pediatric endocrinologists who are remunerated through an alternative funding plan are required to shadow bill for all patient encounters. All laboratory investigations completed at outpatient public/private laboratories are captured in the MSP database. Inpatient laboratory investigations are not captured, however, are almost always unrelated to chronic disease management of pediatric type 1 diabetes. Young people attending college/university outside of British Columbia continue to be covered under their parents' MSP plan and, therefore, their healthcare encounters are captured in British Columbia administrative datasets.

This study includes an administrative cohort of individuals aged 1 to 24 years living in the province of British Columbia who were newly diagnosed with type 1 diabetes at <20 years of age. An age cut-off of <20 years was used to align with the diabetes surveillance methodology of the Public Health Agency of Canada. The cohort was followed from April 1, 2001-March 31, 2008. These individuals were identified by applying a validated diabetes case-finding definition ('case rule')[6] and a validated algorithm that differentiates type 1 and type 2 diabetes (the 'diabetes-differentiating algorithm')[7] to linked administrative health datasets (MSP, DAD, and PharmaNet). By the case rule, individuals with diabetes were identified from 2 physician-billing claims (coded *International Classification of Diseases, 9th revision* 250, diabetes mellitus) or 1 hospitalization (discharge code: *International Classification of Diseases, 10th revision, Canada* E10-E14) within a 2-year period. The diabetes-differentiating algorithm used demographic characteristics and common prescription drug-utilization patterns to distinguish type 1 and type 2 diabetes in administrative datasets. Our patient population was analyzed as a prospective cohort where new cases of type 1 diabetes were identified for each year of data (eg, 2001/02, 2002/03) and were followed prospectively for a maximum of 5 years (ie, those diagnosed in 2001/02 or 2002/03) and a minimum of 2 years (ie, those diagnosed in 2006/07) (**Table I**).

This study was conducted in the province of British Columbia in western Canada. Within British Columbia, there is 1 tertiary care pediatric center—British Columbia Children's Hospital (BCCH), located in the southwest corner of the province. During this study period (2001-2008), there were 3 pediatric endocrinologists at BCCH seeing children with diabetes. In addition, in 2005, 1 pediatric endocrinologist began a community-based practice providing diabetes care to children and youth living in the Vancouver Coastal and Vancouver Island health regions. Community-based pediatric diabetes clinics led by local pediatricians were also available during the study period, predominantly located in the Interior and Northern Health Regions. A pediatric endocrinologist from BCCH also participated in outreach by attending the pediatric diabetes clinic in the Northern health region 2-3 times per year to see complex cases. Since 2009 (after our study period), similar outreach models of care have been established in the Fraser health regions, allowing for access to care closer to home.

Table I. Total unique individuals and person-years (annual records) by year and by cohort

	Cohort						
Fiscal year	1*	2*	3*	4†	5‡	6§	Total person-years
2001/02							257
2002/03	257	250					507
2003/04	252	248	257				757
2004/05	251	246	255	255			1007
2005/06	248	238	255	254	211		1206
2006/07		236	255	253	211	242	1197
2007/08			252	249	210	241	952
Total unique individuals	257	250	257	255	211	242	5883 1472

*Followed for 5 y.
†Followed for 4 y.
‡Followed for 3 y.
§Followed for 2 y.

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